

Internet cancer information use by newly diagnosed individuals:
A mixed methods study of interactions with healthcare professionals and the health care system

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Dedicated to my family:

L, M, C, and S

Dissertation Abstract

Background: People with cancer are increasingly turning to the internet to find information and support. However, little is known regarding the use of the internet and how this impacts patients' cancer experiences and their interactions with, and within, the healthcare system.

Purpose and objectives: The overarching purpose of this dissertation is to explore the ways that patients newly diagnosed with cancer use cancer-related internet information (CRII) and the role it plays in interactions with the healthcare system. The specific objectives were to: (1) qualitatively explore the content of commonly searched websites from a critical nursing perspective; (2) explore patients' prompts to use CRII and how CRII informs the ways in which patients interact with healthcare professionals and healthcare services, and (3) document what CRII is accessed and the patterns and frequency of use.

Methods: An embedded mixed methods study was conducted using interpretive description as the overarching methodology. Data sources included: (1) a qualitative review of 20 cancer websites; (2) 19 individuals newly diagnosed with cancer, who each took part in two in-depth interviews and a brief survey; and (3) 21 healthcare professionals who engaged in three focus groups (n=17) and in-depth individual interviews (n=4).

Results: The dominant discourse in the websites reviewed focused on empirical information about treatment, prognosis, and cure. A dearth of sociopolitical, ethical, personal, and esthetic information was noted. Thus, when seeking CRII, patients predominantly find empirical and biomedical information.

The qualitative interviews with patients revealed three key themes that characterize how patients used CRII: (1) person in context, (2) management of information, and (3) managing relationships with healthcare professionals. These themes explain how patients mobilized CRII to manage their patient experience. Patients described CRII as an important resource to process information, make decisions about their illness, and make sense of their disease. Patients also sought CRII to complement and reinforce information and support provided by healthcare professionals.

The interviews and focus groups with healthcare professionals revealed two key themes with respect to their views of CRII use. These themes relate to healthcare professionals' perceptions of patient use of the internet to manage their pragmatic concerns and priorities as well as to navigate processes and practices of the healthcare system. Healthcare professionals found that CRII could modulate patients' interactions with the healthcare system. Healthcare professionals also acknowledged key points in the cancer trajectory where information may be lacking or where patients may have less informational support; participants felt that CRII served as a beneficial resource to address these gaps. Although healthcare professionals were supportive of patient use of CRII to meet cancer information needs, they also described concerns regarding patients finding and using untrustworthy information.

Conclusions: Together, the findings from this dissertation research inform an understanding of how people with cancer use CRII to manage their cancer experience and interact with healthcare professionals and services. Findings highlight the importance of information diversity in the midst of a lack of holistic and varied information presently online. There is also a need for nurses and other healthcare professionals to be aware of the information that is available online and to understand what patients are accessing. Communication about CRII between patients and

healthcare professionals may also strengthen areas of patient education that are lacking as well as encourage healthcare professionals to raise key topics of interest.

Implications for Practice: There is clearly a growing need for dialogue around pervasive technologies and the nursing role in assessing and directing patients to holistic information. Oncology nurses are well situated to take the lead in their multi-disciplinary care teams to engage patients about their CRII use and to explore the tensions experienced by clinicians surrounding CRII use. CRII use is a growing trend amongst patients across all healthcare settings, and nurses are well positioned to initiate discussions and be leaders in practice. Future research is warranted to expand on the link between CRII use and the utilization of health services, the role of CRII for those in rural areas compared to those in urban areas, and the role of the family in patients' mobilization of CRII in their cancer experience.

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Chapter 1: Introduction and Organization of the Dissertation

The overarching purpose of this dissertation research was to explore the ways in which people diagnosed with cancer use cancer-related internet information (CRII) to manage their cancer experience and their interactions with healthcare professionals and services. This first chapter provides the background to my research topic. I begin by describing and introducing the research problem, the study rationale, the purpose, and objectives, and then outline the overall structure of this document. In the second section of this chapter, I summarize the key extant literature and position this research within the theoretical context of nursing.

Research Problem

Cancer is the most common disease in Canada, with nearly 40% of Canadians expected to be diagnosed in their lifetime (Canadian Cancer Society, 2016). A cancer diagnosis involves complex treatments and surgeries that often lead to disturbances in normal bodily functions, pain, and physical disability (Beaver et al., 2010; McMullen et al., 2011). Although the physical consequences are profound, the psychosocial implications can be equally distressing (Carlson & Bultz, 2003). For example, many people¹ diagnosed with cancer experience disruptions in activities of daily living, undergo changes in emotional and mental health, and report a lack of information about their diagnosis (Adler & Page, 2008). People's need for information about what cancer is, how it will impact them, and how to manage their needs is central to coping with their illness (Faller et al., 2016). Consequently, people with cancer require ongoing and sometimes urgent attention to support the management of these needs.

¹ In this dissertation, the terms 'people' and 'patients' will both be used regarding individuals with cancer. I recognize the inherent limitations of the term patient, and the implication that a patient is a recipient of care and a non-expert with limited power; this is opposed to a person living with illness and an expert on their own body (Alder & Horsfall, 2008; Starfield, 2016). However, the literature on patient-provider relationships, nurse-patient relationships, patient education, and patient experience relies on the term 'patient'. Therefore, when I refer to people on their own, I will use the term 'people with cancer' or 'people', but when referring to the healthcare environment, specifically relationships with healthcare professionals, I will use the term 'patient'.

Despite the importance of health information for people with cancer, constraints in the healthcare system, and the unpredictable nature of peoples' health concerns, information needs frequently exceed the capabilities of healthcare professionals; this leaves people with cancer and their families on their own to meet and manage these needs (Harrison, Young, Price, Butow, & Solomon, 2009; James et al., 2007). This is problematic for nurses as education and the sharing of information is a central aspect of the professional role (Wingard, 2005). Much of nurses' time spent teaching or sharing information takes place during routine clinical care as opposed to scheduled and structured educational interventions (Friberg, Andersson, & Bengtsson, 2007; Friberg, Granum, & Bergh, 2012). Therefore, the amount and type of information nurses can share with patients may be constrained when time is limited during clinic visits.

Since the advent of the internet, many people have chosen to utilize it for health information and support when their healthcare professional is unavailable (Castleton et al., 2011; McHugh et al., 2011). The internet has become pervasive; around 87 percent of Canadians have internet access and most average 34 hours of internet use a month on computers (Canadian Internet Registration Authority, 2015; IWS, 2016). When the patient-centred care movement emerged, it was thought that the internet and related e-health initiatives would be a crucial means of involving people in their own care by allowing them to access their personal health information and make informed choices using internet health information (Delbanco et al., 2001). Despite the slow uptake of such innovations as patient-accessible electronic health records (Gagnon et al., 2016; Urowitz et al., 2008), the proliferation and democratization of medical information on the internet has been swift. Unfettered access to health information is available to anyone with a computer, tablet, or smartphone (Canadian Internet Registration Authority, 2015). As proposed in the early days of the patient-centred care movement (Institute

of Medicine, 2001), access to internet information and related e-health interventions has not replaced the patient-healthcare professional relationship but instead is complementary (Maloney et al., 2015; Ziebland et al., 2004). Accordingly, the internet has become important for people to supplement information provided by their healthcare professionals.

For people with cancer, CRII use has been categorized into four types: (1) content, or information, about illness, (2) community, including online support groups, (3) communication, including email and social networking, and (4) commerce, or the purchase of goods and services related to a cancer diagnosis (Eysenbach, 2003). CRII serves to empower people through access to information and supportive care resources, when and where they may need them. Together, these features speak to enhancing the patient experience with cancer, defined as the cumulative experience of the people, processes, and places encountered during illness (Wolf et al., 2014). Patients report many reasons for relying on CRII, including wanting to reduce pressure on their busy healthcare professionals and to be better prepared for consultations (Loiselle et al., 2013; Maloney et al., 2015). It has also been documented that some people share CRII with their healthcare professional with the goal of asking for further explanation or for a recommendation for further information (Shen et al., 2015). However, many people choose not to share CRII with their healthcare professional for fear of being judged for the information they are searching, or for being perceived as questioning their healthcare professional (Bylund, Gueguen, D'Agostino, Imes, & Sonet, 2009; Newnham et al., 2006). Overall, the literature demonstrates that people with cancer have unmet information needs, CRII is a key source of information, and CRII plays a role in their relationship with healthcare professionals. However, a focused exploration of the connections between peoples' use of CRII, healthcare professionals, and healthcare services has not been documented.

Study Rationale

The purpose of this research is to explore the role of CRII in patients' experience with cancer. Prior research has explored the importance of information for people with cancer and the growing uptake of the internet amongst people with cancer (Peterson, Shen, Weber, & Bylund, 2017). However, the link between CRII use and how this informs patients' interactions with healthcare professionals and healthcare services remains unexplored. Furthermore, although there has been broad proliferation of different types of e-health interventions (Aalbers, Baars, & Rikkert, 2011), patients can use CRII without the guidance or support of their healthcare professionals and without extraneous investment from the healthcare system. Thus, it is worth exploring the types of websites patients are using, the content of these websites, and how patients' use of self-sought CRII relates to their interactions with healthcare professionals.

Study Purpose & Objectives

Research to date indicates that people with cancer have needs for information, psychosocial support, and guidance that are often unmet (Faller et al., 2016; Harrison et al., 2009). To meet these needs, patients increasingly turn to the internet. This growing reliance on CRII by people with cancer poses important questions about how this shift to CRII impacts the patient-healthcare professional relationship and peoples' interactions with healthcare services. This gap in the literature instigates a need to develop and enhance knowledge about the role of CRII and the ways CRII is connected to peoples' interactions with healthcare professionals and services.

The specific objectives of this dissertation are:

1. To qualitatively explore the content of commonly searched websites from a critical nursing perspective.
2. To explore the prompts to use CRII and how CRII informs the ways in which people with cancer interact with healthcare professionals and services.
3. To document what CRII is accessed and the patterns and frequency of use.

Organization of Dissertation

This is a manuscript-based dissertation, wherein the main findings are incorporated into three manuscripts (see Table 1.1 for explanation of each chapter). In accordance with the ‘dissertation by manuscript’ guidelines outlined by the Faculty of Graduate and Post-doctoral Studies (FGPS) at the University of Ottawa, this dissertation contains three manuscripts. These are prefaced with a unified introduction, literature review, and methods section and are jointly concluded with an integrative discussion and implications for nursing. The dissertation is written in APA style (sixth edition, 2009), with a reference list at the end of the dissertation inclusive of references pertaining to Chapters 1, 2, 6, and 7. The manuscripts are written in the style of the target journal; each has an accompanying reference list.

This *first chapter* describes the research problem, objectives, organization of the dissertation, a summary of the key literature, and the theoretical context of this dissertation. *Chapter 2* is a detailed description of the entire dissertation methodology. *Chapter 3* is the first results manuscript, which is a qualitative interpretive description study in which I explore the content of the most commonly searched websites from a critical nursing perspective. *Chapter 4*, the second results manuscript, is a mixed methods study in which I explore the prompts to use CRII and how it informs peoples’ interaction with healthcare professionals and services. This

chapter also contains supplemental findings from the patient interviews that are beyond the scope of the manuscript, specifically data related to patient and healthcare professional relationships.

Chapter 5, the third and final results manuscript, is a qualitative interpretive description study in which I document healthcare professionals' perspectives of the role of CRII in peoples' interactions with healthcare professionals. *Chapter 6* is an integrated discussion, presenting and triangulating all findings and identifying nursing implications for practice, education, and research. The *seventh and final chapter* outlines the role of the co-authors in each manuscript, as required by FGPS.

Table 1.1 Dissertation Organization				
Chapter	Chapter title	Objective	Method	Affiliated manuscript and key journal requirements
1	Introduction, organization of dissertation, literature review, and theoretical context	Describe the research problem. Explain the organization of the dissertation. Provide a summary of the current literature on the research problem. Present the theoretical context for the proposed study.	NA	NA
2	Methodology	Describe the dissertation methodology.	NA	Appendix A: Protocol: <i>International Journal of Qualitative Methods (Published)</i>
3	Website data	Qualitatively explore the content of commonly searched websites from a critical nursing perspective.	Qualitative interpretive description	Results Manuscript 1: Submitted to <i>Nursing Inquiry</i> Maximum 6000 words
4	Patient data	Explore the prompts to use CRII and how CRII informs the ways in which people with cancer interact with healthcare professionals and healthcare services.	Mixed methods study	Results Manuscript 2: <i>Cancer Nursing</i> Maximum 20 pages (excluding figures and texts) Supplement
5	Healthcare professional data	Explore healthcare professionals' perspectives on the role of the internet in the use of healthcare services and in the patient-healthcare professional relationship.	Qualitative interpretive description	Results Manuscript 3: <i>European Journal of Cancer Care</i> Maximum 8000 words.
6	Integrated discussion	Provide an integrated discussion and triangulation of all findings with implications for the discipline of nursing.	Descriptive synthesis	NA
7	Contribution of collaborators	Describe the role of manuscript co-authors.	NA	NA

Literature Review

A diagnosis of cancer is a life-changing experience impacting the person with cancer and their family in numerous ways. Combined, the physical and psychological effects of cancer challenge people to cope with daily life (Adler & Page, 2008). The families and caregivers of people with cancer are also impacted, as they attempt to maintain cohesion and cope with the diagnosis whilst balancing the demands of family and work life (C. A. Robinson, 1998; W. D. Robinson, Carroll, & Watson, 2005; Veach, Nicholas, & Barton, 2013). Patients and their families need assistance and support to manage these demands given the myriad physical, psychological, and social changes occurring (Treacy & Mayer, 2000).

A key necessity for patients and families when faced with a diagnosis of cancer is accurate, timely, and appropriate information (Harrison et al., 2009). However, as people increasingly use the internet to meet their own information needs (James et al., 2007; Shea-Budgell, Kostaras, Myhill, & Hagen, 2014), little is known regarding patients' internet use and interactions with healthcare professionals and services. The purpose of this literature review is to present key extant literature on the subject as well as the theoretical context, thereby establishing the need for the study in its entirety. In the first section, I present literature about people's information needs when diagnosed with cancer and why this is such a critical issue. Next, I move into a discussion of e-health and its promise in cancer care. I then present a synthesis of the literature on patient and healthcare professional perspectives about internet use in general, and specific to oncology. Finally, I move into a discussion of theoretical considerations, including my epistemic position and the theoretical frameworks that set the context for the study.

Cancer information needs.

As people with cancer embark on their journey of consultations, treatments, and therapies, one of the most jarring experiences happens at the outset: being thrown into the confusing and complex maze of the healthcare system (Wells et al., 2008). Equally daunting is that cancer is the leading cause of death in Canada and therefore has a negative, and sometimes fatalistic, stigma (Canadian Cancer Society, 2016; Powe & Finnie, 2003). A diagnosis of cancer can be highly distressing because of this negative stigma but also because of the complicated nature of diagnosis and treatment (Bowles et al., 2008; Hall, Gray, Browne, Ziebland, & Campbell, 2012). The concerns around complexity arise from the potential for multiple treatments, from multiple professionals, all of which create more uncertainty for patients and their families as they navigate the healthcare system (Post et al., 2015). For instance, a person with colorectal cancer may require major surgery, chemotherapy, and radiation, all conducted or administered by different physicians and healthcare professionals (Canadian Partnership Against Cancer, 2010a). Thus, the healthcare system itself presents challenges for patients and their families.

Cancer and its treatments can have debilitating physical side effects, including, but not limited to, severe nausea, loss of appetite, extreme fatigue, impaired sexual function, limited mobility, and pain (Gerber, Solomon, Shaffer, Quinn, & Lipton, 2007; Kirschning & von Kardorff, 2008; Urowitz et al., 2012). Equally pressing are the psychosocial concerns, including difficulty adjusting to bodily changes, fear of surgical complications, and feelings of vulnerability and inadequacy (Soerjomataram et al., 2012; Taylor, Richardson, & Cowley, 2010). Many people also report practical concerns around work disruptions and maintaining, or

returning to, ‘normal life’ alongside diagnosis and treatment (McKay, Knott, & Delfabbro, 2013). As a result, people have many needs as they cope with a diagnosis of cancer.

Unfortunately, unmet needs in both the physical and psychosocial domains are commonly reported amongst people with cancer. Research to identify unmet needs in cancer care—called needs assessment—is a key area of study intended to improve patient care by addressing gaps in healthcare services (Harrison et al., 2009). In the context of cancer, needs are defined as “the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being” (Sanson Fisher et al., 2000, p. 227). Supportive care needs in cancer pertain to both the physical and psychosocial realms, and are often measured using multi-dimensional scales with items regarding daily living, health systems, information, patient care, support, and sexuality. Unmet needs are connected to disruptions in activities of daily living and the ability to maintain, or return to, a new normal and a sense of control (Carlson, Waller, & Mitchell, 2012; Drageset, Lindstrøm, & Underlid, 2016; Harrison et al., 2009; Puts, Papoutsis, Springall, & Tourangeau, 2012).

A key unmet need, and oft-cited source of anxiety and distress for people with cancer, pertains to information (Carlson et al., 2012). For example, in the largest study to date on information needs in cancer, Faller and colleagues (2016) surveyed over 4000 men and women with cancer regarding their information needs. They found that 88% of respondents reported being somewhat well-informed regarding their illness, but 40% still wanted more information. These findings reiterate data from two prior systematic reviews that found informational needs were among the most frequently left unmet (Harrison et al., 2009; Swash, Hulbert-Williams, & Bramwell, 2014). Research on unmet information needs across the disease trajectory—at diagnosis, throughout treatment, and survivorship—indicates they are highest at the time of

diagnosis (Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 2013). However, information needs do continue on throughout the disease trajectory.

The relationship between people's need for information and their use of healthcare services has been suggested in previous studies. Consequently, limited access to timely information was found to be distressing and led to increased use, misuse, and avoidable reliance on health services (Dubois & Loiselle, 2009; Harrison et al., 2011). That is, patients who become overly distressed may need additional information and support from their healthcare professionals to ease their concerns and anxiety, and potentially seek services that are not appropriate, unnecessary, or altogether avoidable had they been provided support proactively (Dubois & Loiselle, 2009). In turn, several researchers suggest that access to psychosocial support and information needs, provided early on by healthcare professionals, may reduce health service use throughout the trajectory of care, ultimately reducing or offsetting healthcare costs (Carlson & Bultz, 2004; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). For example, a recent randomized clinical trial for women with breast cancer compared standard care to extended psychosocial support and information sessions with specially trained nurses, and found the experimental group's care to be more cost-effective than standard care (Arving, Brandberg, Feldman, Johansson, & Glimelius, 2014; Arving et al., 2007). Thus, information and support provided proactively may decrease costs and unnecessary health service use.

In a recent comprehensive systematic review of over 770 patient-centred interventions, Coulter and Ellins found that access to high quality information increased patients' acceptance, knowledge, and ability to cope with illness (Coulter, 2014; Coulter & Ellins, 2006, 2007). These findings emphasize that access to information, and a person's ability to process and understand health information, improves their ability to self-manage, which could potentially lead to better

health outcomes and a more efficient healthcare system. Thus, as people with cancer turn to the internet to address their information and psychosocial needs, research is merited to understand how CRII modulates the patient experience and, in turn, the relationships and interactions with healthcare services or professionals.

The Canadian healthcare system.

An additional contextual factor pertains to the Canadian healthcare system where this study is conducted. The Canadian healthcare system includes a landscape of ongoing budgetary restrictions, where healthcare professionals experience daily challenges in the provision of patient-centred and universally accessible care (Milne, Sheeran, Holmes, Tidhar, & Aranda, 2012). Some of these challenges are related to limited time with patients, rushed clinic visits, and growing and complex patient caseloads (Sutcliffe, 2011). Canada also has a large landmass, with services concentrated in urban centres but sizable populations living in rural and remote areas; this requires people to travel long distances to seek care (Fleet, Archambault, Plant, & Poitras, 2013). Limited access to healthcare professionals often leaves individuals to fill the gaps in supportive treatment and care and to find their own information (Sutcliffe, 2011). In this milieu of limited time and growing patient loads for clinicians, the internet can fill an information gap for both clinicians and patients (IWS, 2016; Murray, Burns, SeeTai, Lai, & Nazareth, 2005). Despite growing interest in the multifaceted impact of the internet and other e-health technologies, there has been little research to date on the intersection of internet use and interactions with healthcare professionals and services. Furthermore, whether individuals in rural areas mobilize CRII in unique ways to manage their patient experience in the absence of ready access to comprehensive health services is a worthy area for investigation.

A final factor to consider regarding the healthcare system pertinent to cancer care pertains to patient navigation. Patient navigation has emerged as one approach to connect patients with appropriate healthcare services in a timely streamlined fashion (Freund, 2011; Pratt-Chapman, Simon, Patterson, Risendal, & Patierno, 2011). In Canada, navigation serves to address the aforementioned challenges with the healthcare system, especially complexity. Patient navigation is defined as a proactive and intentional process of collaborating with individuals and their family as they navigate treatments, services, and barriers faced throughout the cancer journey (Canadian Partnership Against Cancer, 2010b). Patient navigation originated in the United States in the 1990s with the goal of addressing disparities in breast cancer screening in minority women (Freeman, 2006). Three types of navigation have been identified that may be used alone or in complement to one another: professional, peer, and virtual (2010b). Professional navigators (typically nurses or social workers) are often situated within the hospital or institutional system and work with the interprofessional team to coordinate and manage care (Pedersen & Hack, 2010). Peer navigation is typically volunteer-led, and utilizes individuals with personal or family experience with cancer to provide guidance to others with cancer (Braun et al., 2012). Virtual navigation is essentially a tailored website, or intervention, intended to electronically connect patients with institutional contacts and provide information about the patient's diagnosis and their medical centre (Canadian Partnership Against Cancer, 2010b). Patient navigation presents a significant opportunity to optimize patient interactions with healthcare services and professionals. However, where CRII fits within (and alongside) the various types of patient navigation has yet to be explored.

Information sharing and patient-education: nursing context

Within the Canadian healthcare system, nurses are an essential member of the healthcare team (Canadian Nurses Association, 2009). Nurses provide holistic care for people and their families in health and illness through research, education, and practice that is person-centred, strengths-oriented, timely, and accessible (Fawcett, 1984; Gottlieb, 2012; Scott, Matthews, & Kirwan, 2014). Nurses deliver care oriented in multifaceted disciplinary knowledge, which enables them to provide whole person care (Carper, 1978; Gottlieb & Gottlieb, 2007). The metaparadigm of nursing proposes that the person, their environment, health, and the profession of nursing form the foundation of disciplinary knowledge (Fawcett, 1984; Thorne et al., 1998). Consequently, as the nursing mandate is to provide holistic supportive care, patient education is a central priority for nurses caring for patients at all stages of the cancer trajectory (Chelf et al., 2001; Wickham, 2015).

In practice, care is guided by the nursing process—a dynamic and cyclical schematic that assists nurses to prioritize and organize nursing care through assessment, diagnosis, planning, implementation, and evaluation (Alfaro-LeFevre, 2014; Husband & Torry, 2004). Patient-education corresponds with multiple stages of the nursing process, and involves listening and building a collaborative partnership versus a top-down nurse-led approach (Gottlieb, Feeley, & Dalton, 2006). Furthermore, the Registered Nurses Association of Ontario (RNAO) guidelines on facilitating client-centred learning (Registered Nurses Association of Ontario, 2012) cite the need to create a safe space, assess patient learning needs, tailor education to patient needs, and use a combination of approaches (such as print, telephone, computer, etc.). The RNAO also put forth a model for leading patient-centred education using the acronym LEARNS: Listen to the person and their needs; Establish the relationships; Adopt an intentional approach with every

patient; Reinforce health literacy; Name the new knowledge; and Strengthen self-management abilities by linking to community resources (Registered Nurses Association of Ontario, 2012). Finally, the Canadian Association of Nursing Oncology identifies teaching and coaching patients, alongside the nursing process, as a key competency for oncology nurses (Canadian Association of Nurses in Oncology, 2001). Thus, core responsibilities within the discipline of nursing are to share information, question patients about their information needs, assess patient needs, and provide information and resources to allow patients to understand and manage their own health (Coster & Norman, 2009).

The theoretical and conceptual frameworks and best practice guidelines present what should happen in practice. However, realities within the clinical milieu can limit the actualization of optimal patient education and information sharing. In the present nursing context, we recognize constraints on nurses' capacity to provide education to every patient and their family, and answer every question, due to factors such as reduced staffing, increased workloads, and budgetary cutbacks (Scott et al., 2014). Moreover, the healthcare landscape has evolved to include people with multiple comorbidities, older patients, and shorter acute care hospital stays (Friberg et al., 2012). Thus, nurses working within this complicated landscape are challenged to address the information needs of their patients while contending with reduced resources and complex patients.

E-health and the internet.

As the internet and related technologies have evolved, so too has their role in healthcare. E-health is a term used to describe the use of technology in healthcare and can include the use of any interactive technology, from telephones to computers, in any aspect of healthcare intended to improve patient care (Cote, 2007; Oh, Rizo, Enkin, & Jadad, 2005). The internet, as one

modality of e-health that is particularly self-directed, is now in the homes of 83% of Canadians (Statistics Canada, 2012). The internet has changed how people communicate, find, and exchange information on a range of subjects, including health (Chou, Prestin, Lyons, & Wen, 2013).

Discussions of the internet as a tool to assist people to cope and self-manage health and illness centre around two operationalizations: the open internet or internet-based interventions. The term ‘open internet’ refers to the internet at large, where people access information and content via an internet address or website, or they use a search engine to query information via their personal computer, tablet, or smartphone (Hanberger, Ludvigsson, & Nordfeldt, 2013). The open internet is now broadly available in Canada, and provides information and support based on what patients choose to search, at their own pace and on their own terms. For health purposes, the open internet contains websites with information as well as for mutual support, networking, and health-related purchases (Leykin et al., 2012). Conversely, internet interventions are designed to be structured, self-guided, or human-supported websites with the intention of supporting decision making, symptom management, behaviour change, or some other aspect of physical or mental health (Barak, Klein, & Proudfoot, 2009). The key difference between these two ways of using the internet is that the open internet is available to anyone using the internet and users do not receive guidance on how or what to do. Internet interventions often require passwords, vary in complexity, and are not accessible to the general public (Aalbers et al., 2011). In this study, I am interested in the self-initiated, unmediated use of the open internet by people with cancer, because less knowledge exists about self-sought internet information seeking and how it relates to interactions with healthcare services and relationships with healthcare professionals.

Internet use and cancer.

The importance of information for individuals with cancer, the related constraints of meeting information needs, and the growing ubiquity of the internet create a context where it is not surprising that many people now seek and find cancer information on the internet. In this section, I address general studies about CRII use by individuals with cancer, sharing CRII with healthcare professionals, and patients' prompts to use CRII.

The popularity of CRII use by those with cancer is supported by numerous surveys; for example, a recent American survey found 63% of respondents (n=500) used the internet to search for health information (Castleton et al., 2011). In the Canadian context, a 2014 survey of 411 individuals attending a Canadian cancer clinic for post-treatment follow-up found that healthcare professionals were patients' most trusted source of information; the internet was the second most preferred source, with 80% reporting regular use (Shea-Budgell et al., 2014).

In the context of cancer care, the use of the internet is growing (An, Wallner, & Kirch, 2016). People with cancer report using the internet to help facilitate encounters with healthcare professionals (Dickerson, Reinhart, Boehmke, & Akhu-Zaheya, 2011) and to verify information (Bylund et al., 2009; Girault et al., 2015; Loiselle et al., 2013). Another impetus for CRII use is a lack of informational support from healthcare professionals (Dolce, 2011) or support when they are unavailable (James et al., 2007). This means that patients are seeking their own information online when their healthcare professionals do not provide it or when they do not feel comfortable asking.

Whereas some people may feel comfortable sharing CRII with their provider, studies report some patients choose not to share their CRII with their oncologist due to concerns of being

perceived negatively for finding their own information on the internet (Bylund et al., 2009; Imes, Bylund, Sabee, Routsong, & Sanford, 2008). Some patients will only discuss this information if they perceive sufficient trust with their healthcare professional and ample time, which is often lacking (Kirschning & von Kardorff, 2008). When patients do raise CRII, they expect healthcare professionals to acknowledge this information and assist them in making sense of it (Bylund et al., 2009).

Accessibility is just one reason why people with cancer use the internet, as numerous reports describe the motivations drawing people to find information online. Some patients report turning to the internet to prepare for meeting their healthcare professionals, to verify information received in consultations (Loiselle et al., 2013), or to gain a sense of confidence around cancer information their healthcare professional has provided (Ziebland et al., 2004). One study with 202 haematology patients found internet use increased people's confidence in their specialist and improved confidence in their decision-making ability (Rider, Malik, & Chevassut, 2014). In Canada, the vast populations of rural and remote dwellers, living great distances from health services, may prove an additional motivation for people with cancer to rely upon the internet (Yli Uotila, Rantanen, & Suominen, 2013). As the reliance on CRII grows, so too does our understanding and awareness of the rationale, benefits, and potential drawbacks of internet use for health information.

Healthcare professional views on internet use.

Due to patients' growing interest in the internet, the relationship between internet use and interactions with healthcare professionals warrants clarification. Furthermore, how these interactions might influence, deter, or increase use of services is also worthy of exploration

(Cline et al., 2007). In this section, I discuss healthcare professionals' views on patient internet use generally, and in cancer care, concluding with literature about nurses' views.

Studies on physician-patient relationships have found that some physicians are anxious about patients' use of the internet and their capability to discern appropriate and reliable information (Newnham et al., 2005; Urowitz et al., 2012). One qualitative study exploring the role of internet information in patient-physician encounters found that many physicians were concerned about patients using the internet, and thus devised positive strategies to approach this information when patients presented it (Ahluwalia, Murray, Stevenson, Kerr, & Burns, 2010). For example, physicians would tell themselves to take a deep breath or to listen to the patient. Physicians felt these strategies allowed patients to feel 'heard' even if the physician disagreed with the information or had to tell them the information was incorrect.

Oncology healthcare professionals have also reported mixed reactions to internet use (Helft, Hlubocky, & Daugherty, 2003). A survey of oncologists (n=226) found most (56%) were accepting of patients' use of the internet and generally supportive of information seekers, although 91% believed it could cause harm (Newnham et al., 2005). Another study surveyed oncology residents (n=39) during their training program to ascertain their views of patient internet use and videoed interactions when standardized patients raised the topic of CRII (Bylund, Sperka, & D'Agostino, 2015). A total of 56% of trainees asked for clarification when patients discussed internet use, and 26% raised concerns and cautioned patients about internet use. Thus, healthcare professional responses to patients' use of CRII is not 'one size fits all'.

In the literature, providers' responses to internet information seeking have been categorized in three ways: (1) feeling threatened (health-professional centred); (2) collaborating with the patient by obtaining and analyzing the information (patient-centred approach); and (3)

guiding patients to reliable websites (prescribing information) (McMullan, 2006). It has also been documented that many healthcare professionals still caution people against using the internet because they feel it is unsuitable for every patient (Iacovetto & Allen, 2015).

Turning to nursing, integration of CRII into practice is an evolution of patient-centred care and part of ongoing situation-responsive patient education (Feeley & Gottlieb, 2000; Sopczyk, 2016). In an in-depth investigation of oncology nurses' views on internet use, Dickerson and colleagues (2005) report that nurses felt patients were using CRII to become more educated partners in care, and that it allowed patients to have greater control and understanding of their illness. However, the same nurses identified time constraints associated with engaging patients in discussions about CRII and with providing additional patient education with limited resources.

Nurses' feelings of favourability towards CRII are also noteworthy when contrasted with physicians. A study that included nurses and medical specialists (n=130) found that most professionals (84%) felt patients need more information and directed them to suitable websites (67%), but only 20% proactively referred patients to CRII (Emond, Groot, Wetzels, & Osch, 2013). Key differences were noted between nurses and medical specialists about their views of CRII. Nurses were significantly more likely to agree that CRII gave patients a greater sense of control, have a positive attitude to patients using CRII, and feel it was important to refer patients to appropriate CRII. Conversely, medical specialists were more likely to find that referring patients and their families to CRII was time consuming and that patients were prone to misunderstanding CRII. These mixed reactions and responses by healthcare professionals require further investigation, particularly as they relate to patients' use of the internet and interactions with their healthcare professionals and services.

Concerns about CRIL.

Despite the positive aspects of gathering information on the internet, it is not without actual or perceived drawbacks. One key concern about using the internet for health information cited by both healthcare professionals and patients is that a great deal of information on the internet is of questionable quality and relevance (Deshpande & Jadad, 2009; Lam, Roter, & Cohen, 2013; Verma et al., 2006). For example, one study assessed over 10,000 cancer websites to assess website quality and readability, and found inconsistencies in information across cancer type and languages (Lawrentschuk et al., 2012). Recent studies have identified comparable concerns with websites for kidney cancer (Alsaiani, Joury, Aljuaid, Wazzan, & Pines, 2016), cancer diet (Herth et al., 2016), cancer-related physical-activity (Buote, Malone, Bélanger, & McGowan, 2016), breast cancer (Nghiem, Mahmoud, & Som, 2016), colorectal cancer (Wasserman, Baxter, Rosen, Burnstein, & Halverson, 2014), and adolescent/young adult cancers (Stinson et al., 2011).

Many website analysis studies use a tool called DISCERN² (Charnock, Shepperd, Needham, & Gann, 1999; DISCERN project, 2014) or similar linear methods to assist in understanding the quality of website information, site visits, page hits, and web traffic (Booth & Jansen, 2009). Quality, as defined by the DISCERN metric, focuses primarily on a post-positivist hierarchy of evidence wherein evidence-based information, with an emphasis on Cochrane reviews and randomized clinical trials, is considered superior to all other types of content (Evans, 2003; Polit & Beck, 2012). However, limitations of the outcomes of such a narrow analysis as an indicator of quality pertain to the need for broader information about a range of topics by people with cancer.

² Charnock and colleagues do not define the acronym DISCERN in the literature.

From a nursing perspective, appraising evidence-based information as the most important, or gold-standard, for quality is problematic given the acknowledged view that the discipline accepts and holds multiple types of information and ways of knowing as a cornerstone of disciplinary knowledge (Carper, 1978; Holmes, Perron, & O'Byrne, 2006). Accordingly, there is a need to broadly consider website content to account for the multiple types of knowledge and information that might be important to people with cancer. Furthermore, many questions that might be asked from a critical and holistic nursing perspective remain unaddressed when focusing primarily on evidence-based information. A few examples include existential dilemmas raised after being diagnosed with a life-threatening illness, availability of information about cancer's impact on the family, culture, sexuality, and witnessing the experiences of others who have had the same illness. Beyond content, what websites look like and how they attract or deter people with cancer may also be worth exploring. These are all aspects of a more complete and holistic analysis that warrants consideration.

The importance of broader conceptualizations of 'quality' gain additional traction for nursing because prior studies indicate that patients may use the internet in place of information from their healthcare professional (James et al., 2007; Shea-Budgell et al., 2014). This is significant because conversations between people with cancer and their nurse (or healthcare professional) do not focus solely on evidence-based practice or clinical practice guidelines. Rather, nurses draw on their holistic knowledge base and clinical knowledge to tailor care to the whole person (Jennings & Loan, 2001). Thus, prior research assessing website content solely on the amount of evidence-based information may be of limited value when considered from a holistic nursing perspective.

Another key area of literature relates to the types of information available for different diagnoses; information available for all cancers is not equal. Numerous studies indicate an abundance of information for breast cancer but only limited information of variable quality for other cancers, such as colorectal cancer (Brigo, Igwe, Nardone, Orioli, & Otte, 2016; Nghiem et al., 2016). For example, a recent meta-analysis of colorectal cancer information revealed the internet information is incomplete and does not provide patients with sufficient information to make informed decisions (Wasserman et al., 2014). Similar concerns regarding the amount of health information are identified for laryngeal cancer (Narwani, Nalamada, Lee, Kothari, & Lakhani, 2014) as well as prostate cancer (Shah, Paly, Efstathiou, & Bekelman, 2013) and advanced cancers (Chik & Smith, 2015). This literature presents additional questions regarding the amount and type of information available online for a given diagnosis, and how this impacts peoples' subsequent or concurrent experiences and reliance on CRII and healthcare services.

The intersection: internet use and healthcare services.

Studies have documented that CRII use is prolific amongst those with cancer, but few illuminate the intricacies of CRII use and its role in interactions with healthcare services. For example, in one qualitative investigation into the role of internet use by individuals with cancer, Ziebland and colleagues (2004) conducted a narrative analysis and interviewed 175 men and women aged 19 to 83. The authors found that participants used the internet to become more competent and 'make sense' of their disease. Participants described the rationale for internet use as two-fold: to display competence to their healthcare professional and to validate the advice received from their healthcare professional. A gender analysis of this study revealed that men were more fixated on using the internet to learn about physical ailments while women were more interested in emotional and social support (Seale, Ziebland, & Charteris-Black, 2006). Thus,

men's use of CRII tended to focus on informational sources whereas women relied upon networking or social support sites, as has been documented elsewhere (S. S. Dickerson, Boehmke, Ogle, & Brown, 2006; Suzanne S Dickerson et al., 2011).

Other studies suggest that e-health interventions and internet use may hold promise for different aspects of cancer care—from diagnosis to follow-up—but limited concrete research exists. For example, one systematic review of e-health follow-up after cancer identified patients were accepting of using technology; however, data from the 13 studies considered were not sufficient to comment on the relationship with health service use or interactions with healthcare professionals (Dickinson, Hall, Sinclair, Bond, & Murchie, 2014). These findings point to the need for more qualitative research to explore and clarify the connections between CRII use and healthcare professionals and services.

Prior work.

In my Master's and other pre-doctoral research, I studied a cancer care internet intervention for patients newly diagnosed with cancer. A key concern was how it would impact the relationship between patients and healthcare professionals (Loiselle et al., 2013). For example, oncology healthcare professionals (n=16) expressed that too much exposure to the intervention could be overwhelming for patients (Haase & Loiselle, 2012). Healthcare professionals also expressed concerns about sharing the studied internet intervention with patients as it might increase the length of patient consultations in their resource-limited setting. In a secondary analysis (Haase, Strohschein, Lee, & Loiselle, 2016), patient and healthcare professionals views of the same tool were contrasted; patients described how the intervention would allow them to be more educated, take charge of their own health, and feel a sense of control but healthcare professionals were less open and described feeling that time constraints

and the risk of information overload posed a substantial challenge to their support of implementation. Thus, there was a considerable difference in the opinions of patients and healthcare professionals regarding this particular internet intervention.

This pilot work raised important questions. For example, as a precondition to participating in the study, patients were required to be internet users, but it is methodologically difficult to ask patients to differentiate their use of an internet intervention from their use of the open internet. Second, and more importantly, although providers may have considerable input into institutional internet interventions (Lapointe, 2005; Lapointe & Rivard, 2006), they do not control whether patients use the internet. They can (and sometimes do) discourage internet use or suggest websites, but patients ultimately do what they want. The literature reviewed above emphasizes the positive nature of internet use, with people describing feelings of confidence and being better able to engage with their healthcare professional. However, the mounting data have yet to explore specific questions around self-sought CRII use and interactions with healthcare professionals and services and whether patient use of CRII use plays a role in these interactions.

Summary of the Literature Review

The literature reviewed herein indicates that people with cancer are using the internet in increasing numbers, but healthcare professionals' reactions to CRII use and interactions with patients are mixed. Prior research documents a divide between healthcare professional and patient views of how CRII will impact their relationship; however, I was unable to locate any studies that explicitly explored this intersection. Moreover, analysis of CRII to date used mainly quantitative tools that assess quality using a linear positivist approach and eschew a broader holistic view of CRII, which is of particular interest to nursing. Thus, the purpose of this study is to address these shortcomings in the literature by clarifying how the context and use of CRII by

individuals newly diagnosed with cancer informs and shapes their interactions with healthcare professionals and healthcare services.

Theoretical Considerations

In this section, I position myself as a researcher, and describe my philosophical beliefs and how they have shaped the design and conduct of this research. I will also present the theoretical models and frameworks that guide this research, thereby situating this dissertation research within the context of nursing theory and philosophy.

Epistemic position.

I begin by positioning myself as a researcher, as I believe this undoubtedly shapes how this research was conducted. As a registered nurse, I believe my research should focus on the care of individuals and their families in health and illness, while maintaining a concern for the environment in which individuals and communities live (Fawcett, 1984; L. N. Gottlieb & Gottlieb, 2007; L.N. Gottlieb & Rowat, 1987). I also believe strongly in the patient-centred care movement (Delbanco et al., 2001; Lusk & Fater, 2013) and that nurses should work with individuals and families in a collaborative manner to maintain or improve quality of life (L. N. Gottlieb et al., 2006). These beliefs are the foundation on which this dissertation was built.

Philosophically, I ascribe to a constructivist view of the world. That is, I do not believe there is one truth and one true objective reality. Instead, each of us holds our own subjective truths and meanings based on our experiences in this world. Guba and Lincoln (1989) also make the argument against a universal reality, “asserting instead that realities are social constructions of the mind, and that there exist as many such constructions as there are individuals (although clearly many constructions will be shared)” (1989, p. 43). Furthermore, because realities are

socially constructed, I also believe that we cannot divorce the knower from the known; thus, positioning myself within this research is of the utmost importance because of the influence I will have on the outcome. For this reason, I feel most comfortable conducting research using naturalistic methodological approaches and qualitative methods. This also relates to my academic and research experience using feminist methods, which espouse (amongst other things) the need for reflexivity and eschew the rigidity and overreliance on objectivity often implied when using positivist methods (Doucet & Mauthner, 2006; Letherby, 2003).

At the same time, I am a registered nurse with considerable experience conducting research in cancer care and working in medical and surgical domains as a clinician and clinical teacher. Working in a positivist biomedical environment reinforces the practicality of taking an objectivist stance to apprehend certain types of phenomena. For example, a blood pressure is an objective measure and, although no two people have the same blood pressure, there are important physiological outcomes when blood pressure is far outside of the normal range. For this reason, I find merit in the values and principles of the pragmatic paradigm. That is, I accept that at certain times quantitative and closed-ended approaches to data collection can provide important information and may be the most suitable way to understand certain phenomena.

Pragmatism's main thesis is that both constructivist and positivist paradigms offer value, depending on the research question by:

...questioning the dichotomy of positivism and constructivism and calling for a convergence of quantitative and qualitative methods, reiterating that they are not different at an epistemological or ontological level and that they share many commonalities in their approaches to inquiry (Feilzer, 2010, p. 8).

In a pragmatic paradigmatic approach, researchers choose the best methods to address the problem at hand, regardless of their personal beliefs (Morgan, 2007). Many mixed methods researchers ascribe to a pragmatic paradigm because the work of mixing methods from different paradigms demands flexibility, and multiple methods allow the researcher to robustly address the research problem (Mackenzie & Knipe, 2006). In this dissertation, I use both open-ended constructivist strategies (focus groups, open-ended interviews, thematic analysis) and closed-ended objectivist strategies (consensus sampling, surveys). Although mixing methods from different research paradigms has been pejoratively referred to as ‘method slurring’ by paradigmatic purists (Baker, Wuest, & Stern, 1992), other methodologists support the importance of using a problem-focused approach rather than one that is paradigm-focused (Greene & Caracelli, 2003; Johnson & Onwuegbuzi, 2004). Thus, the pragmatic paradigm offers an opportunity to use the methods that garner the best possibility to answer the research question rather than rigidly adhering to either naturalistic or objectivist methods (Cresswell, 2014).

In summary, my main goal as a nurse researcher is to improve the lives of individuals experiencing challenges with health or illness and their families. I believe I have a responsibility to conduct research in a rigorous manner and feel my philosophical and theoretical beliefs position me well to do so. I do not inflexibly eschew either constructivist or objectivist epistemological approaches. Ascribing to a constructivist and pragmatic approach allows me to be reflexive to the research questions and to choose methods and methodologies that best address the problem at hand.

Theoretical frameworks.

This research was guided and informed by several theoretical frameworks and conceptual models within and outside of nursing. Given the diverse range of methods and the numerous research objectives, various theoretical perspectives were used. The theoretical frameworks guiding this study include an overarching theoretical perspective and models or theoretical frameworks that pertain to specific objectives. I will begin this section by presenting the overarching theoretical perspective and situating the project within contemporary nursing theory. Next, I will explain how specific models and theories were applied to certain aspects of the research project.

Overarching theoretical perspective and contemporary nursing theory.

The overarching theoretical perspective guiding this dissertation is Barbara Carper's (1978) fundamental patterns of knowing in nursing. This seminal work in nursing theory put forth the notion that the discipline of nursing is uniquely characterized by multifaceted and holistic knowledge. In her paper on the fundamental patterns of knowing, Carper articulates how the knowledge base of nursing unifies multiple ways of knowing, thereby allowing the nurse to understand the whole person (Holmes, Perron, et al., 2006). Carper's work emerged from her dissertation research, where she sought to understand the structure, form, and types of knowledge that nurses held and enacted in practice (Holtslander, 2008; Tarlier, 2005). Her work depicts the epistemological diversity in nursing, categorizing knowledge into four types: (1) aesthetic, or the art of nursing; (2) empiric, the scientific way; (3) personal, what is learned through practice; and (4) ethics, the moral aspect of nursing.

The knowledge base in nursing is often elucidated by reference to nursing practice as both art and science, capturing the aesthetic and empirical aspects of knowing (Fawcett, Watson, Neuman, Walker, & Fitzpatrick, 2001). These two types of knowing present a sharp contrast between objective empirical knowledge and subjective aesthetic knowledge. Empirical knowledge in nursing is a dominant form of knowledge in the discipline, is verifiable based on averages of group data, and, according to Fawcett and colleagues (2001), is “well established in nursing epistemology and methods” (2001, p. 116). This is in contrast to aesthetic knowledge, which has been described as a realization of the unique and particular or what is significant about the individual and the experience (Archibald, 2012). According to Carper, the artful aspect of nursing lies in the performance of nursing practice and manual skills, and also in more traditionally accepted forms of expressive visual art.

Personal and ethical knowing are two additional types of knowledge introduced by Carper (1978). Personal knowing emerges from interpersonal relationships between nurses and patients, a patient’s family members and caregivers, and members of the interprofessional team (Silva, Sorrell, & Sorrell, 1995). Carper (1978) described personal knowing as essential to understanding health and illness from the patient and family perspective; the final type, ethical knowing, refers to “matters of obligation and what ought to be done” (Carper, 1978, p. 20). Ethical knowing guides nurses to treat patients with dignity and respect, generates discussions about values and beliefs, and forms the basis of ethical guidelines of practice (Fawcett et al., 2001).

Together, the four types of knowledge create what Carper (1978) describes as the fundamental patterns of knowing. Subsequent analysis and critique of the patterns of knowing by other scholars generated three additional types of knowing. Unknowing was described by

Munhall (1993) as the intersubjective space that allows two people to come to know and understand one another(Munhall, 1993)(Munhall, 1993)(Munhall, 1993)(Munhall, 1993). White (1990) offered that the importance of contextual knowing was essential to how nurses come to understand and care for their patient, and proposed the addition of sociopolitical knowing. And, most recently, Chinn and Kramer (2011) called for consideration of factors related to social justice and health equity, calling this emancipatory knowing. Although these updates provide critique and expansion, they also reiterate the relevance and importance of Carper's original perspectives on contemporary debates about nursing theory and practice. Furthermore, many scholars have reiterated Carper's original thesis and noted that these many forms of knowledge are most valuable when taken together, rather than seceding dominance to any one type of knowledge (Bonis, 2009; Holmes, Perron, et al., 2006; Silva et al., 1995).

Carper first published her work on the fundamental patterns of knowing in 1978. Since then, healthcare and the landscape of nursing and nursing practice have changed significantly. However, the debate about the phenomena of nursing knowledge, what it is, and what it ought to be is ongoing. Most significantly, the emergence of the evidence-based practice (EBP) movement in nursing has brought new life to debates about nursing knowledge and created stark divisions in the discipline of nursing (Holmes, Murray, Perron, & Rail, 2006). Supporters of the EBP movement are scholars who believe in a hierarchy of evidence, which appraises randomized clinical trials, meta-analysis, and best practice guidelines as the most valid tools to generate knowledge, guide practice, and practice decisions (Cochrane, 1972; Mitchell, 1999; Polit & Beck, 2012). Conversely, critics of the EBP movement argue that it discounts certain forms of research that generate valuable knowledge for the discipline of nursing and excludes ways of

knowing and knowledge that are essential to nursing practice (Holmes, Murray, et al., 2006; Holmes, Perron, et al., 2006).

Unquestioned support of EBP is fraught with methodological and ontological contradictions when oriented within the discipline of nursing (Jennings & Loan, 2001). The randomized clinical trial (RCT) as the ‘gold standard’ for knowledge generation is an excellent illustration of the problems with an exclusionary positivist hierarchy of evidence (Goldenberg, 2009; Miles, Loughlin, & Polychronis, 2008). In a randomized clinical trial, patients are randomly allocated to treatment or control groups, where the control group often receives standard care. In a nursing intervention, standard care would be inclusive of the multi-faceted care that is always tailored to each patient. RCTs are considered the gold standard for their ability to control for numerous factors creating internal and external validity and to mitigate the potential for bias and spurious outcomes (Cartwright, 2007). However, within a discipline that appraises tailored care, the notion of standardized care is a tenuous assertion that presents serious challenges to the notion of internal and external validity of any resultant data (Cartwright, 2007). An empirics-focused standardized approach is also problematic as nurses have an ethical responsibility to tailor care to the sociopolitical, personal, and ethical circumstances of each person and family (Holmes, Murray, Perron, & McCabe, 2008; Porter, 2010).

Amidst dissenting viewpoints about nursing knowledge in the contemporary nursing literature, and the rise of the EBP movement pushing the superiority of empirics, the inherent value of Carper’s work persists. A recent concept analysis summarized nursing knowledge as “a uniquely personal type of knowledge, constructed of objective knowledge interfaced with the individual’s awareness and subjective perspective on personal experience; it is a dynamic process and result of personal reflection and transformation” (Bonis, 2009, p. 1330). Thus, as

debate about the dominance of empirics continues, the broader disciplinary literature seems to represent a balanced and holistic body of knowledge as originally theorized by Carper. These debates are relevant to my dissertation as they demonstrate the disconnection between factions within the discipline of nursing and where I situate my research. Thus, despite the age of Carper's original work, the classification of knowledge remains a useful lens through which to explore and critique the nature of CRII as it relates to holistic nursing knowledge.

Specific theoretical frameworks.

For Objective 1, *to qualitatively explore the content of the commonly searched CRII from a critical nursing perspective*, I used Carper's (1978) ways of knowing and Ihde's (2005) Philosophy of Technology to guide the analysis. The internet is the context of this study, thus it merited exploration to understand what patients find when they search for CRII. Despite the pervasive presence of the internet in our lives, there has been little critique in nursing about its impact on care. Philosophy of Technology provides the framework for a critical approach of new technologies, as it encourages researchers to think critically about technology (Barnard, 2002; Ihde, 2004, 2005). For nursing, this means exploring the impact of technology on nursing care and the patient experience. In this study, I used this approach to look critically at the CRII that patients accessed, with an attempt to question and critique the content of the CRII and what this means for the patient experience and for nursing. Given the nursing focus of this dissertation, I also used the work of Barbara Carper (1978) to frame the analysis of the commonly searched websites. Carper's work provided a framework to analyze the diversity of knowledge on commonly searched CRII from a holistic nursing knowledge perspective.

For Objectives 2 and 3, I sought *to explore the prompts to use CRII and how CRII informs the ways in which patients interact with healthcare professionals and services* and to

document what CRII is accessed and the patterns and frequency of use. For these objectives, the Behavioral Model of Health Service Utilization (BMHSU) was used as a sensitizing framework (Andersen, 1995). The BMHSU is one of few models designed and used extensively for the purpose of studying the process of seeking and utilizing healthcare services. This model espouses that an individual's health service use is a function of their societal and personal contexts and influences (see Figure 1.1). The model identifies four main factors shaping service utilization: (1) the environment, (2) population characteristics, (3) health behavior, and (4) outcomes.

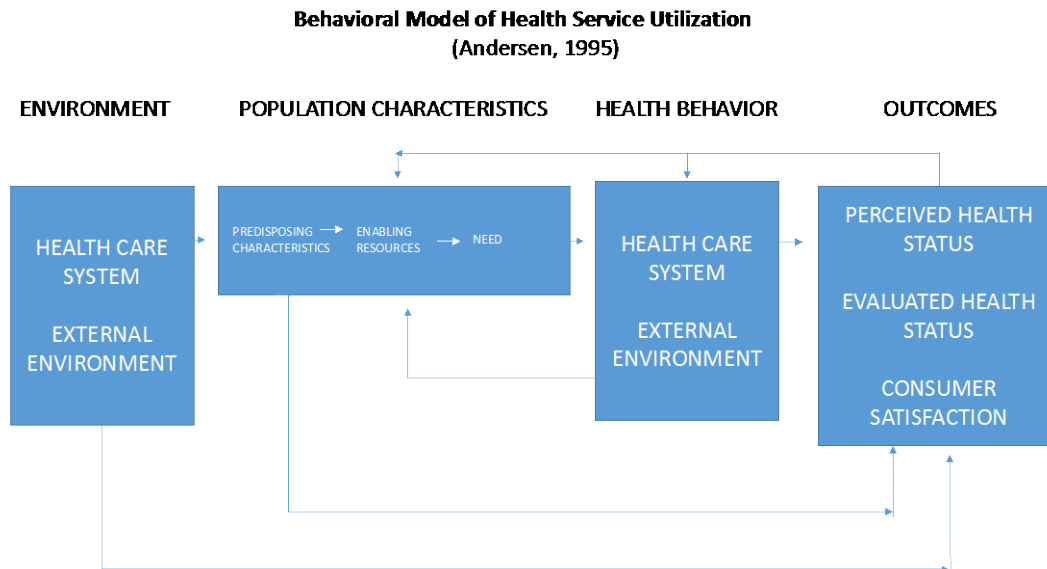


Figure 1.1

Central to this model is that health services utilization (HSU) is a function of population characteristics—categorized as predisposing, enabling, and need factors—and how these relate to health behavior. Predisposing factors are generally the sociodemographic factors that influence access to services, and include education, ethnicity, culture, age, and gender. However, some subjective elements, such as health beliefs and attitudes, values, and knowledge about healthcare,

are included (Strain, 1991). Enabling factors include logistical aspects of accessing care, for example personal and family resources and the community in which the individual lives. These factors consider the individual's proximity to care, their social relationships, insurance, and income status as well as the community's endowment with health services and resources. The final aspect of population characteristics includes perceived and evaluated need. Perceived need refers to an individual's view of their own health and whether they seek care, whereas evaluated need refers to a professional's appraisal of an individual's need for medical care (Andersen, 1995). According to the BMHSU, when an individual chooses to seek care is a function of predisposing, enabling, and need factors.

Environment and health outcomes were not part of the original BMHSU model but were added in later revisions. Initially, the terms technology and norms were meant to be inclusive of the medical environment (technology) and societal norms (norms) pertaining to the funding of healthcare and social services environment (Andersen, 1995; Andersen & Newman, 1973). The most recent model characterizes the environment as the physical, political, and economic factors, and is said to acknowledge broader social and political inputs and how these influence HSU (Evans & Stoddart, 1990). Andersen and Newman added health outcomes to the model to bring attention to an individual's perceived health status, evaluated health status, and consumer satisfaction. Health outcomes lend insight into the impact of HSU on objective and subjective measures of health. For instance, increased HSU might cost more money but create better health (effective access), and thus it is a beneficial type of HSU. Attending to health outcomes provides a mechanism to understand the impact of the aforementioned factors and is particularly important for broader health policy discussion (Andersen, 1995), in that increased HSU is not always negative but may in fact be warranted. The BMHSU is the most commonly employed

model in studies of HSU, particularly regarding access to services and predictors thereof. For example, review papers in chronic disease research (de Boer, Wijker, & de Haes, 1997), acute care (McCusker, Karp, Cardin, Durand, & Morin, 2003), and minority equity research support its predominance (Schepper, van Dongen, Dekker, Deertzen, & Dekker, 2006).

For this dissertation, the BMHSU and related literature were used as means to understand the nature of health service utilization and the factors that might drive people towards or away from services. In particular, I found the concepts of environment and population characteristics to be useful in the development of the interview guide and in participant interviews. For example, factors that could be explored regarding the patients' environment and use of CRII include whether they live in a rural or urban environment, propinquity to health services, and costs associated with the use of health services (i.e., if they do not live nearby, must they take time off of work, find childcare, pay for hotels, etc.). Whereas political factors may be less relevant in the Canadian healthcare context and to the present study, it is relevant to consider the political nature of the healthcare environment and other sociopolitical factors, such as culture and sexuality. Population characteristics were also important concepts to understand at the outset of the study as well as throughout data collection and analysis. I considered how predisposing need factors related to age, gender, and ethnicity interplay with people's use of CRII and health services. Furthermore, I explored whether enabling factors related to the logistical aspects of accessing care and people's perceived need were linked to their interactions with healthcare professionals and services and CRII use.

Summary of Literature and Theoretical Considerations

In this chapter, I have presented a summary of the extant literature underpinning the research problem. Because I have proposed to look at this issue from multiple perspectives, I

have presented literature on the context and emergence of the internet in healthcare and society at large, in the patient and provider context, the nursing context, and specific to cancer. I have also presented theoretical considerations that include my epistemic position and the theoretical work that supports and guides this study. This chapter sets the context for the study and is the foundation for the methodology and subsequent manuscripts.

Chapter 2: Methodology

In this chapter, I present the methodology for the entire dissertation. This chapter expands upon the methodological information provided in each manuscript, as I present a detailed rationale for decisions made before and during the study. The research protocol provides an account of the planned study, but here I detail how the study unfolded with details of reflexive decisions made throughout (Haase, Thomas, & Gifford, 2016) (see Appendix A). A summary of the differences between the published protocol and the narrative in this chapter can be found in table 2.1. The overarching purpose of this dissertation is to explore how the context and use of CRII by people diagnosed with cancer informs and shapes their interactions with healthcare professionals and services.

Table 2.1: Variations between the published protocol and actual study methods		
	Published Protocol	Actual study methods
Patient sample size and composition	16-20 people with breast, colorectal, prostate, and lung cancer	19 people with breast, prostate, colorectal, and gastrointestinal cancer
Sample population	People newly diagnosed with cancer	People newly diagnosed with cancer and healthcare providers
Analysis	Use of DISCERN criteria in website analysis	Chose not to use DISCERN based on goals of paper and research question.

Research design

I chose an embedded mixed methods design to address the complexity of the research objectives and generate a comprehensive understanding of the research problem using inductive and deductive methods (Cresswell & Plano Clark, 2011). The embedded design mixes different types of data at the design level, where one type of data is embedded within the methodological approach of the overarching data type. In this dissertation research, the overarching methodology

is Interpretive Description (ID), which guides the collection and analysis of *qualitative data* and addresses *Objectives 1 and 2*. The qualitative data come from three data sources: (1) a review of 20 websites, (2) 38 interviews with 19 individuals newly diagnosed with cancer, and (3) three focus groups and four interviews with 21 healthcare providers. The supplemental *quantitative component* relies upon surveys completed by the same 19 patient participants and provides a further description of the research problem, thereby addressing *Objective 3*. Finally, the data from the qualitative and quantitative components were integrated and triangulated, thereby clarifying the role of CRII in interactions with the healthcare system by individuals newly diagnosed with cancer and addressing the overarching goal (see figure 2.1).

Embedded Mixed Method Design: Data sources and integration plan

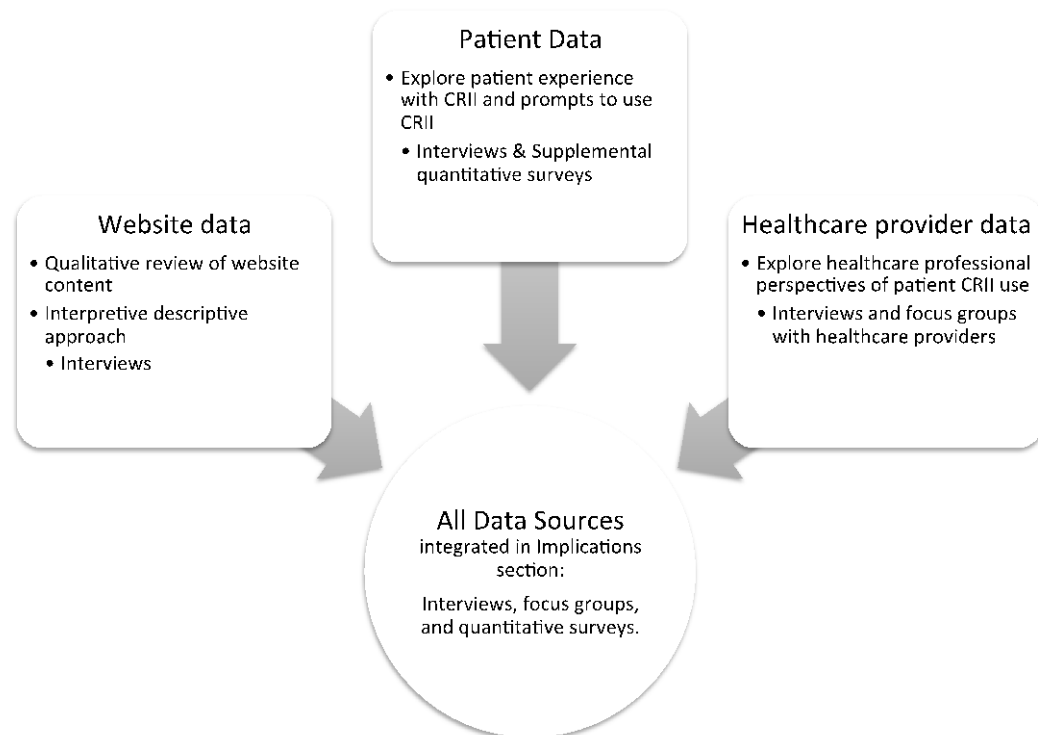


Figure 2.1

The overall paradigmatic thrust of this study ascribes to a constructivist epistemology and uses a pragmatic methodology (Guba & Lincoln, 1994). The overarching methodological approach is ID, which is compatible with a constructivist approach and with mixed methods designs (Thorne, 2016). Thorne (2016) describes ID as an appropriate method to generate a better understanding of complex questions that arise from practice-based disciplines, such as nursing, without sacrificing rigour or taking on overwhelmingly large studies with the risk of losing a practice focus. ID is a suitable methodology for addressing research questions pertaining to nursing practice when it is not feasible or appropriate to attempt to meld these questions into the research methodologies originating in other disciplines, such as sociology (grounded theory), anthropology (ethnography), or philosophy (phenomenology). According to Thorne (2016), ID is

...an approach to knowledge generation that straddles the chasm between objective neutrality and abject theorizing, extending a form of understanding that is of practical importance to the applied disciplines within the context of their distinct social mandates. It responds to the imperative for informed action within the admittedly imperfect scientific foundation that is the lot of human sciences (Thorne, 2016, p. 29).

ID serves to guide the generation of knowledge for practical disciplines by providing a methodological approach attuned to the complexities inherent in human sciences, such as nursing.

The goal of ID is to move beyond qualitative description and provide a detailed account of a clinical problem, interpret the meaning, and understand the relationships and patterns of the phenomena of interest. A further clarification is that ID should not create a new theory or a whole new truth; rather, the goal is to create a sense-making structure about the common nature of clinical phenomena that informs clinical reasoning (Thorne, Reimer Kirkham, & O'Flynn-

Magee, 2004). Thorne (2016) encourages researchers to look below the surface of clinical issues via systematic exploration and thorough analysis of these issues, providing new knowledge and understanding of the given phenomena within the confines of a practically-oriented methodology. Thorne (2016) also supports the use of mixed methods alongside an ID approach, and asserts that the method is nimble enough to work flexibly with both qualitative and quantitative methods, noting it is

...unfettered ... by the more theoretical baggage of some of the conventional social science approaches and more pragmatically suited to posing questions that are strategically targeted toward that which lurks in the shadows beyond what can be illuminated by measurement options (Thorne, 2016, p. 267).

In summary, ID is a reflexive and responsive methodological approach, allowing diverse use of research methods to create robust understanding of the research problem.

Setting

This study was conducted at the Saskatchewan Cancer Agency, a University-affiliated cancer treatment centre in Saskatoon, Saskatchewan. This cancer centre provides cancer treatment to the local and northern populations of the province. The cancer centre has two main sites: the Centre and the Lodge. The Centre is where treatment and clinical appointments take place and is physically connected to Royal University Hospital. The Lodge is located a short walk from the Centre and provides accommodations for individuals from out of town who are receiving a course of treatment or attending appointments. Participants involved in this study—including patients and healthcare professionals—were recruited at both locations.

Sample

The study sample encompasses three data sources: websites, people with cancer, and cancer healthcare professionals.

Cancer websites.

Initially, a purposeful sample of 12 websites was selected using a consensus search strategy. In this case, consensus refers to the agreement achieved by querying common search terms on popular search engines. Specifically, this strategy included searching cancer-related terms on three of the most popular search engines (Google, Yahoo, and Bing) (Experian, 2014) and sorting the findings into the top three results from each search engine; this method is increasingly accepted in the study of websites (Alsaiani et al., 2016; Kaicker, Debono, Dang, Buckley, & Thabane, 2010). An additional sample of eight websites was incorporated as participants were queried about them during interviews. Based on feasibility balanced with the need for depth, a sample of approximately 30 pages was analyzed for each of the 20 websites reviewed. Website data were reviewed between June 2015 and July 2016. Details of the analysis follow below.

Patient sample.

The sampling strategy for people newly diagnosed with cancer was both purposeful and theoretical. Initially, a sample of maximum variation was sought; theoretical sampling strategies were initiated later in recruitment and are detailed below.

Participants recruited for the study met the following inclusion criteria:

- (1) A histologically confirmed, first diagnosis of cancer (all stages);

- (2) Diagnosis within the last 6 months, or prior to seeing an oncologist;
- (3) At least 18 years old;
- (4) Fluent in English;
- (5) Able and willing to take part in interviews and complete questionnaires;
- (5) Unrestricted access to the internet; and
- (6) Affirmed use of the internet for cancer-related information.

Participants were excluded if they had been previously diagnosed with cancer (excluding superficial skin cancer).

Although the notion of data saturation is commonly relied upon in qualitative work (Caelli, Ray, & Mill, 2003), Thorne (2016) argues it is inappropriate as one can never know if new information will arise in subsequent interviews, especially within the context of non-random sampling strategies. Similarly, arbitrarily specific numbers of participants have been suggested, such as 12 (Guest, Bunce, & Johnson, 2006) or 15 (Kvale, 1996), after which saturation might be expected to occur. Instead, Thorne argues that researchers should expect a sample size based upon the anticipated number of unique patient profiles or cases as well as consider what is feasible within the constraints of the study. Thorne also urges flexibility in the sampling approach, using strategies such as concurrent analysis and constant comparison to be responsive to the emerging sample and to topics that warrant further exploration. Based on the aforementioned sampling approaches, a sample of 16 individuals was desired at the outset of this study with the intention of revisiting this sample as recruitment efforts and constant comparison analysis evolved.

During data collection, many of the patients approached by clinicians and willing to participate in the study had breast cancer. After approximately 12 participants had been interviewed, I noted commonality in the emerging themes. At this point, only two men and a handful of individuals with a diagnosis other than breast cancer had been interviewed. I consulted with the clinicians recruiting patients and asked them to focus on men with cancer and women with diagnoses other than breast cancer. This proved useful to explore variations according to both gender and cancer type. Seeking a more diverse sample also allowed an understanding of the phenomena amongst those with varied diagnoses. Variations in information by cancer type have been documented. For example, an abundance of information about breast cancer exists, whereas information about other cancers, such as colorectal, is harder to find (King et al., 2010; Nagler et al., 2010). Thus, the final sample was larger than planned (n=19), which only served to more robustly address the research problem.

Healthcare professional sample.

As data collection and concurrent analysis were occurring, interaction with the healthcare professionals involved in recruitment proved fruitful and insightful. Therefore, I consulted with my supervisors and made the decision to add a purposeful sample of healthcare professionals to the inquiry. Healthcare professionals working directly with patients at the cancer centre were approached to take part in the study. These professionals included medical oncologists, registered nurses, social workers, dieticians, and pharmacists. A sample size of ten individuals was sought initially, as this represented the approximate number of providers involved in patient recruitment. However, I had an excellent response from clinicians, which garnered a larger and more interprofessional sample than anticipated (n=21).

Recruitment

Patient recruitment.

Recruitment was completed through three strategies (discussed in more detail below): (1) physician and nurse referral; (2) the new patient intake coordinator; and (3) new patient orientation sessions. To ensure the success of this strategy, several meetings were held with stakeholders at the cancer centre to ensure the feasibility and acceptability of these recruitment approaches. I worked closely with the Director of Nursing and Director of Supportive Care to connect with appropriate gatekeepers at the cancer centre. Recruitment of patients took place between September 2015 and July 2016.

Strategy 1.

Medical oncologists and nurses were asked to refer newly diagnosed patients fitting the study criteria (Appendix B). Healthcare professionals involved in recruiting for the study approached patients at their clinic visits. When the healthcare professionals determined a patient was eligible, they would ask the patient if they were interested in the study (see Appendix B). If interested, the patient's name and contact information was recorded and a list of such information was provided to me once a week. I contacted interested patients over the phone and provided more in-depth information about the study (see Appendix B). If patients were interested in taking part, a time for a first interview was set.

Strategy 2.

All new patients at the cancer centre are contacted by a social worker in the role of New Patient Navigator (NPN). During this phone call, patients are provided with information about their course of treatment and invited to attend a monthly orientation session. I met with the

NPNs, first as a group and then individually, to explain the study. NPNs agreed to mention the study to patients during their new patient phone call, when they felt it was appropriate, using a provided script (see Appendix B). The contact information for interested participants was recorded and reported to me by phone as needed.

Strategy 3.

New patient orientation sessions are held on a monthly basis to provide information to newly diagnosed patients. I attended these information sessions on three occasions in 2016, and was invited to talk briefly about my study at the end of each session. I stayed at the orientation session until all patients had left and provided information and brochures to interested patients. The contact information of interested patients was recorded and, when possible, appointments for an initial interview were arranged.

Healthcare professional recruitment.

Healthcare professionals involved in the study were contacted by phone and email (Appendix B) and asked about their willingness to take part in an interview or focus group. Specifically, medical oncologists, nurses, and social workers with direct patient contact were invited to take part in the study. Dietitians and pharmacists also heard about the study and expressed interest and were subsequently recruited. Recruitment of healthcare professionals took place between April and August of 2016.

Data sources

This study had four data sources: (1) cancer websites; (2) quantitative surveys; (3) qualitative interviews with patients; and (4) qualitative interviews and focus groups with healthcare professionals.

Cancer websites.

The website data addressed *Objective 1: to qualitatively explore the content of the most commonly searched ICIR from a critical nursing perspective*. Although a number of tools have been developed to determine quality, accuracy, and readability of websites and focus on rating or ranking quality (Kaicker et al., 2010), the goal of this analysis was to qualitatively explore the context of CRII from a critical nursing perspective. We initially planned to use partial criteria from DISCERN (Deborah Charnock, 1998; DISCERN project, 2014), a tool designed to help patients and professionals assess the quality of health information online, alongside qualitative analysis. I proposed drawing on DISCERN sections related to reliability and quality of information alongside criteria from Carper's (1978) framework to facilitate analysis from a holistic nursing perspective. However, as the analysis began it became clear that DISCERN was less useful than anticipated, and questions such as "is it clear" or "is it relevant" were difficult to address. As such, it added little knowledge to the critique and exploration of website knowledge. Instead, I relied solely on Carper's framework and Ihde's (2005) Philosophy of Technology and felt this approach more adequately addressed the objective.

Surveys.

Surveys with each participant addressed *Objective 3: To document the CRII accessed and the patterns and frequency of use*. Data on patients' age, gender³, income, education, diagnosis, treatment, and existing medical conditions were collected through a self-report questionnaire that was designed for the purpose of this study (Appendix C). Data on CRII were collected through a self-report survey, drawing on prior surveys of internet use by individuals with cancer

³ Throughout this dissertation I use the term gender to refer to male/female differences. In keeping the Canadian Institutes of Health Research (CIHR) Gender and Sex definitions, gender is used to refer to the "socially constructed roles, behaviors, expressions, and identities" (CIHR Gender and Health, 2015).

(Eysenbach, 2003; Kelly, Jenkinson, & Ziebland, 2013; van de Poll-Franse & van Eenbergen, 2008). Surveys were conducted prior to the qualitative interviews.

Qualitative interviews with patients.

In-depth interviews were a key source of patient-derived data in the qualitative inquiry. The initial interview guide (see Appendix C) addressed *Objective 2: To explore the prompts to use CRII and how CRII informs the ways in which patients interact with healthcare professionals and services*. The interviews were semi-structured around a list of trigger questions to facilitate exploration and description of the areas described above (Thorne et al., 2005). The questions were informed by concepts from the BMHSU, specifically regarding environment and population characteristics. Example questions included “What role has the internet played in your use of health services?” and “Can you think of a time when you went to the internet instead of your healthcare professionals for information?” Due to the emergent nature of qualitative research, the interview questions were modified as interviews evolved and as concurrent analysis took place (Thorne, 2016).

Participants took part in two interviews. The second interview was conducted anywhere from 2 weeks to 4 months after the initial interview; this discrepancy was related to patient and researcher availability. In many cases, the second interview was conducted over the phone to facilitate the ongoing participation of patients in rural and remote areas who only come to the clinic sporadically. The second interview revisited topics from the initial interview that required further clarification. The second interview was also an opportunity to clarify themes brought forward in interviews with other participants. I also engaged in a process of member checking related to salient emerging themes. However, I went beyond a straightforward presentation of “is this what you said” (Carlson, 2010) and sought clarification and expansion by asking “this is

what you said, can you tell me more about this” (Thorne, 2016). This proved extremely insightful, allowing patients to expand upon their initial ideas. Using this strategy, I was able to gain a deeper understanding of patient perceptions.

All initial interviews lasted between 30 and 60 minutes. In some cases, interviews were cut short due to treatment ending or other patient-related constraints. In cases where initial interviews were shortened, relevant questions were revisited during the follow-up interview. All interviews were digitally audio-recorded with participant consent.

Qualitative interviews and focus groups with healthcare professionals

In-depth interviews and focus groups with healthcare professionals emerged as an interesting and important source of information as the study unfolded. These interviews also addressed *Objective 2: To explore the prompts to use CRII and how CRII informs the ways in which patients interact with healthcare professionals and services* from the healthcare professionals’ perspective. An interview guide of open-ended questions was generated based on concepts emerging from patient interviews (see Appendix C). Example interview questions included “Can you describe for me what kind of information you think your patients find on the internet?” and “Can you think of a time when a patient shared information they found on the internet?” All interviews and focus groups lasted between 30 and 90 minutes and were audio-recorded with each healthcare professional’s written consent.

Data collection procedures

Websites.

Collection of the initial sample of website data was completed prior to participant interviews. Additional websites were analyzed as participants discussed them during their

interviews. Some participants were unsure of what websites they used. For these participants, we used a ‘think aloud’ method to elicit which websites they visited (Fonteyn, Kuipers, & Grobe, 1993; Hoppmann, 2009). This method sees the researcher and patient engage in a step-by-step conversation to understand what the participant did. For example:

Interviewer: Tell me how you searched?

Participant: I clicked on this compass button on my iPad.

Interviewer: Okay, and then what did you do next?

Participant: I typed in the words ‘breast cancer’.

Interviewer: And which results did you click on?

I found this method useful, particularly with older adults who were less familiar with computers, technology, or which websites they had visited. This allowed me better insight into the search terms they used, the websites they used, and how they settled on certain websites. New websites that patients mentioned were added to the sample and analyzed, whereas duplicate websites were noted and not re-analyzed.

Surveys.

Before patient interviews were completed, participants were asked to complete a questionnaire on their background information and CRII use. This took approximately 10 minutes.

Interviews.

Both patient and healthcare professional participants meeting the eligibility criteria were asked to identify a convenient time for an interview. Interviews took place at a mutually

agreeable and suitably private location, such as a clinic room or the participant's home. At the beginning of each interview, participants were asked to read and sign a consent form to take part in the interview, and reminded that interviews would be audio-recorded and that their participation was voluntary. Interviews lasted approximately 30 to 60 minutes. Following completion of the first interview with patients, the second interview was arranged. A second interview was not conducted with healthcare professionals.

Healthcare professional focus groups.

Healthcare professionals in groups of three or more people (i.e., nurses) were invited to take part in focus groups. Focus groups were scheduled at mutually agreeable times in the Centre or the Lodge. At the beginning of each focus group, the purpose was explained and participants were asked to sign a consent form and reminded that their participation was voluntary. A discussion about confidentiality took place before each focus group started and emphasized that participants could not be guaranteed anonymity because there were other members present. As such, I requested that group members keep the discussions private. Focus groups lasted between 45 and 90 minutes and were audio-recorded. For groups of four or more, two recorders were used and two facilitators were present. Notes were kept during the focus groups in case recordings were unclear and to note salient concepts or ideas.

Data analysis

Qualitative analysis.

All qualitative data analysis was conducted using ATLAS.ti qualitative software (version 7) and was concurrent with data collection; that is, transcripts were analyzed after each interview and prior to the second interview (for those participants interviewed twice). Thorne (1997)

recommends that analysis in ID commence with immersion in the data, reading and re-reading the data, and then attempting to gain an overall impression of the data by asking “what is happening here?”; subsequent “synthesizing, theorizing, and recontextualizing” (p. 175) of the data commenced via a step-by-step analytic strategy described in further detail below.

Websites.

The website analysis commenced by reading pages of website data guided by the questions described above to address *Objective 1: To qualitatively explore the content and context of the online environment*. The website analysis was also a critique, informed by a critical view of technology, described in the Philosophy of Technology (Ihde, 2005). Screen captures were taken of pages from all pertinent sites and saved in ATLAS.ti. Next, using the probes from Table 2.2, website data were reviewed with examples of exemplary information highlighted and coded. Themes were generated and applied to notable exemplars on each screen shot. Memos regarding researcher interpretations and comments were kept in ATLAS.ti. Codes were grouped according to emerging themes. Themes were then compared across websites and between the initial sample of websites and those reported by participants. Themes were then fitted into a framework with the corresponding types of knowledge.

Table 2.2: Carper's fundamental patterns of knowing (Carper, 1978)

Pattern of Knowing	Questions for analysis
Empirical	How are medical treatments and tests addressed? What data sources are referenced? What is the positioning and placement of biomedical versus psychosocial information? Are certain types of information predominant compared to others?
Personal	What aspects of personal reflection are addressed? Are existential, reflective or personal aspects addressed?
Ethical	Are matters of conflict or ethics addressed? Are conflicts of interest declared?
Aesthetic	What visuals are presented? How is the information expressed?
Sociopolitical	How are factors known to influence cancer care, such as location (rural/urban), age (e.g., of people in photos), ethnicity, ability/visible disabilities, social status attended to on the websites?

The initial framework of findings was then shared amongst members of my dissertation committee before being presented at an international conference on cancer nursing. Discussion and negotiation around the themes in each category occurred until all parties were satisfied with the analytic framework. During the conference, feedback about the categories and salient concepts pertinent to cancer nursing were raised and incorporated into the ongoing analysis. For example, one nurse raised the importance of literacy level or readability. Although this was not a key finding in the analysis, it did open up a discussion about other factors of equal importance; the analytic framework was refined to accommodate these comments. The goal of the analysis—to qualitatively explore the content of commonly searched CRII from a critical nursing perspective—was revisited throughout the analytic process.

Interviews and focus groups.

Recordings of patient and healthcare professionals interviews and focus groups were transcribed verbatim and analyzed according to the method of thematic content analysis described by Thorne (1997b; 2004). Transcripts were first read to gain an overall understanding of the interview. Following the initial reading, transcripts were read again with the goal of

inductively deriving conceptual themes and assigning codes, first within and subsequently across the transcripts. Detailed notes about codes were kept in the electronic documents in ATLAS.ti, and emerging codes and notes were analyzed and grouped according to emerging themes. Next, conceptual themes were organized into an analytic structure to guide exploration within and between individual cases. The analytic structure took shape through ongoing analysis, writing, and conversations with my supervisors and committee members. Categories were populated with themes, and themes were expanded, revised, and discarded through ongoing analysis. In keeping with Thorne's (2016) advice, I tried to approach the analytic structure from multiple angles by asking myself contrary questions and theoretically sampling to refrain from becoming attached to the analytic framework too early in the analysis process. For example, some participants were willing to take part in the study but reported not using the internet for cancer information as a deliberate strategy. I chose to interview one of them to explore and understand the decisions she made and her rationale, which helped to understand the experiences of those who did not choose to use the internet for cancer information.

Once the analytic structure was refined through the process of ongoing analysis and comparison, I revisited two initial questions: "what is happening here?" and "what is the relationship between CRII and interactions with healthcare professionals and services?". The goal was to go beyond describing the problem and attempt to interpret the meaning of the findings within the context of the study. I tried to create an analytic framework fitting with Thorne's guidelines: it should inform clinical reasoning, assist in practice and practice decisions, and be a sense-making structure for differences that might occur in practice (Thorne, 2016; Thorne et al., 2004). The refined analytic structure was then shared with my dissertation

supervisors, wherein discussion and negotiation took place to flesh out and clarify the categories and enhance the analytic framework.

Quantitative analysis

All quantitative data analysis was carried out using SPSS (version 22). Data were checked for accuracy and completeness to ensure the data attributed to each variable were valid and accurate (Clarke & Cossette, 2000). Descriptive statistics (means, medians, and frequencies) were used to depict sample characteristics. Patterns of CRII use were generated by calculating summary scores of total CRII by type and frequency of use.

Integration of qualitative and quantitative data

In concordance with a mixed methods design, decisions about the integration of the many types of data were made prior to the outset of the research and revisited during the study. The plan to integrate the data was as follows: (1) results from the quantitative analysis would be used to interpret participant CRII use in greater depth; and (2) data from interviews, websites, and surveys would be triangulated to construct a better understanding of how CRII informs patients' interactions with healthcare professionals and healthcare services.

In reality, the quantitative patient data did lend depth and insight into the understanding of the qualitative data. These data were integrated in the results phase. That is, both datasets were first analyzed independently and then triangulated to assist with the interpretation of results (Morse & Niehaus, 2009). The second step, to triangulate all data—interviews, focus groups, website data, and survey data—also took place in the results phase. The purpose of triangulation, as it is applied in this dissertation is to engender multidimensionality of the research findings, and not to enhance validity. Enhancing validity through triangulation is not congruent with the

constructivist methodological orientation of this project. Triangulating this many data sources and integrating the results was challenging, particularly for a novice researcher. However, together these findings provide rich and robust data to address the research problem. To integrate and triangulate all of the study findings, I used an approach similar to the triangulation protocol described by Farmer and colleagues (Farmer, Robinson, Elliott, & Eyles, 2006). These authors suggest the use of a convergence coding matrix, wherein the findings from all studies are compared using a table format. This approach guided me to consider agreement and disagreement between themes collectively, rather than related to the method (O’Cathain, Murphy, & Nicholl, 2010). The table found in Chapter 6 acted as the convergence coding matrix to compare all study findings.

Evaluation of rigour

In consideration of methodological rigour, several steps were taken before, during, and after the research commenced. Rigour in qualitative research is key to establishing the trustworthiness of the findings (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Thorne (2016) distils many approaches to rigour into one unified approach that presents integrity, credibility, analytic logic, and interpretive authority as guiding principles. In this study, I used these approaches to ensure a rigorous and trustworthy outcome. I saw this as a process occurring throughout the research, with each decision I made, rather than a checklist of tasks to be completed and forgotten.

Epistemological integrity refers to ensuring defensible coherence between the research question, study design, and methods (Thorne, 1997a). In this study, I used a constructivist mixed methods approach that relies upon inductive and reflexive methods. For example, I found it important during the research process to add the voices of healthcare professionals, and therefore

additional approvals were sought and healthcare professionals were interviewed. I also clearly outlined my epistemological positions to ensure transparency with respect to researcher influence on the study findings (Finlay, 2006).

Credibility is defined as confidence in the believability and trustworthiness of findings (Lincoln & Guba, 1985; Whittemore, Chase, & Mandle, 2001). Numerous strategies were used to ensure credibility, including triangulating multiple data sources, theoretically informed sampling strategies, negative case analysis, and member checking (Barbour, 2001). Sampling strategies were purposive and theoretical, and recruitment continued until a solid and rich description of the research problem emerged from multiple and diverse perspectives versus sampling until a predetermined notion of saturation occurred. For example, I noticed repetition of themes from 12 participants (as described above), but chose to broaden the sample using theoretical sampling strategies rather than ceasing sampling at this point. Member checking occurred during the second interview with each participant. However, I heeded the caution urged by several authors and did not use the member checks simply to confirm my findings or what participants had said at the risk of becoming overly confident in the analytic framework (Carlson, 2010; Cho & Trent, 2006). Rather, I used member checking to allow participants to expand upon, or refute, my interpretations of their words. This was an insightful and fruitful analytic and methodological tool.

Analytic logic is defined as the ability of an outsider to understand the decisions made by the researcher from the outset (Miles & Huberman, 1994). I attempted to explicate the research process through memos kept in Atlas.ti and an audit trail of key decisions. These pieces of evidence were invaluable when revisiting key decisions pertaining to coding or sampling strategies. For instance, when conducting the analysis of the websites I kept memos regarding

my impressions of certain information on each website. These memos provide insight into the codes that were then fitted into each theme. During conversations with my committee, these memos were revisited as I was asked to justify or explain certain aspects of the analysis, themes, and codes.

Interpretive authority is defined as the goal to “ensure that a researcher’s interpretations are trustworthy, that they fairly illustrate or reveal some truth external to his or her own bias or experience” (Thorne 2016, p. 235). This also includes clarifying the difference between experiences that may be unique to one individual and experiences that might be more commonly shared amongst all or more than a few participants. I attempted to demonstrate interpretive authority by grounding the findings in the data and using supporting exemplary quotes to demonstrate the truths shared by participants. For instance, in each of the manuscripts I used exemplary quotes to support the interpretations and conclusions I made.

Together, these four strategies demonstrate the numerous steps taken to adhere to a rigorous and trustworthy process throughout this mixed methods study. These strategies ensure a technically strong study with practical application (Thorne, 2016).

Ethical considerations

Ethics approval was sought and received from the University of Ottawa and the University of Saskatchewan (see Appendix D). All individuals interested in study participation received full verbal disclosure. All participants who expressed interest following the disclosure were asked to read and sign a consent form explaining the study (see Appendix D). Participants were again reminded that their interview would be recorded and of their right to withdraw. Participant privacy was preserved by coding participants’ identity on all information collected by assigning each participant a number and storing the data in password protected electronic files on

a password protected computer, with restricted access to the participant coding key. Use of the participant data in publications is not/will not be specific enough to permit the identification of individual participants. For example, patient participants will not be identified by age, diagnosis, and treating centre, and healthcare professional participants will not be described beyond their profession or specialty area. All data (electronic and paper) will be stored for a maximum of ten years after which time it will be destroyed.

Chapter 3: Manuscript 1

A qualitative review of cancer websites from a critical nursing perspective

Relationship of manuscript 1 to the dissertation

The manuscript presented in the following section is a qualitative review of websites from a critical nursing perspective. This analysis was guided by Carper's (1978) patterns of knowing in nursing and an interpretive descriptive methodological approach (Thorne, 2016). The websites reviewed herein capture an array of cancer information and content, focusing on diagnosis, treatment, and survivorship. Findings from the analysis reveal an emphasis on detailed empirical information focused on treatment and diagnosis with limited information on more holistic content. For nursing, the results of this analysis imply a need to critically assess patient resources and the type of information patients find online. Contrasted with the holistic multifaceted knowledge that nurses provide, website information alone proves problematic due to its heavy focus on empirical information.

This manuscript was written in APA format (sixth edition, 2009) to meet the guidelines for the journal *Nursing Inquiry* where it was submitted in August 2016. It has been reviewed, revised, and resubmitted according to reviewer comments.

Abstract

People diagnosed with cancer typically want information from their doctor or nurse. However, many individuals now turn to the internet to tackle unmet information needs, and to complement healthcare professional information. The purpose of this study is to qualitatively explore the content of commonly searched cancer websites from a critical nursing perspective, as this information is accessible, and allows patients to address their information needs in ways that healthcare professionals cannot. This qualitative examination of websites is informed by Carper's fundamental patterns of knowing, and complemented with the critical view to technology espoused by the philosophy of technology. We conducted a review of 20 websites using a two-step interpretive descriptive approach and thematic analysis. We identified the dominant discourse to be focused on empirical information on treatment, prognosis, and cure, and a paucity of sociopolitical, ethical, personal, and esthetic information. In place of holistic, nuanced, and accurate knowledge nurses may provide, patients find predominantly empirical and biomedical information online. Discussion explores and critiques online cancer content, gaps in information, and the importance of information diversity. Implications focus on needed discourse around pervasive technologies and the nursing role in assessing and directing patients to holistic information.

Word limit: 200 words (current 195)

Manuscript 1

A qualitative review of cancer websites from a critical nursing perspective

Cancer is a leading cause of morbidity and mortality both globally and in Canada (Canadian Cancer Society, 2015). Individuals faced with a diagnosis of cancer have many information needs regarding their physical and psychosocial health as they face a cancer diagnosis (Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 2013). To meet these needs, most individuals with cancer prefer to receive health information from their nurse or physician (James et al., 2007; Shea-Budgell, Kostaras, Myhill, & Hagen, 2014). However, clinicians are not typically available around the clock, clinic visits can be rushed, and patient questions do not always come up during clinic appointments (Davis, Schoenbaum, & Audet, 2005). This puts patients in a precarious situation, where they may want and need information but their preferred source is not always readily available. This has led patients to seek more readily accessible cancer information via the internet, in growing numbers (Shea-budgell et al., 2014). Exploring and critiquing the content of cancer information patients access on the internet is worth further exploration related to its potential implications for the patient experience, and nursing practice.

Since the advent of the internet, individuals have turned to their computers and, more recently, their mobile devices for health information (Bryans et al. 2015). This affinity for internet cancer information has grown exponentially, particularly as access to the internet has become more widely available (Peterson, Shen, Weber, & Bylund, 2017). Health information that was once reserved to libraries and hospitals has been democratized and is readily accessible at all hours of the day from virtually anywhere (Timmons, 2001). Reliance on internet information is both a complement and a challenge to cancer clinicians. For example, patients can more readily find information to manage their illness (While & Dewsbury, 2011), but clinicians

have concerns about the quality of information patients access and their ability to understand it (Bylund, Sperka, & D'Agostino, 2015). Due to the ubiquity of online information, there is a sense of urgency with respect to testing and studying the effects of a broad range of internet-based programs and websites on various patient outcomes (Murray, Burns, SeeTai, Lai, & Nazareth, 2005). Although some research has documented patient access and search patterns, many of these studies draw anonymously from website analytics and use quantitative methods (Ofra, Paltiel, Pelleg, Rowe, & Yom-Tov, 2012; Wasserman, Baxter, Rosen, Burnstein, & Halverson, 2014). Unfortunately, these studies are limited as they do not closely examine the content of the websites, nor do they provide in-depth analysis of the information available to patients.

For nursing, the turn to information on the internet poses additional questions beyond issues of metrics and accessibility. Nurses possess expert knowledge about health and illness from a holistic perspective — the whole person and the environment in which it is experienced (Fawcett, 1984; Thorne, 2013). A holistic perspective reflects the pluralistic nature of nursing knowledge and the importance of multiple ways of knowing to understand and care for the whole person (Holmes, Perron, & O'Byrne, 2006). Carper (1978) identified that nurses express this knowledge in four fundamental patterns: empirically, esthetically, ethically, and personally. When communicating health information to people with cancer, nurses mobilize these multiple ways of knowing to provide complete and holistic care. Conversely, when people with cancer turn to the internet for health information, instead of to their nurse, the nature and quality of the information patients' access should be questioned. We feel that further exploration is warranted to determine if the information people find online is holistic and nuanced, such as what nurses may provide.

The purpose of this study was to explore and critique the content of the internet cancer milieu to better understand cancer-related internet information (CRII) from a nursing perspective. We do so in the spirit of moving past superficial analysis of website traffic patterns and analytics, to examine the nature of the information and content that patients access, when they look for cancer information, without the guidance of their nurse or healthcare professional, which is so often the case. The research question guiding this study is: What is the content and context of commonly searched cancer websites from a critical nursing perspective?

Conceptual Framework

As the goal of this study was to explore and critique the content and context of commonly searched cancer websites from a critical nursing perspective, we considered theoretical frameworks and models that reflect the complexity of nursing knowledge. Carper's (1978) fundamental patterns of knowing in nursing is a seminal work in nursing knowledge. Carper presents a classification of numerous sources from which knowledge is derived in nursing practice, and reflects the epistemological diversity of thought in the discipline (Holtslander, 2008; Tarlier, 2005). Carper's original work emerged from a qualitative analysis of the concepts, structure, form, and patterns of nursing knowledge (Carper, 1978). These ways of knowing form a foundation for thinking about nursing knowledge in a holistic sense and, moreover, form "horizons of expectation and exemplify characteristic ways of thinking about phenomena" (Carper, 1978, p. 13). The four knowledge types, or patterns, identified by Carper are empirical, esthetic, personal, and ethical; later additions include socio-political knowing (White, 1995), emancipatory knowing (Chinn & Kramer, 2011), and unknowing (Munhall, 1993). Carper's characterization of knowledge in nursing reflects the complex and holistic nature of nursing knowledge and provides a practical framework to approach the analysis of cancer-related internet

information. Carper's work remains relevant today, as it highlights the multi-faceted essence of nursing knowledge, where all knowledge types are regarded as equal. However, it is an additional contribution to the voices in nursing problematizing the dominance of post-positivist knowledge, which appraises empirically focused evidence-based practice, clinical practice guidelines, and randomized clinical trials as the most valuable type of knowledge (Holmes, Murray, Perron, & McCabe, 2008; Holmes et al., 2006).

For the purposes of this analysis, the four original types of knowing plus socio-political knowing were considered. Empirical knowledge has long been characterized a dominant source of knowledge for nursing. It encompasses fundamental knowledge for nurses, such as the physiology of the body, disease, and principles of objectivist positivist and post-positivist science (Tarlier, 2005). This is perhaps often conflated to be the main, and most valuable, type of knowledge that nurses possess, particularly in the age of the evidence-based practice movement (Mitchell, 1999). In contrast, personal knowing incorporates ideals around personal reflection and existentialism and "knowing, encountering, and actualizing, of the concrete, individual self" (Carper, 1978, p. 28). Described as the most difficult to demonstrate and to teach, but essential to understanding an individual's health and wellness, this type of knowledge sees the nurse move away from person as object and toward an authentic interaction between two individuals. In this analysis, we look for ways that information goes beyond the facts and attempts to create transactional and reflexive space for individuals with cancer.

Esthetic knowing refers to the art of nursing, relating to the here and now. This type of knowing encompasses the expressive and empathic aspects of nursing and includes "designing and providing nursing that is effective and satisfying" (Orem, 1971, p. 110). The nature of the esthetic is also difficult to describe, and particularly challenging to apply to website data. In this

regard, we have also taken into consideration the expressive, and the way that information, beyond text, is presented, including images, sounds, sights, and colors. Ethical knowing pertains to matters of obligation, or what an individual feels they must do (Carper, 1978). Conversations around what ought to be done and difficult decisions about health and illness all reside within the ethical space. In cancer care, conversations about end of life, side effects of treatment and their true impact on quality of life, and access to information form a few of the many ethical concerns presented in the internet milieu.

Finally, socio-political knowing considers the contextual knowledge wherein all other nursing knowledge resides (Tarlier, 2005; White, 1995). Socio-political knowing takes into account the intersection of location, ethnicity, income, education, and all circumstantial factors nurses attend to when providing care. In our analysis, we sought to observe how these factors were addressed on the websites we reviewed. Taken together, these five types of knowing form an important framework for the knowledge nurses have, that they enact in practice, and share with their patients. In our analysis, we did not judge one type of knowledge to be more important than another, and view the sum of all knowledge types to be of greater value together, as a unified whole (Tarlier, 2005). The framework provides a useful road map to interpret the types of knowledge people find when they seek and obtain cancer information on the internet from a nursing perspective.

Guided by the framework outlined above, the authors of this paper also identify with a critical approach towards technology and want to explicate how these views shaped our analysis. Despite the aforementioned ubiquity of the internet and its pervasive presence in our lives, limited theoretical work or critique has been conducted regarding how the internet shapes our experiences of health and illness from a nursing perspective (An, Hayman, Panniers, & Carty,

2007; Barnard, 1996, 2002). Many scholars argue -and we agree- that critique is important in the analysis of new technologies that offer the promise of advancement, as they are often problematically considered unquestionably good (Dickerson & Brennan, 2002; Ihde, 2005). Philosophy of technology is a philosophical approach that responds to the complexity of technology, by critiquing the neutral or means-end perspective toward technology, often implicit in healthcare, and examines the sociocultural implications of technological artifacts (Barnard, 2002; Ihde, 2004). We have observed that nursing is a discipline where technology has a significant impact, but nurse scholars present limited critical discourse on these technologies (Barnard, 1997; McGrath, 2008). For example, the shift towards using the internet for health information clearly plays a role in how individuals come to understand their illness, but little discussion exists on the multifaceted ways in which this alters and informs the work of nurses as well as the patient experience. While there seems an inherent good in these technologies, they influence the way nurses practice and how people understand their illness, and, to some extent, replace the work of nurses and other clinicians (Dickerson & Brennan, 2002). With the philosophy of technology as a guiding lens, our approach goes beyond an analysis of the quality or content of internet information to create a critical discourse and critique about the role of such resources in the patient experience of cancer.

Methods

This inquiry is guided by a qualitative interpretive descriptive approach, as pioneered by Thorne (Thorne, 2016). Interpretive description provides a flexible and rigorous method for clinicians to answer questions relevant to their discipline, advocates the use of multiple data sources, and encourages an incorporation of clinical wisdom into the design, analysis, and interpretation of results. This inquiry had two stages. First, an initial sample of websites was

determined using a deductive, consensus search strategy, where the top results on the top search engines are analyzed. This first step was a means of becoming familiar with the patient's digital environment, to sensitize the researchers to the types of information and websites commonly used (based on search engine metrics), and develop an initial understanding of the collective information. The second phase involved interviewing individuals newly diagnosed with cancer and inquiring about the websites they most frequently utilized. Any additional websites encountered in the second phase were added to the sample from the first phase and analyzed using constant comparison.

Sample & Setting

The two-step strategy used to select the sample of websites began with a purposeful sample of 12 websites, selected using a consensus search strategy, followed by interviews with 19 individuals newly diagnosed with cancer. The consensus search was conducted as follows. First, the terms cancer, breast cancer, colorectal cancer, and prostate cancer (Experian, 2014) were searched on the three most popular search engines (Google, Yahoo, and Bing). The search terms reflect the most common types of cancer and the types of cancer of the participants being recruited to the study. The results were subsequently ordered according to their rank on each search page, an accepted method in the study of websites (Kaicker, Debono, Dang, Buckley, & Thabane, 2010). The top three results on each search engine were selected for each search term (advertisements excluded). This approach focuses on the top three hits, as search engine algorithms order websites according to frequency of use whereas paid or sponsored websites pay to be placed first, and are identified as advertisements or paid endorsements. After removing duplicates, the findings of this search formed the initial sample of websites (n=12).

In the second phase, 19 individuals diagnosed with cancer were interviewed about their use of the internet for cancer information as part of a larger study. Specifics of the larger study and full content of the interviews are beyond the scope of this paper, but further detail can be located in the published protocol (Haase, Thomas & Gifford, 2016). One objective of these interviews was to ask patients about specific websites they used; these websites were added to the initial sample on an ongoing basis. In total, eight additional unique websites were added to the sample (five websites duplicated those already reviewed). Member checking was conducted as websites were added to the sample by asking participants about their use of each website in the sample. Based on feasibility balanced with the need for depth, a sample of approximately 30 pages on each website was analyzed. Websites were reviewed from June 2015 to July 2016.

Patients who provided website information were recruited from a university-affiliated cancer centre, located in an urban center in western Canada. Patients attending the clinic come from urban, rural, and remote areas. Due to the geography of the region, many patients also travel long distances for specialized cancer care (Statistics Canada, 2011). The study was approved by the relevant university research ethics boards. Patients over the age of 18, fluent in English, and diagnosed with cancer within the last 6 months were initially approached by their oncologist or social worker and, if interested, were contacted by the first author to arrange a suitable meeting time. Interviews were conducted in their home or the cancer centre and lasted between 40 and 60 minutes.

Analysis

Data analysis was conducted using Atlas.ti qualitative analysis software (version 7) concurrent with data collection. Thorne (2016) recommends that analysis in interpretive description commence with immersion in the data, reading and re-reading the data, and then

attempting to gain an overall impression of the data by questioning and theorizing about emerging patterns via a step-by-step analytic strategy. Pages of each website were read with the approach described above, guided by the following research question: what is the context and content of the most commonly viewed cancer websites? We also developed questions based on each type of knowledge (See Table 3.1) to guide the analysis. Screen captures were taken of all pertinent website pages and saved in Atlas.ti. The conceptual framework identified five key types of nursing knowledge that framed the reading of the data.

Table 3.1: Carper's fundamental patterns of knowing (Carper, 1978)	
Pattern of Knowing	Questions for analysis
Empirical	How are medical treatments and tests addressed? What data sources are referenced? What is the positioning and placement of biomedical versus psychosocial information? Are certain types of information predominant compared to others?
Personal	What aspects of personal reflection are addressed? Are existential, reflective or personal aspects addressed?
Ethical	Are matters of conflict or ethics addressed? Are conflicts of interest declared?
Esthetic	What visuals are presented? How is the information expressed?
Sociopolitical	How are factors known to influence cancer care, such as location (rural/urban), age (e.g., of people in photos), ethnicity, ability/visible disabilities, social status attended to on the websites?

As websites were reviewed and codes were developed, instances of exemplary information were highlighted with codes applied to each exemplar. Exemplars were identified as website information that fit the definitions of five distinct types of nursing knowledge. For instance, pages coded as 'treatment and prognosis' fit into the empiric category and were

exemplars of this knowledge type. Memos were kept in Atlas.ti regarding researcher reflections and interpretations as data were coded. For example, a note was made if a certain webpage seemed to have only empiric information or if there was overlap between categories. Codes were grouped according to emerging themes and assessed for their fit within each type of knowledge identified in the conceptual framework. Memos were kept to clarify decision-making about how codes were fitted within each type of knowledge. These memos were reviewed throughout the analytic process, and were crucial as we negotiated and justified the goodness of fit of each code within each type of knowledge (See Table 3.2).

Table 3.2: Framework of key themes with exemplars

Pattern of Knowing	Theme	Examples
Empirical	Medically focused language Medical focus Complementary and alternative medicine Up-to-date Information sources Empirical Pain management Palliative	“cancer refers to cells that grow out-of-control and invade other tissues. Cells become cancerous due to the accumulation of defects, or mutations, in their DNA.” “Alternative therapies are not research based and have not been shown effective or safe in treating cancer. Delaying or refusing conventional therapies to use alternative therapies may have serious health consequences. These may include, the cancer tumour growing or spreading to other parts of the body.”
Personal	Support services Life narrative Informed decision making Person-led information seeking FAQ Survivorship Pt-provider communication	“Breaking the news that you’ve been diagnosed with breast cancer can be just as difficult as first hearing that news from your doctor. You may feel concerned about upsetting your family and friends or worried about how they will react. Even after you have shared the news, at times you may find it difficult to communicate openly. Sometimes it’s uncomfortable to ask for help, answer questions about how you’re doing, or tell well-meaning relatives and friends that you need some time and space for yourself.” “Learn enough about cancer to make decisions about your care. Ask your doctor about your cancer, including your treatment options and, if you like, your prognosis. As you learn more about cancer, you may become more confident in making treatment decisions.”
Ethical	Holistic health Attribution Palliative care Ethics End of life	“You may want to consider: How long to continue treatments that are focused on cure? – Your answer depends on your treatment goals, the effectiveness of the treatments in reaching those goals and the burden the treatments add to your life...” “There also still exists a general misconception about palliative care. Some people believe that palliative care is only end-of-life care. This can lead to patients being referred to specialized palliative care later in their disease course, sometimes not until the last days of life...Without advance care planning and honest discussions about their care wishes, an individual is less likely to have their future care aligned with their wishes.”
Sociopolitical	Gender Economic challenges Culture Work concerns Second language Returning to work	“Elders hold a special place in Aboriginal cultures. Many traditional healers are elders. They know the traditions and values of their particular group and serve as guides and teachers” “If you’ve chosen to work during your treatment, let your doctor know. Your doctor may be able to schedule treatments around your working hours or give you suggestions on dealing with work stress while in treatment.”
Esthetic	Togetherness Gendered Strength Clear and concise Multi-media	Images of couples and families Images of male/female couples Giving back Culture Use of music and videos Pink/blue images

To meet the high standards of rigor expected in qualitative research, we used several strategies, as outlined by Thorne (2016), including epistemological integrity, credibility, analytic logic, and interpretive authority. For example, our inductive design, responsive methods, study approach and questions all demonstrate epistemological integrity and coherence. To achieve credibility and analytic logic, we utilized memos, author agreement during analysis, and triangulating multiple data sources, and sampling strategies. Finally, we demonstrate interpretive authority through the provision of exemplary quotes and the source of websites where the information was retrieved.

Results

In total, 20 websites were reviewed (Table 3.3). Analysis of the websites demonstrated diverse and abundant cancer information addressing the multiple ways of knowing. The appearance, tone, and accessibility of information varied across and within disease-specific websites. Generally speaking, all websites we reviewed had homepages with links to information about testing and diagnosis, treatment, and daily life. Empiric information varied by website, with all providing information on physical- and treatment-related information; this was a consistently present component on all websites we reviewed. Visually, elements of websites were generally attractive, but sometimes cluttered, whereas those for breast/prostate cancer seemed tailored to gender. Some websites provided more information on ethically and personally challenging issues, such as ending treatment and disclosing a diagnosis. Herein, we present an in-depth analysis of our findings framed by knowledge type.

Table 3.3: List of websites	
Website name	Website address
Canadian cancer society	www.cancer.ca
Breast cancer.org	http://www.breastcancer.org/
Prostate cancer Canada	http://prostatecancer.ca/
Colorectal cancer Canada	http://www.colorectal-cancer.ca
Web MD- Breast cancer center	http://www.webmd.com/breast-cancer/
Canadian cancer society- Breast cancer information	http://www.cancer.ca/en/cancer-information/cancer-type/breast/breast-cancer/?region=on
Mayo clinic – Breast cancer information	http://www.mayoclinic.org/diseases-conditions/breast-cancer/home/ovc-20207913
Cancer.net	http://www.cancer.net/
Cancer chat Canada	https://cancerchat.desouzainstitute.com/
Canadian breast cancer foundation	www.cbcf.org
Colon cancer Canada	http://coloncancercanada.ca/
Wikipedia – Breast cancer	https://en.wikipedia.org/wiki/Breast_cancer
Wikipedia CRC	https://en.wikipedia.org/wiki/Colorectal_cancer
Wikipedia: cancer	https://en.wikipedia.org/wiki/Cancer
Wikipedia prostate cancer	https://en.wikipedia.org/wiki/Prostate_cancer
Breast cancer society of Canada	http://www.bcsc.ca/
Web md: CRC	http://www.webmd.com/colorectal-cancer/
Women’s health matters: breast cancer	http://www.womenshealthmatters.ca/health-centres/breast-cancer-info-reviewed-by-doctors-research-treatment-symptoms-and-amp-diagnosis/
Medicinenet: colorectal cancer	http://www.medicinenet.com/colon_cancer/article.htm
Rethink Breast Cancer	https://rethinkbreastcancer.com/

Empirical

Empirical information, or the science of nursing, has long been considered a cornerstone of nursing knowledge and forms the foundation of biomedical disease knowledge (Carper, 1978). Given the dominance of the biomedical paradigm, this type of knowledge encompasses the majority of information available about cancer on the websites we reviewed. The analysis resulted in two key themes comprising the category of empirical knowledge: medically focused language and treatment of non-biomedical information.

Medically focused language

Much of the information on each website was (expectedly) medically focused. Most sites provided a thorough breakdown of the anatomy of the disease site, the pathological processes involved in cancer, and current or emerging treatment therapies. Most of the websites used both medical language and simple terms a non-medical person could understand. Complex medical language was present on most websites, but key terms were often ‘clickable’, meaning that definitions were provided to the reader upon clicking or hovering. In the context of cancer, the use of complex medical language seems unavoidable, particularly regarding the anatomy and physiology of disease and treatment terms. Providing definitions of key terms may therefore equip patients to better understand the medical terminology, especially in consultations with healthcare professionals.

Another key finding was that empirical information lacked attribution on many of the reviewed sites. Information about treatment and outcomes, for example, would be presented as fact, without support. The following is an example statement from one cancer website: “chemotherapy can extend life and improve quality of life for those who have had or are living with metastatic cancer”. Information such as this should be presented with appropriate attribution

so the patient, and possibly the medical team, can discern the quality and authenticity of the information. In this particular case, these comments had a notation “reviewed by a doctor”, but this further obfuscates the origins and veracity of the information.

Treatment of non-biomedical information

One problematic finding noted throughout analysis, and on most websites reviewed, was the variable non-biomedical content. By non-biomedical information, we mean any information pertaining to treatment or management of symptoms and well-being using non-pharmacological or biomedical interventions. These are commonly referred to as complementary and alternative medicine (CAM), and include, for example, herbal preparations, yoga, acupuncture, qigong, etc. The approach to this information was highly variable: some websites presented no information, some presented a simple disclaimer stating that these types of therapies may be helpful but do not replace medical treatment, and yet other sites presented some information with limited detail about CAM.

Ethical

Ethical knowledge is defined as moral issues, issues of obligation, and conflict (Carper, 1978). The information reviewed fell into two categories: disclosing conflict and unethical omissions.

Disclosing conflict

The category of conflict arises from a marked absence of detail regarding where information comes from and how it is attributed. We noted above that attribution is mostly absent, but sometimes this can also present a conflict. Drug companies donating to a website, for example, could potentially create a conflict in how material about their drugs is presented. Who are the donors and what are their interests? If the sources of information are attributed - for

example to peer-reviewed research- perhaps the perception of conflict is addressed. Attribution may also allow individuals to better understand the context of the information, thereby permitting more informed choice and decision making.

Unethical omissions

The category of omission emerged as it became apparent that the topics of death and palliative care were seldom introduced on many of the sites reviewed. Noting this admission, sites were deliberately searched for the terms palliative and death; such information proved difficult to locate. One site presented a multimedia video explaining the difference between palliative care (symptom management) and end of life care (care in the last days or hours of life), focusing on the importance of symptom management through palliative care. But, generally speaking, little information was provided about palliative care as it pertains to symptom management at end of life, end of life supports, advanced directives, or other such topics crucial to the whole cancer trajectory. The absence of this type of information presents stark contrast to that which would be accessible from a knowledgeable nurse.

Personal

Carper (1978) stated that “[o]ne does not know about self; one strives simply to know the self” (Carper, 1978, p. 18). Thus, the notion of personal reflection and self-understanding are key components of personal knowing. The nurse’s knowledge of the personal refers to knowing the patient, or assisting the person to know thyself. The codes comprising this category focused on information presented to assist with thoughtful, reflective, and informed decision-making, and attention to the importance of care of the whole person.

Information to allow informed decision-making

Whereas some websites seemed to be portals for immense information and lists, others contained thoughtful and directive information geared towards guiding patients through the decision-making process and providing the tools to do so. Some websites provided lists of “questions to ask your doctor” that were insightful and thorough. One website provided a detailed table of the various treatment options in an easy to understand format: what is the treatment, what is done, what to expect, and side effects and risks. These simplified approaches allow individuals to compare information, reflect upon it, and make an informed decision. While the basis is typically empirical information, the design and structure invite personal reflection, and weighing of risks that a conversation with a nurse may also stimulate.

Whole person care

Knowledge to support care of the whole person, particularly the existential concerns, was not a major focus of the websites reviewed. For example, some websites presented information about meditation exercises and journaling as a means to create “a written account of events and emotions [experienced]”. The absence of information about end of life is relevant here as well, as the topic of death goes beyond discussion of physical (empirical) and functional concerns. These whole person considerations are worthy of deliberation as they relate to the multi-faceted impacts of cancer in the person and their family.

Esthetic

Esthetic knowledge is defined by Carper (1978) as the art of nursing, and refers to the expressive ways nurses perform their practice. During analysis of the websites, codes were generated that fell into the esthetic or expressive, including visual depictions, general presentation of information, and the gendered nature of website design.

Images: togetherness & strength

Strength and unity were key repetitive themes in the images featured on all websites. Such images were located across websites and displayed individuals of varying ages, ethnicity, and ability. Photos were typically of people who appear to be well and healthy versus those who are sick. Photos of families with young children were also displayed, advancing a notion of youth and unity.

Variation in display: clarity versus clutter

Variation was noted in the clarity of the information displayed on each webpage. Some websites were very cluttered or crowded with information with considerable small text, whereas others had a clearer display with limited text and more white space. Although readability or literacy level was not assessed in this analysis, the interpretability of the information was certainly altered and enhanced through the use of white space, color, and graphics. Cross-linked information was also noted on many websites; as described above, this was useful for taking patients to related materials to bolster their understanding on complex topics. However, how these links are presented, whether in list format or embedded in the text, could create navigational challenges for those who are not technologically proficient. Smaller text size was a common occurrence, and is a concern as it makes reading the information difficult, and less accessible to those with sight impairments.

Gendered designs: tailoring for appeal?

Gender-specific cancer websites appeared to employ esthetic tailoring to suit stereotypical binaries of male/female preferences. For example, breast cancer-focused websites used pink and purple colors and feminine images, such as hearts and flowers, whereas prostate

cancer websites tended to use the color blue and depict caricatures of neckties and mustaches. Pictures and images tended to depict youthful, healthy, male/female heteronormative families.

Sociopolitical

Sociopolitical knowing was an addition by White (1995), and encompasses the social, political and economic world. Concepts such as ethnicity, culture, location (urban or rural), age, and other factors that might impact cancer care were considered. This type of knowledge was categorized by information focusing on the economic and functional challenges associated with cancer and culture.

Economic and functional challenges

The concept of economic and functional challenges was a recurrent topic on most websites viewed. Not surprisingly, these issues are of significant importance for individuals with cancer. For example, most hospitals and cancer centers in Canada charge a fee for parking, which can be prohibitive for low-income individuals, and thus some websites provided information about funds available to offset these costs. Other potential costs are those incurred by individuals who must travel long distances to obtain care. Several sites provided information about available cost offsets, including access to hotel discounts and cancer lodges with reduced lodging rates. Another topic frequently presented in great detail was returning to work, taking time off of work, and getting support from co-workers.

Attention to culture

Culture was not a prominent theme attended to on most websites, although some Canadian websites did present relevant, albeit sparse, discussion. For example, one website included content about how culture might affect what happens when you die. Another Canadian website had content about traditional Indigenous healing considerations, including a brief

discussion of the medicine wheel and traditional practices. For the most part however, discussions or images that would integrate diverse perspectives and cultures were largely absent.

Discussion

This analysis of websites generated an understanding and critique of the information to which patients are exposed and the way that information can be classified within a framework of knowledge familiar to nurses. The theoretical framework guiding this analysis provides a structure from which to understand the multi-faceted nature of the online cancer discourse and elucidates that the information on the internet is not simply empirical and textual, as some modes of website analysis would infer; rather, esthetic and contextual elements contribute to how this information is perceived. A significant and perhaps most obvious finding of this study is that internet information is not completely holistic in the way that Carper describes nursing knowledge. Alone, internet information pales in comparison to the expert wisdom of nurses. This is noteworthy, as many patients report seeking information and support online when their healthcare professional is not accessible (Shea-Budgell et al., 2014), and this too, requires further discussion.

Together, these findings generate important questions regarding patient reliance on cancer-related internet information in place of the multifaceted knowledge they can glean from interacting and communicating with nurses. Based on our analysis, we can conclude that the nature of cancer information online is often limited and lacks the multi-dimensionality of a knowledgeable nurse who holds multiple types and ways of knowing as Carper asserts. This poses further questions about the impact of substituting versus supplementing the skilled and nuanced knowledge from nurses and other members of the cancer care team with online information. Do patients believe this information is of equal value to that provided by nurses

and, if so, what are the implications? How does access to unidimensional empirically-focused information impact the patient experience with cancer? These findings should also move nurses to discuss cancer-related internet information with patients, so as to complement patients' online information seeking efforts with holistic and tailored nursing knowledge.

The most salient and poignant example of omitted information we discovered pertained to palliative and end of life care. Even with deliberately searching for this information, it was difficult to find. Although an explicit focus on death may reinforce fatalistic stigmas associated with cancer and scare patients (Powe & Finnie, 2003), it is not unreasonable to assume that a website covering the full range of information about cancer - from diagnosis to staging- would include information about end of life or palliative care. It is problematic, that this is inadequately represented as an awareness of death and approaches to palliative care may actually enhance both life and death. Raising nurses' awareness of the paucity of information related to death and palliative care on these commonly searched websites has important implications for nurses. Specifically, what nurses can expect patients to learn online regarding death and palliative care is limited, therefore nurses should expect to provide guidance and support on these critical topics.

This study also demonstrates that cancer information is readily available to individuals with cancer but, even on the most popular sites, the nature of the information is variable (Nghiem, Mahmoud, & Som, 2016). Of particular concern is the common provision of online information without attribution. Although the attribution of sources is typically an academic activity, websites providing medical information should recognize that providing references for patients validates the source of information. Furthermore, if and when patients choose to share this information with their healthcare professional, they too can be assured of its validity. Omitting attribution raises important questions about the ethics of presenting information

regarding serious illnesses without telling the reader where it is from. How can one begin to make an informed choice, if the information source is unclear?

One reassuring result from this inquiry pertains to the accuracy of information on the internet. Although challenges with attribution and breadth of information are documented in this analysis, our search did not turn up any scam websites in the first page of results. The search results revealed that the searcher must make a deliberate attempt to find biomedical or empirical information that is wholly inaccurate. That is, the main search results for the terms searched returned results from reputable, and government-funded sources on the first page on all search engines. This should be encouraging for those clinicians still unconvinced that patients can find suitable information on the internet and reinforces what has been documented elsewhere about good quality biomedical cancer information being available on the internet (Davies & Yeoh, 2012).

One area where information was lacking pertains to alternative and complementary approaches or CAM. Some websites failed to address these aspects of holistic health, or else addressed them by simply presenting a disclaimer of the dangers of combining ‘some types’ of therapies with biomedical approaches, such as chemotherapy. This is an unfortunate approach, as alternative and complementary therapies tend to encompass a broad range of interventions and applications — from green tea to qigong — and are widely used amongst those with cancer and the general population (Harris & Rees, 2000; Horneber et al., 2011). Furthermore, many alternative and complementary therapies have demonstrated positive results for individuals with cancer. For example, hypnosis, acupuncture, and imagery are useful strategies for pain management (Bardia, Barton, Prokop, Bauer, & Moynihan, 2006). This information is valuable to individuals with cancer with respect to their ability to make decisions and cope with their

illness. Presenting this information in a detailed and thorough manner, rather than leaving patients to their own, possibly problematic information seeking behaviour, would be a more effective and proactive approach. Whereas it may be an unreasonable expectation that all websites address these topics, it is important to note and reflect upon the absence of CAM information. Given the growing reliance on CAM by people with cancer, it may not be an unreasonable expectation that reputable national websites have comprehensive information about CAM. Nurses also need to be aware of the absence of this type of information, and take pause to consider the implications this may have for their patients seeking this information.

Significant social and economic disparities exist amongst those with cancer in the developed world (Dixit, Crawford, Lemonde, Rittenberg, & Fernández-Ortega, 2016). However, the internet seems to be provide opportunities for equitable access to privileged medical and health-related information. That is, with access to the internet, individuals have access to reams of information regardless of sociocultural or demographic differences. For example, Han and colleagues (2010) found that, if provided free access, women with breast cancer of a lower income and education level used the internet for health information to the same extent as more educated, higher income counterparts. Although the present study did not consider all sociopolitical factors, it points to the importance of facilitating access to information for those who might be marginalized because of their income, education, gender, sexuality, or physical or cognitive ability. For that reason, simple gestures such as providing information about return to work, cost-saving measures, using plain language, and clear font are important for broadening access to online information.

Findings of the visual and expressive analysis of websites provide a few key points for discussion around age, sexuality, and image choice. Most patients diagnosed with cancer

(including those in this study) are over the age of 50 (Canadian Cancer Society, 2015) and therefore clean, clear, legible text is important, and perhaps more pivotal to older adults' understanding of the content than readability or literacy level. This is particularly relevant given the prevalence of cancer amongst the elderly, shifting demographics, and growing ubiquity of the internet as a key source of information amongst this age group (Levy, Janke, & Langa, 2015).

These findings also reinforce that esthetic display of information has the ability to lure a person in, or turn them off, on first glance (McCarthy et al., 2012). Although healthcare providers can easily prescribe sound health internet information sources (D'Alessandro, Kreiter, Kinzer, & Peterson, 2004), it may also be worth considering how these sources appear through an esthetic lens to patients, family members, and caregivers. Furthermore, some websites contain only text, whereas others provide much more, such as links to videos, community information, fundraisers, and online communities. This is an important point for clinicians to acknowledge: patients may not only be looking for cancer information but rather a more engaging online experience. The benefits of online groups and supportive communities are well documented (Klemm et al., 2003), and thus clinicians might consider asking patients what, exactly, they are seeking on the internet because different websites offer different types of information and support.

The use of pictures of individuals and families who appear relatively healthy is also worthy of critique. Many of these images present men and women who appear youthful, vivacious, and full of life, yet the websites provide information for people with a life-threatening illness. These images are hopeful, but possibly not truthful. This reiterates research findings that indicate images of cancer parlay an ageist attitude, particularly on hope for a cure, above all else (Duggleby, Holtslander, Steeves, Duggleby-Wenzel, & Cunningham, 2010). The imagery

presented on most websites is also largely heteronormative, depicting pink, purple, and flowers for feminine cancers versus blue, neckties, and moustaches for male cancers. These images, while useful and possibly galvanizing, may alienate those who do not fit the gender binaries as presented.

Limitations

In this study we sample websites in two ways: through the consensus search strategy, and by approaching a sample of individuals with cancer. However, some of the participants in this study were unaware of the websites they visited; either they couldn't remember because it had been so long since they had searched for cancer information, or because they had visited many websites. To address this, we made an attempt to find the sources of information they used by inquiring about the search process using 'think aloud' methods (Fonteyn, Kuipers, & Grobe, 1993). We then retraced their search strategies. Although, we cannot be certain that this process was comprehensive, it did address some of the challenges with participant recall.

A second limitation pertains to the assumptions made in the deductive search strategy regarding the definition of commonly used websites. We chose to exclude advertisements from the search, but people may view and use these sources of information.

Implications for Practice

This study generates discussion about the content and implications of commonly searched cancer websites from a critical nursing perspective. Whereas much research has explored the benefit of the internet and the ubiquity of its use by patients (Shea-Budgell et al., 2014), we provide a theoretically guided exploration of the content of the information. These results go beyond suggestions for the design of an ideal website, or an ideal online intervention, because most individuals appear to use different websites to meet different needs. Because we

have found that the content of cancer information online is not always comprehensive, the implications and questions pertain to practice: what can nurses do to engage patients in a discussion about internet information, and how might nurses adjust their practice in light of this information? We also emphasize that the dominance of empirical and biomedical cancer information online is not in itself problematic; instead, we argue that empirical information should be presented in context with information and support that takes into consideration the needs of the whole person.

Nurses are well-positioned to recognize that most patients desire information about their illness and can intervene by providing direction to appropriate internet information; this is a low cost, high impact solution. Nurses can engage patients in discussion about the potential for encountering incomplete, inaccurate or harmful information, and encourage patients to bring their questions to their healthcare professionals. Nurses in oncology are also well situated to facilitate these discussions given that typical relationships occur over a long period of time. Prior research reports that patients sometimes shy away from sharing internet information with their nurses and other healthcare professionals because of fear of retribution or judgment (Kirschning & von Kardorff, 2008). However, encouraging nurses to be proactive, by engaging patients in discussion about appropriate information may also lessen the potential for negative implications associated with seeking and acting upon harmful or inaccurate information, without consultation or support.

An additional role for nurses and allied clinicians is to encourage formal or informal assessment of internet information preferences. For example, nurses can suggest appropriate websites if patients desire communities of support versus textual cancer information. Nurses can also use their diverse knowledge of the patient and refer them to websites they think would be

appropriate, based on their needs. Nurses in oncology commonly report patients using their phones and tablets to pass the time during treatment and clinic visits, which may be an ideal time to engage patients in discussion about what they are looking for and to help them find it (Dickerson, Boehmke, Ogle, & Brown, 2005). Through these conversations with patients, nurses can address the gaps in the empirically focused information patients may find independently.

This study also has implications with respect to research on technologies and the internet, insofar as more critique and dialogue are needed on the content and impact on patients and practice. As noted by philosophers of technology in nursing, these technologies have a way of seeping into our practice without critique (Barnard 2002; Mitcham, 1994). To better understand the impact of technology — especially one as ubiquitous as the internet — it needs to be critically examined as we have done in this study. Naturally, this study will lead to more research and more exploration because of the many questions it raises. In particular, topics to be explored in future studies include how patients view the nature of information on the internet and how that shapes their relationship with their healthcare professionals.

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Chapter 4: Manuscript 2 and Supplement

Managing cancer experiences: An interpretive description study of internet information use

Relationship of Manuscript 2 and Supplement to the Dissertation:

In this chapter, I present findings from the manuscript entitled *Managing cancer experiences: An interpretive description study of internet information use*. This chapter also contains supplementary findings not included in this manuscript. The manuscript and supplement describe the results of a mixed methods interpretive descriptive study exploring the role of cancer-related internet information use in the patient experience of cancer. Patients diagnosed with cancer who reported using CRII were interviewed on two occasions. The results capture personal factors related to who uses CRII and how people with cancer mobilize CRII. CRII was an integral resource for patients to process information and guide their interactions with healthcare professionals. In the supplement that follows the manuscript, I present results on the theme of managing relationships with healthcare professionals. These findings were beyond the scope of the present manuscript, but I feel they highlight important patient accounts about CRII use. These findings will be incorporated into an additional manuscript at a later date.

This manuscript has been prepared for submission to the journal *Cancer Nursing* and will be revised for submission. In keeping with journal requirements, the paper does not exceed 20 pages of text and is prepared in AMA style (tenth edition).

Abstract

Background: People with cancer are increasingly using the internet to find information about their illness. However, little is known regarding peoples' use of cancer-related internet information (CRII) to manage their patient experience, defined as patients' cumulative perceptions of interactions and exchanges with the healthcare system during their illness.

Objective: The purpose of this study was to create an understanding of CRII use by people newly diagnosed with cancer, how it shapes their patient experience, and informs their interactions with healthcare professionals and healthcare services

Interventions/Methods: An embedded mixed design guided this study. Nineteen people with cancer were interviewed twice and completed a survey about CRII use. Qualitative data were analyzed using thematic analysis. Descriptive statistics summarized the quantitative findings.

Results: Participants of all ages and education levels reported using CRII as a pivotal resource. CRII played a central role in how patients understood their illness and when they sought and used healthcare services. Two key themes emerged based on patient interviews: (1) person in context, and (2) management of information.

Conclusions: CRII plays a crucial role in how people manage their illness and take control of their patient experience. Participants used CRII to learn about their illness, support their efforts to self-manage, and complement information from professionals.

Implications for Practice: Individuals and institutions can promote and encourage tailored CRII use by engaging patients and suggesting websites based on their needs. Doing so may create efficiencies in service use and empower patients to be more involved in their own care.

Word limit: 249 (max 250 words)

Manuscript 2

Managing cancer experiences: An interpretive description study of internet information use

Cancer is an all-consuming experience that affects multiple aspects of a person's life. When diagnosed with cancer, individuals typically experience uncertainty around both their diagnosis and how it will affect them.¹ The process of diagnosis and entering cancer care and treatment involves navigating numerous complexities, including exposure to new care providers, treatments, medicines, and care facilities.² These concurrent stressors can create significant distress.³

For many individuals diagnosed with cancer, the need for information regarding their physical and psychosocial health is high at the time of diagnosis and throughout the cancer trajectory.⁴ Unfortunately, information needs often remain unaddressed.^{5,6} A lack of information is problematic because it can create further anxiety and distress, and may also create strains on health services as patients seek to address their concerns.⁷ Although patients frequently report that their healthcare professional is their most preferred information source,⁸ access to healthcare professionals in Canada is often constrained by clinic hours, large patient caseloads, and sporadic clinic visits.⁹ Many Canadian patients also face a challenge of geography, and live in rural and remote communities with limited access to healthcare services; this makes addressing information needs even more complex.^{10,11} Together, patients' cumulative perceptions of their interactions with healthcare professionals and services across the continuum of care form the 'patient experience'.^{12,13} However, less is known regarding patients' attempts to independently address information gaps using cancer-related internet information (CRII), and how this relates to their patient experience.

The internet has become a key source of health information, as an estimated >3.5 billion people worldwide (48% of the global population) use the internet.¹⁴ In Canada, approximately 80% of adults have access to the internet and the Pew Research Centre reports that 72% of Americans access the internet for health information.¹⁵ Although barriers to internet use such as advanced age, low income, and lower education levels have been documented,^{16,17} providing access and support (e.g., via hospital libraries) for the internet can mitigate some of these barriers.^{16,18} Other social factors, such as limited access to healthcare services,^{19,20} and presence or absence of family support, may also play a role in how individuals use the internet to manage their health. For example, a study of people with cancer in Finland found participants (n=74) used the internet for social support and information about their diagnosis, doubly emphasized by participants living in rural areas.²⁰ Taken together, the evidence indicates that the internet may prove more useful for some populations, as compared to others, and is not equally accessible. Thus, the growing use of the internet in people's self-guided search for health information²¹ warrants further exploration of these nuances, particularly in relation to cancer.

For individuals with cancer, the internet is the second choice of information for 57% of cancer survivors if their healthcare professional is unavailable.⁸ Internet use amongst those with cancer has been grouped into four domains: information, community, networking, and communication.²² These domains encompass a broad range of activities that serve to address information needs and allow people with cancer to better understand their illness.²³ Patients report using the internet to be better prepared for consultations,²⁴ and to share information with their healthcare professionals.²³ Furthermore, CRII may support people with cancer as they encounter information gaps and discordance in the timing of information delivery from their healthcare professionals.²⁴

However, some healthcare professionals express concerns about patients finding harmful information^{25,26} and the additional time it may take to discuss such information in consultations.^{27,28} Consequently, prior reports indicate that CRII users are more likely to be younger and are more often female.^{29,30} Furthermore, CRII for breast cancer is reportedly abundant, whereas information on other cancers may be more difficult to locate.³¹

In the context of growing reliance on the internet by people with cancer the role of CRII in the patient experience and healthcare interactions remains unclear. For example, how does self-guided CRII seeking alter patients' relationships with their healthcare professionals? Do patients use more or less healthcare services when they have access to information on the internet? How does CRII relate to their patient experience? The purpose of this study was to create an understanding of CRII use by people newly diagnosed with cancer, how it shapes their patient experience, and informs their interactions with nurses and other healthcare professionals. The specific objectives in this manuscript were to (1) document what CRII is accessed and the patterns and frequency of use, (2) explore prompts to use CRII and how it informs the ways in which patients interact with healthcare professionals and healthcare services, and (3) understand how people use CRII to manage their patient experience.

Conceptual Framework

This study was shaped by Andersen and Newman's (1973) Behavioral Model of Health Service Utilization (BMHSU).^{32,33} In this model, HSU is defined as the process of seeking and obtaining healthcare services with the intention of maintaining or improving health. The general assumption of the model is that HSU is a function of both individual and societal influences. Four main areas shaping HSU are outlined: the environment, population characteristics, health behavior, and outcomes. In this study, the model was used as a means to explicate sensitizing

concepts of interest to inform an in-depth exploration of HSU (see Table 4.1 for a detailed explanation of each factor).

Table 4.1: BMHSU		
Concept	Definition	Example
Environment	The physical, economic, social and political inputs influencing HSU [70].	• Rural or urban environment and propinquity to health services. • Costs associated with the use of health services (i.e., time off of work, childcare, hotels, etc.). • Socio-political factors surrounding HSU (i.e., universal healthcare, pharmacare, etc.).
Populations Characteristics	Access to health services is conceptualized as a function of personal characteristics related to predisposing, enabling, and need factors.	• Predisposing factors: Access to health services (i.e., education, gender, ethnicity, culture, age and gender, health beliefs). • Enabling factors: Logistical aspects of accessing care, such as personal, family and community resources, including proximity to care, social relationships, insurance/income, and endowment with health services and resources. • Perceived need: Individual's view of own health, whether they seek care.
Health behavior	Behaviors that enhance, maintain, or inhibit well being via: (1) personal health practices and (2) use of health services.	• Personal health practices: diet, exercise, and self-care behaviors. • Use of health services refers to HSU within the context of a health need.
Outcomes	Perceived health status, evaluated health status, and consumer satisfaction, which demonstrate impact of HSU.	• Patient reported outcomes (i.e., quality of life, patient reported anxiety) • Change in objective measures of health (i.e., blood pressure, weight, distress screening)

Methods

This study was guided by an embedded mixed methods design with a constructivist orientation. In an embedded design, a supporting data type compliments the primary, or overarching data type. In this study, quantitative data supported the primary qualitative data; the qualitative and quantitative data are integrated at the design level.^{34,35} The overarching approach is qualitative interpretive description, with the quantitative data subsumed within this dominant methodology. The study design is suitable because the quantitative data complement the

qualitative data and are not interpreted independently. Interpretive description is an inductive qualitative approach for research in practice-derived disciplines, generating knowledge that has implications for clinical practice.³⁶

Setting and sample

Data collection took place at a university-affiliated cancer treatment centre in Western Canada. Ethics approval was sought and received from the University of the first author (KRH) and at the recruitment setting. Purposeful and theoretical sampling strategies were used, and 45 individuals newly diagnosed with cancer were approached to take part in this study over a 10-month period. Of the participants approached, those recruited to the study met the following inclusion criteria: (1) a histologically confirmed, first diagnosis of cancer (all stages); (2) diagnosis within the last 6 months or before a first visit to the oncologist; (3) at least 18 years old; (4) fluent in English; (5) able and willing to take part in interviews and complete questionnaires; and (6) affirmed use of the internet for health information. Participants were excluded if they had been previously diagnosed with cancer (excluding superficial skin cancer). Recruitment ended when a robust description of the research problem emerged from patient interviews, themes were repeated by participants, and a sound framework of themes was verified in follow-up interviews.

Data collection

Participants were interviewed on two occasions. After providing consent, participants were asked to complete a brief questionnaire about background information and CRII use. Data on CRII were collected through a self-report questionnaire designed for the purpose of this study. This survey was developed by drawing on prior surveys of CRII use by individuals with cancer, and included questions about the mode of interest use, amount of time spent looking for CRII,

types of CRII searched, and how CRII was incorporated into interactions with healthcare professionals (see Table 4.2).^{22,37,38} The survey took approximately 10 minutes to complete.

Table 4.2: Internet use questionnaire

1. Mode of internet use
2. Where do you use the internet?
3. How often do you access the internet?
4. How many hours per week do you spend on the internet?
5. Do you discuss CRII with your healthcare professional(s)?
6. What types of CRII did you search for?

Participants then engaged in an in-depth interview led by the first author (KRH) or a PhD-prepared research assistant experienced in qualitative interviewing. Initial interviews lasted 30-60 minutes and covered a range of topics (see Table 4.3). The interview guide was modified throughout data collection to reflect salient evolving themes in concordance with an emergent research approach. For example, some participants talked about using the internet to look up their diagnosis and prepare for physician appointments, so this was incorporated into subsequent interviews. The second interview was conducted in-person or over the phone. Phone interviews permitted ongoing participation of participants who did not live near the cancer center, or were unable to travel. The second interview revisited themes from the initial interviews, and verified emerging concepts from other interviews. All interviews were digitally-recorded with participant consent and transcribed verbatim.

Table 4.3: Sample interview questions

1. Can you tell me about your interactions with healthcare professionals during your cancer diagnosis and treatment?
2. What kind of information was important to you after you were diagnosed with cancer?
3. What was the role of the internet in your search for cancer information?
4. What was your main purpose for internet use?
5. Tell me about a time when a concern arose related to your cancer and you were not sure what to do.
6. Can you think of a time when you used the internet to help you find a health service or to decide what kind of services you might need?

Analysis

Interview data were analyzed by thematic content analysis, concurrent with data collection, using Atlas.ti (version 7) qualitative analysis software. The process of analysis followed the method outlined by Thorne³⁶, starting with an initial reading of each transcript. Subsequent readings included coding salient ideas and inductively deriving conceptual themes, first within and subsequently across transcripts. Detailed notes and emerging codes were kept in the electronic documents in Atlas.ti and analyzed and grouped according to emerging themes. Conceptual themes were then grouped into categories and organized into an analytic framework to guide exploration within and between individual cases. As the analytic framework was refined, we revisited the initial question around CRII use and interactions with healthcare professionals.

Several steps were taken to ensure the trustworthiness of findings from conception through analysis and presentation of results.³⁹ The approach to trustworthiness as identified by Thorne³⁶ was employed, relying on the strategies of epistemological integrity, credibility,

analytic logic, and interpretive authority. The principles and accompanying strategies taken to achieve these ends are described in Table 4.4.

Table 4.4: Strategies to achieve trustworthiness		
Principle	Definition	Strategies
Epistemological integrity	Coherence between the research question, study design, and methods	• Choice of design (embedded mixed methods approach) • Clearly describing epistemological positions
Credibility	Confidence in the believability and trustworthiness of the findings ⁴⁰	• Triangulating multiple data sources • Theoretically informed sampling strategies • Negative case analysis • Member checking
Analytic logic	Ability for an outsider to understand researcher decisions	• Memos • Audit-trail of key decisions
Interpretive authority	Ability to discern if researchers findings are trustworthy	• Use of exemplary quotes

Analysis of survey data was carried out using SPSS (version 22). Data were checked for accuracy and completeness to ensure the data attributed to each variable were accurate.⁴¹ Descriptive statistics (means and frequencies) were used to depict sample characteristics. Patterns of internet use were generated by calculating summary scores of totals by type and frequency of use.

Results

The final sample was comprised of 19 individuals newly diagnosed with cancer. Of the 45 patients approached, a total of 26 patients did not participate for the following reasons: did not use the internet (n=6,) not interested (n=5), second cancer (n=5), and unable to contact

(n=10). The final sample of 19 participants was diverse in terms of age (mean 65.5 years, range 44-87 years) and gender (12 female, 7 male) (Figure 4.1). The types of cancer diagnoses included breast (n=9), gastrointestinal (including esophageal, pancreatic, and colorectal cancer (n=7)), and prostate cancer (n=3). Participants were asked to identify their cancer stage, 1 identified stage 1, 3 at stage 2, and 6 at stage 3, leaving 9 participants who were not aware of their cancer stage. Ten participants did not live in the city where the cancer center was located, and eight of these people lived more than 100 kilometers away. Diversity was also reflected in terms of education, with the highest level of education noted as elementary or high school (n=7), technical or vocational school (n=7), or university (n=5).

CRII use

Participants reported searching for CRII by computer (n=5), mobile device (n=6), or both (n=8) (see Figure 4.2). Men reported using the internet every day, whereas only some women used it daily (n=10) and a small number used it weekly (n=2). The variation of average internet use per week between women and men was minimal (mean 13.7 h, range 2-30 h vs. mean 12.9 h, range 2-28 h). Approximately half of the participants (n=9) reported sharing CRII with healthcare professionals.

In terms of the timing of CRII use, all individuals reported searching for information about cancer before meeting their oncologist, before their diagnosis, during treatment, and after treatment. The pattern of CRII use by women stayed consistent after diagnosis whereas men reported using CRII less during and after treatment. The CRII patients searched covered a range of topics, with treatment, cancer type, and treatment side effects being the most common. Women were more likely than men to look up information on alternative medicine. Women also looked up information about their oncologist, more often than men. More men searched for

information on sexuality than women (4 men vs. 1 woman). Fertility and end of life topics were only searched by male participants.

Qualitative findings

The qualitative findings encompass two main themes: (1) person in context, and (2) management of information. Each theme represents a synthesis of participants' experiences using CRII. These themes begin to provide an understanding of how patients use CRII to manage their illness and their cancer experience.

1. Person in context

Several personal and social factors that seem to shape CRII use and how CRII informs healthcare interactions emerged in the interviews. They include age, gender, distance from healthcare services, education level, family support, and sociopolitical context.

Age

Most study participants were older adults, but they did not feel their age was a limiting factor to finding and using CRII. For example, one participant in her late 60s stated: *“my age it doesn't- that doesn't reflect on it [CRII use]. I'm learning every day. I'm struggling with things about the internet, but I'll get by even with my age.”* This sentiment was echoed by many participants who felt that, while they might not be as capable at navigating the internet as younger people, they were still able to obtain the CRII they sought. However, older adults had difficulty recalling which websites they used, and where they had searched. When asked which websites they used, they would often cite “Google” or other search engines, rather than specific websites. Despite the unfamiliarity with technology, older adults still described the internet as a key resource for managing and understanding their cancer diagnosis. For example, an 87-year-

old participant described using Facebook to communicate with family about her diagnosis: *“I wanted information because there’s a lot of questions about family history. So I sent my sister a message on Facebook about when she had cancer, and what age she was.”*

Gender

An underlying goal of recruitment was to achieve sufficient gender representation to generate comparisons across genders. Both men (n=7) and women (n=12) described finding and using CRII to manage their cancer experience. Men and women also reported using CRII for technical or functional reasons, for example to watch videos or view pictures to prepare for their appointments and learn more about their disease. As one woman with breast cancer stated:

“[t]hey said that before I would start my radiation I would have a CT scan and I was like hmm, I wonder what that machine looks like because I’m claustrophobic...so I just looked for a picture of it.” Another man described using the internet to view videos of peripherally inserted catheter (PIC) insertion for a similar reason: *“at least you know what’s going on... videos are on there [the internet] so you can see what’s coming up. It takes away a lot of anxiety, I think because you’ve got a rough idea but it might create some [anxiety], too.”*

Both men and women reported looking for cancer survivorship stories on the internet. Women described going into chat rooms or Facebook hoping to connect with people, or gather information, whereas male participants did not utilize this aspect of CRII. As one woman with breast cancer stated, *“I have maybe a couple women that I do chat with but we kind of eventually ended up on Facebook instead of trying to chat through that [chat] group because to me it’s just, it’s too complicated.”*

Rural communities

Seven of 19 study participants lived in rural areas. Many participants raised the added burden of travel and the differential experiences related to being geographically distant from cancer care providers. One woman described living in a rural area with limited health services, stating: *“you can’t run to the doctor right away, so you might look things up on the internet. I think most people, if they’re not sure, probably look up information before running to the doctor if it’s not an emergency.”* Another woman with breast cancer reported the following: *“I think if I were in a bigger city, I would probably go down to the cancer center and ask them questions, but because I’m in a rural area and can’t access them I use the internet.”* Thus, patients in rural areas described CRII as a key resource, in place of ready access to healthcare services.

The reliance on CRII for those in rural areas was reportedly higher than those in urban areas, but also of a different nature. For example, as one male participant stated: *“I would also find that I probably use it a lot more than if I was in town, because you’re checking out how long this is going to take, how long that’s going to take; you get more info, and gotta ask different questions.”* Patients in rural areas also need information about locations, distances, and where to go; this adds a layer of complexity to information needs for which they also rely on CRII. For rural patients, CRII served to address the same needs as those in urban areas, but also supported their need to travel and obtain health services in an unfamiliar setting.

Education level and access to information

Two participants had experience working in healthcare and this made them more adept at asking questions and understanding health information. However, many participants did not have advanced education, but participants did not view this as a limiting factor to using CRII and

deciphering medical information. Several participants said that they appreciated having access to information that would otherwise only be available in a library or through a healthcare professional. For example, one man with a grade eight education regularly went online and watched videos of surgeries, radiation, and other procedures: *“I watched videos of surgeries, videos of radiation and stuff like that and yeah...I mean I look for other stuff on YouTube, you know if I gotta do something and see how it’s done if I haven’t done it before. So I thought, what the heck.”* For the majority of participants, CRII provided access to medical information that participants felt was easy to understand, regardless of their education level.

Regarding access to information, it was clear that participants valued the ability to access medical information from the comfort of their homes. CRII was described as an important readily accessible source of information, alongside information provided by their healthcare professional, including books, and informational leaflets. Participants discussed what they would do if they did not have access to CRII. One patient mentioned she would utilize the library, but almost all others indicated that they would rely on healthcare professionals more, due to their expert health knowledge. One participant stated: *“Without the internet I would have to rely on the doctor more to become informed”*. Accessing CRII allowed patients to independently find information about their illness. Although patients stated they would use their healthcare professional more if CRII was not available, constraints related to accessing healthcare professionals may make this challenging.

Family support

Many participants described using the internet with family members’ assistance. For example, one participant with prostate cancer described a situation where he had been sick for several days with diarrhea and nausea. Too unwell to manage the symptoms on his own, his wife

searched his symptoms on the internet where she found strategies for managing his nausea and information as to when she should contact the nurse. Another participant spoke English as a second language, and described that her husband would translate the CRII for her: *“I also have my husband to help when I need it, there’s a lot to go through...and too many things I don’t know, medical information. I say, “Oh what are they talking about?” But he knows and we figure out together.”*

Some participants also reported that their children or family members helped them to navigate the internet by referring them to reputable websites. This was clearly stated by one man with prostate cancer: *“Well when I told my kids they thought I might have prostate cancer...my son jumped all over the internet and then sent me three or four websites where I could study up on it.”* Many respondents reported surrogate information seeking as a means of involving their family, but also as a way of ensuring they had sound information. However, some participants felt that unsolicited information could be overwhelming. For example, one participant with colorectal cancer described needing to develop strategies to reject CRII being sought by others: *“See my sister, she said, you have to go online and you can see your whole surgery, what they did and how they done it. All of this. Do I want to see that right now? I said, ‘No.’”* Thus, CRII was often a helpful family resource, but also required patients to create boundaries and strategies to refuse unwanted information.

2. Information management

The second theme synthesizes participant accounts of how they used CRII to manage their patient experience. CRII was used to support self-management, corroborate information from healthcare professionals, and glean information to guide decision-making.

Symptom and self-management

Many patients described using CRII as a way to manage symptoms and then consult with providers as needed. For example, one participant described experiencing mild nausea related to radiation treatments: *“I didn’t remember hearing about the nausea and there were times I’d sort of get this wave come over me; I’m like, hmm, not sure what this is. So I specifically [searched] ‘Can nausea be associated with radiation?’ And yes it is, so I did check that out...Probably I would not have gone to anybody because it wasn’t a big deal unless it became severe.”* To summarize, participants felt capable of looking for CRII, and making the determination as to whether they could manage a particular situation on their own, or whether they needed to consult and share their concern.

Many participants also used CRII to gain knowledge, as a means to mitigate their anxiety and concerns about cancer, particularly at the time of diagnosis. These participants described a therapeutic effect related to searching and finding information about their diagnosis. According to one participant: *“In the beginning it’s pretty overwhelming, but I don’t feel overwhelmed now. I kind of got through that by reading and researching.”* Another woman described how she accessed the internet after her diagnosis, to assuage her concerns: *“I went to it after I went to my family doctor. He said that I needed to have a biopsy, so I looked up the discharges, the colors, the diversion of the nipple, the whole thing.”* For many participants, the idea of taking control and becoming a knowledgeable consumer of health information resonated. Patients described that having some control enabled better self-management.

Participants also addressed information needs that arose at unexpected points in their cancer trajectory via CRII. The need to find CRII for self-management was not always attributed to a knowledge deficit left by a healthcare professional; rather, participants seemed to relate it to

the abundance of needs that arose. One woman with colorectal cancer described CRII use as follows: *“I think for me the searches would be about, ‘Okay so how come my wound isn’t closing?’ Or how much pain am I going to be in? I was looking more about after the surgery. What’s my diet going to consist of? Because I was sent home with no dietary guidelines. I’m three months post-op and I still can’t eat anything. I can’t eat a whole lot of stuff. But I was told within 48 hours I could eat anything.”* Another man described preparing himself for the treatments he was about to experience, even though he felt his healthcare professionals were supportive and provided ample information. He described searching for more information from Google and YouTube: *“I was searching on YouTube and Google about all that kind of stuff [radiation and surgery]...The doctors were very good; they answered the questions that I had. They explained them very well. I was very happy with that... It [Google and Youtube] was very informative because I’d never gone through cancer before. I like to know what I’m going through before I go through it.”* Thus, situations where patients used CRII varied, and were not consistently the result of positive or negative interactions with healthcare professionals or services.

Physician reviews and second opinions

A few participants in this study described having the ability to choose their physician, and using CRII to help them make that decision. For example, patients reported reading physician reviews online to determine if they would use a certain physician or if they ‘liked’ them. As one man with pancreatic cancer stated: *“When I found out that I had the cancer I found out that I could be referred to a doctor in City A or a doctor in City B and I made the choice using reviews on the [internet].”*

People also talked about using the internet as a ‘second opinion’. For example, one participant’s son asked him why he was not going out of province for his surgery, as there might be better experts elsewhere. This prompted the patient to look up other physicians and experts on the internet. After his assessment, he found that he was confident and comfortable with the local surgeon.

Guiding decision-making

Patients who had to make a decision about cancer treatment described CRII as a tool that supported their ability to understand their treatment choices. Uncertainty around decisions was a key point of stress for many participants. For example, several women with breast cancer were given the option between a mastectomy or breast-conserving surgery. Patients described using CRII to cross-reference and consolidate information they were given by healthcare professionals to make a decision. Participants also talked about looking at multiple sources of CRII to corroborate, verify, or contradict what they were told at consultations with their oncologist. Participants also mentioned the paper materials that healthcare professionals provided, and described comparing these books, pamphlets, and leaflets with their CRII. One man described having a meeting with a surgeon, who suggested surgery was the best option for his cancer; but, upon reviewing CRII, he felt that chemotherapy and radiation before surgery may be a better option. He planned at his next appointment to raise this as an option, but the surgeon had in the interim consulted with the oncologist and recommended the same treatment plan. This relates to the resourcefulness of the patient, but also, the quality CRII that this patient was able to find independently.

Participants also talked about validating or reinforcing information provided by their healthcare professional through CRII. For example, one man described it as follows: “*Well*

[CRII] gave me a little more understanding on what the doctors were telling me and I could visualize it, I could read about it so it helps a lot.” This points to the significance of broader CRII, i.e., information is not limited to text, which may be particularly helpful for people who do not have a medical background, or have lower literacy levels. One woman reiterated this, stating that she did not understand where or what lymph nodes were. Being able to see illustrations of them online allowed her to better comprehend what they were and enabled her to make a more informed choice about her treatment. Another man shared how using the internet helped him to ask questions and make his treatment decision: *“You go into a meeting with your doctors and you’re getting a lot of information in areas you’re not familiar with, rather rapidly. Being able to go on the internet and look up information from different sources and understand what’s real and what isn’t real, helps you to ask questions of your doctor.”*

For those who used CRII to support their decision-making about treatment, the potential benefits of complementary therapies were also investigated. Participants described looking online for information about supplements and alternative therapies to support their health while going through treatment. For example, one participant stated: *“we did lots of research on nutritionally based information, there’s lots of stuff out there that’s natural. For example we were looking for different things to help with healing and stuff like that.”* Some participants also wanted to know more about potential alternatives to biomedical cancer treatment. One woman with breast cancer ultimately decided to have a mastectomy, but was very curious about alternatives to what she saw as typical medical treatments, she stated: *“I was looking for anything that wasn’t medical. I’ve never really understood the whole chemo-radiation thing – it does so much damage and I know that there are other options. I just started looking at those kind of things and things like your diet or exercise or essential oils.”* Information about alternative

therapies was also important for people who chose not to have any biomedical cancer treatment, such as chemotherapy or radiation. One woman with breast cancer who chose not to have treatment primarily used CRII to identify supplements to support her wellness as she lives with cancer.

Self-navigation

Some participants described feeling adrift on their cancer journey, with little guidance as to what would happen next; notably, however, this was not mentioned by any participants with breast or prostate cancer. One woman with colorectal cancer described feeling that there was no clear treatment pathway, and that she relied heavily on CRII to prepare and understand what was coming next. She stated: *“There was lack of information from a patient centered perspective... Like give me a darn pathway that if- okay within one week this happens, this person will refer you here, this person will do this here... Like it feels like nobody really knows what the hell is going on.”* Another participant with colorectal cancer described feeling that she had a more generalized presentation that took longer to diagnose. This, in turn, made her more reliant on CRII leading up to her diagnosis.

Knowing where to look and when to stop

A key oft-cited concern of healthcare professionals is that patients will not be able to find quality information, or they will become overwhelmed by the abundance of CRII and be unable to process it. Regarding the first concern, patients seemed to enable numerous strategies to determine their information was reputable. Most participants described feeling confident with the information if they read the same thing in multiple places, and if it came from a reputable

organization. According to one man: *“One way I do it is by cross referencing between different organizations, different websites right? Because yes there is a lot of stuff out there.”*

The concern around becoming overwhelmed by CRII seemed to be an exception, as only one participant reported this experience, she said: *“anybody’s story can be on the internet right, and you read everything; like I did anyway.”* She did not have a strategy when approaching the information, and became quite anxious as a result. All other participants talked about self-regulating by developing proactive strategies to find CRII without becoming overwhelmed. Three main strategies developed, including (1) avoiding CRII altogether until they saw their specialist; (2) stopping when they felt they had enough; or (3) looking retroactively after treatments were completed. For example, one woman with breast cancer preemptively chose not to use CRII before her oncologist visit: *“I want to put my trust in this group of people, otherwise you get really scrambled up. That was a strategy, an intentional strategy.”* Another woman with colorectal cancer fell into the second category, and described using CRII about cancer-related weight loss until she had enough information about her illness and felt that looking at more information would make her anxious. Following that realization, she made a deliberate effort to stop.

Many participants described looking for information retroactively, after they had made treatment decisions, met with oncologists, or finished treatment. They described this as a clarifying process to consolidate all of the information they had received, and reflect upon it. One man with prostate cancer summarized this nicely: *“To be honest, I didn’t really look at much on the internet until I had met with all of the different professionals. And then I went back and spent a couple of hours just refreshing everything they told me and it made more sense.”*

Discussion

The findings from this study begin to clarify how patient use of CRII informs use of healthcare services, interactions with healthcare professionals, and the cancer experience. This is not a linear process; instead, CRII acts as a pivotal source of information throughout the cancer journey. People use CRII to determine how to manage their illness, how to use healthcare services, and with whom to connect. As has been documented elsewhere,^{24,42} participants herein used CRII to manage their symptoms and complement the information they received from healthcare professionals. Having access to CRII allowed participants to find information when and where they needed it, and without relying solely on healthcare professionals. This strategy also relates to patient autonomy and self-management of their own cancer experience at a time when little was within patients' control.

In terms of participant characteristics, the number of older adults and the varied levels of education of participants were surprising because numerous reports indicate that internet users are younger, more educated, and female.^{29,43} Saied and colleagues³⁰ reported that individuals with cancer between the ages of 65-70 are more reluctant to use the internet; however, over half of our participants (11 of 19), were over age 60 and readily used the internet, refuting common generalizations about how older and less educated people with cancer use CRII. These findings warrant further exploration to determine if these patterns of CRII use are prevalent amongst a broader population of individuals with cancer.

Despite numerous reports⁴⁴⁻⁴⁶ about the quality of cancer websites being poor or unaccredited, participants did not express concern about the information they found. For example, participants described viewing videos of upcoming procedures and found these resources useful for decreasing their anxiety; this is despite prior reports^{36,37} indicating the need

for higher quality resources, particularly videos.^{47,48} Participants developed strategies to crosscheck information and validate their findings via numerous online sources in order to feel comfortable that the CRII was accurate; this occurred regardless of education level or healthcare experience. Some participants' describe seeking CRII from 'reputable websites' because it was more trustworthy, but this cannot be said for all participants as many were unsure of the exact websites they used. It is worthy to note that most participants engaged in deliberate strategies to ascertain the trustworthiness of CRII and checked it against multiple sources, rather than choosing it arbitrarily. We find this particularly important as it counters reports of healthcare professionals' concerns regarding how people use the internet to find information, and the potential harm it may cause.

As documented in the extant literature, the needs of the patient and their ability to find CRII are related to the type of cancer. For example, participants in this study with CRC described having challenges finding CRII. Brigo and colleagues³¹ echoed this concern in a recent study where less CRII was found about CRC or prostate cancer compared to breast cancer and melanoma. This may point to a need for healthcare professionals to realize and address these disparities in information, providing more information and more direction to those with types of cancer, for which there is less information.

Several patients in this study from rural and remote areas (where physician and healthcare services are less readily available) reported using CRII to manage symptoms and information needs. These findings are supported by recent studies that suggest a relationship between internet use and barriers to service utilization, with proximity to health services being one important barrier.^{19,20} Relatedly, many participants delayed seeking services and choosing to self-manage using CRII. This strategy illustrates the value of CRII in self-management, but also

points to the importance of other contextual factors, such as social support networks, that may be at play. Other authors^{49,50} also indicate that seeking, or delaying seeking, care is related to a complex interplay of personal characteristics, decision-making, and socio-cultural factors.

A final comment pertains to the current transition between paper and electronic resources. Participants in this study all used CRII and many described it as a key resource, but this same cohort valued paper information given to them by their healthcare professionals. This affinity for paper information has been documented elsewhere⁵¹ and points to the fact that many people prefer to have multiple sources of information and engage in a process of sifting through information to find the information that suits them best.²¹ This consideration of multiple sources improves satisfaction with care and confidence in decision-making ability.

Limitations

The sample for this study is relatively small and was purposively and theoretically derived, thereby limiting the generalizability of the findings (which is not a goal of qualitative research). The quantitative data presented were limited to the patterns and frequency of CRII use, were not reported using percentages, and were not employed to overextend conclusions.

Conclusions and Implications

CRII plays an important role in the patient experience and how people newly diagnosed with cancer understand and manage their illness. The process is not linear or straightforward and varies from person to person, but evident consistencies arose in participants' accounts of CRII use. Notably, certain stereotypes about CRII use amongst older adults are inaccurate and should be further researched; specifically, population characteristics such as being elderly or having a lower education level did not appear to exclude use of CRII amongst participants.

Importantly, participants identified their nurses and physicians as a critical link in the clarification of CRII. In light of patient concerns about where to look for information online, healthcare professionals are certainly well-positioned to provide this guidance. This is doubly important as many participants described using CRII to manage symptoms or concerns before consulting their healthcare professional. Therefore, patients will benefit from suggestions of accurate and high-quality websites. This is not an endorsement to build another website, or to direct users to specific websites, as is so often suggested in studies of internet use. Instead, the findings lead to the conclusion that ample information is available on the internet but patients may still need some assistance in parsing this information and knowing where to turn for what they need. Participants reiterated their trust in their healthcare professionals⁴³, who are thus well positioned to facilitate these conversations and assess patient CRII needs.

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Figure 4.1: Sample Characteristics

Gender and Age

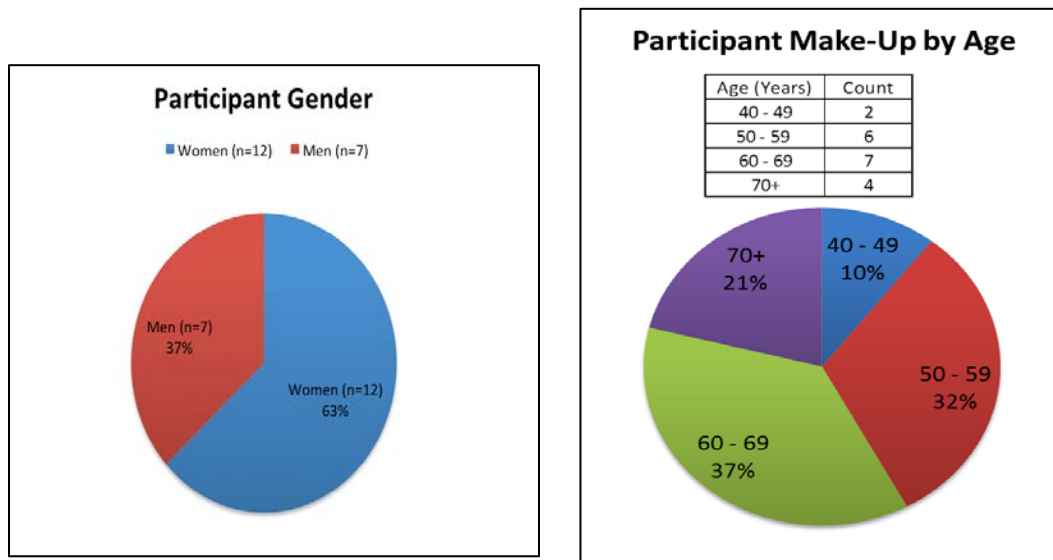
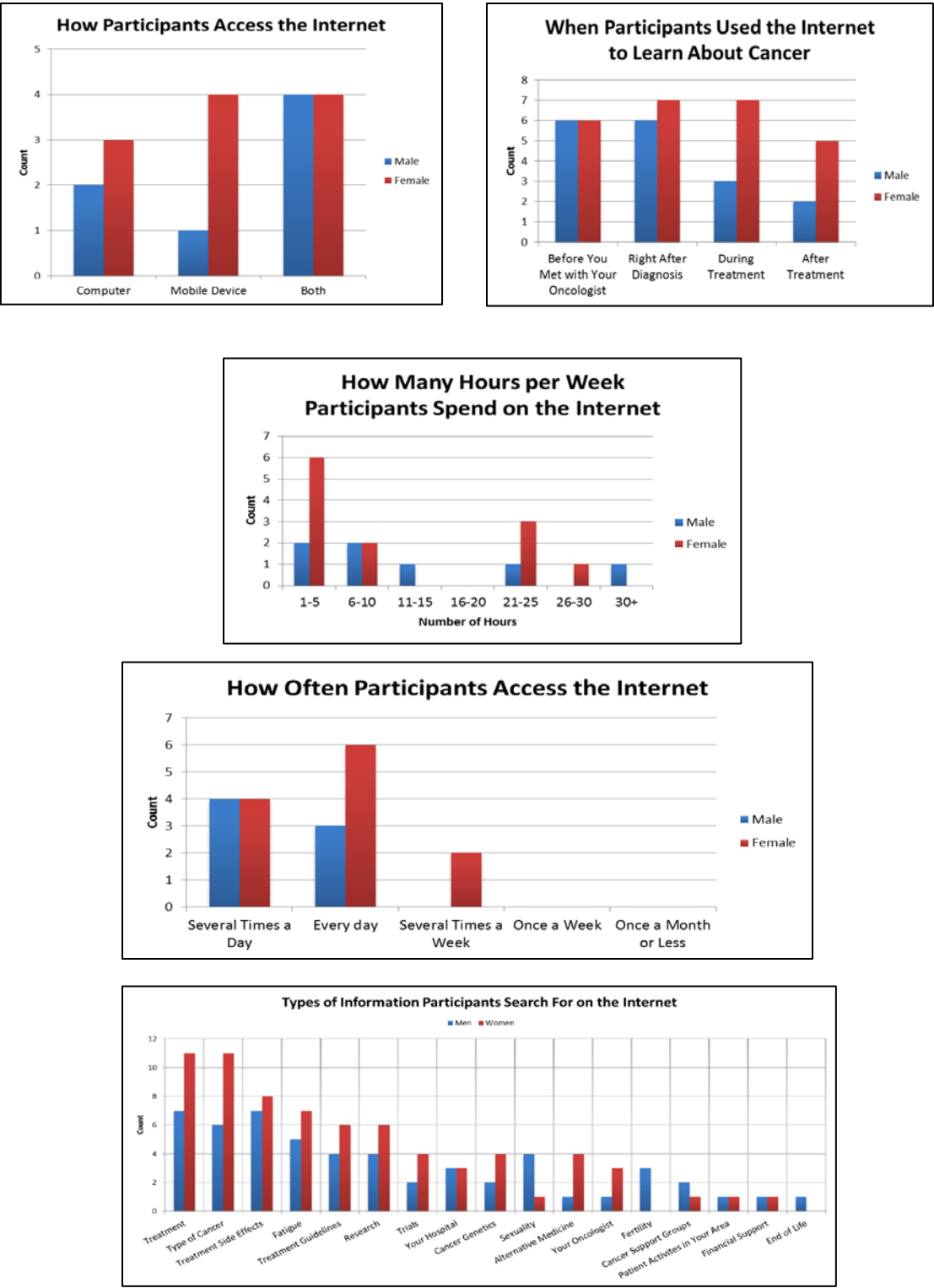


Figure 4.2: CRII Use



Supplement to Manuscript 2

In this supplement, I present additional findings from the patient interviews beyond the scope of manuscript two. This theme pertains specifically to CRII use and the relationship between healthcare professionals and patients. This theme was determined to be supplementary to the second manuscript, in order to achieve depth in the content of the manuscript, whilst working within the parameters of the journal requirements. These findings will be developed into a fourth manuscript following completion of my dissertation work.

Managing relationships with healthcare professionals

The final theme describes how patients used CRII to manage and complement their relationships with healthcare professionals. This theme captures patient-led strategies related to addressing gaps in information and the importance of timing, sharing information, and being prepared for consultations with healthcare professionals.

Filling the gaps

A key theme shared by participants was the need to support, or complement, the information received from healthcare professionals. For example, three participants described being called by their physician with their biopsy information over the phone. As one woman stated, “[w]hen my doctor called to tell me it was DCIS, immediately he said remember these initials and go look it up, find out what it’s all about. So I looked it up”. Another man with prostate cancer described a similar situation; his doctor was on vacation and called to tell him his biopsy was positive and that he would be referred to an oncologist. The participant described a need to find more information “*because we are creatures who want to understand and we now have this tool called the internet*”. These patients were pleased to be given information in a

timely fashion, but also recognized the need to address their lack of knowledge, and mobilized CRII to do so.

Timing

A central reason for patients turning to CRII relates to timing of information provided by healthcare professionals and the ability to digest and absorb information. As one man with prostate cancer stated, *“when you are diagnosed, you can’t absorb [information], so you go to the internet later, when it makes sense and you’re ready”*. People also talked about different information needs across the illness trajectory, for example at diagnosis, after treatment, or before surgery. One patient described how he looked for information about his diagnosis and treatment when he was first diagnosed, but after treatment ended, he became interested in recurrence: *“So now I started to focus – okay there’s a high probability that it’s going to come back and if it does come back then what are you going to do about it, right? So that’s kind of the focus now, looking at clinical trials, looking at other processes or procedures or looking at what other things that are going on out there that could be used.”* These signposts in his illness seemed to signal the need for new types of information and the need to gather and review different types of information. CRII was a means to complement information provided by healthcare professionals because, as one patient noted, you did not usually have the chance to go back to them and ask new questions once treatment was complete, or between appointments.

Being prepared and making use of valuable time

Another key dynamic in the patient-healthcare professional relationship was how CRII enabled patients to better engage in consultations. Many participants described the desire to ask better questions, but were only able to do this once they had some grasp of the subject matter.

For one man, knowing about everything from the disease site to the dose of radiation allowed him to participate in his own care: *“If you have the information, you can ask the right questions”*. Although no other patients were interested in the dose of radiation, many participants echoed the sentiment of his comments. Those patients who went on the internet before they met with their doctor also talked about using CRII as a means of more efficiently using their time with their clinicians: *“it’s all about what questions to ask right? Otherwise you don’t know or you have to have a little bit of information to even know what questions to ask right?”*

Choosing not to share information

The final theme regarding the interaction of CRII in the patient-healthcare professional relationship pertains to the sharing of CRII with healthcare professionals. Only half of the participants explicitly shared information from the internet or told their healthcare professional it was from the internet. The range of reasons for this included it not occurring to patients to share it with their provider, to feeling they would be judged, to feeling their healthcare professional would feel threatened by them seeking their own information. For example, one woman (who was a healthcare professional herself) described the following situation: *“There was a little bit of- I don’t want to say animosity, but a little bit of skepticism. But if I said, hey you know what- one of her colleagues that I worked with- I was talking to her about my symptoms, she was wondering if it was this. What do you think? That was better received than, hey here’s something that I found on Pub Med.”*

Many patients also talked about skepticism and fear of judgment regarding their searches for information about alternative and complementary treatments. Those who did share CRII with their healthcare professional found it helped when their professional would acknowledge their information, not dismiss their concerns, and assist them in clarifying the information.

Chapter 5: Manuscript 3

***“The human element – that’s the part that’s missing”*: Oncology healthcare professionals’ views on the intersection of patient internet use and health service interactions**

Relationships of Manuscript 3 to the Dissertation

This third manuscript is a presentation of results from an in-depth qualitative study with oncology healthcare professionals regarding their views on patient use of CRII and how this relates to patient-healthcare professional interactions. Healthcare professionals were sensitive to patient CRII use, and felt that it supported patients to meet their pragmatic concerns and priorities. Healthcare professionals acknowledged the dynamic nature of cancer care and patient education exchanges, which sometimes left less time and attention for patients than desirable. Still, a tension exists between healthcare professionals concerns about patients’ self-sought CRII and their desire to support patients’ autonomous information seeking. Implications for interprofessional oncology practice and future research are suggested.

The manuscript has been prepared for the *European Journal of Cancer Care* and will be revised for submission. It is written in the style indicated in the journal’s author guidelines.

Abstract

In this study, we document cancer healthcare professionals' views of patients' use of cancer-related internet information (CRII), and how it informs the ways patients interact with healthcare professionals and services. We used an interpretive descriptive approach, conducting interviews and focus groups with oncology healthcare professionals (n=21) at a university-affiliated western Canadian cancer treatment center. Data were analyzed using thematic analysis. We present an initial understanding of how CRII alters, informs, and modulates patients' cancer experience and relates to their interactions with healthcare professionals and services. Findings were synthesized into two themes: Pragmatic concerns and priorities; and Processes and practices. Healthcare professionals were supportive of patients' needs for more information, particularly at key points in the cancer trajectory when information may be lacking. Participants concurred that CRII could positively benefit patients and, if shared with their healthcare professional, could benefit the patient-healthcare professional relationship. Oncology healthcare professionals provide pivotal information to patients; thus, they are well situated to engage patients in discussions about CRII and incorporate this into patient encounters. These actions may open new lines of communication with patients, strengthen the patient-professional relationship, and empower patients to be engaged in their own care.

European Journal of Cancer Care, 3000-8000 words.

Current: 6000 words

Manuscript 3

***“The human element – that’s the part that’s missing”*: Healthcare professionals’ views on the intersection of patient internet use, relationships, and health service use in cancer care**

As cancer is the most common disease and leading cause of death in Canada, the stigma and uncertainty associated with this illness are well known (Powe and Finnie 2003). For the individual with cancer, the diagnosis is distressing, life-altering, and poses practical, psychosocial, and physical concerns (Stanton, Rowland et al. 2015). Practically speaking, patients face a complicated healthcare system and myriad consultations, treatments, and therapies associated with managing their illness (Bultz and Carlson 2006). Patients also face psychosocial challenges, including disruptions in mental health and functional concerns, that exist against a backdrop of physical consequences of illness, such as challenges with mobility, pain, and interruptions in activities of daily living (Adler and Page 2008, Beaver, Latif et al. 2010, Ziegler, Hill et al. 2011). Together, these physical and psychosocial circumstances create many stresses for patients to manage.

Information is a key asset people use to manage the demands of a cancer diagnosis. Equipped with information, people are better able to understand, cope with, and manage the stresses of their illness (Iconomou, Vagenakis et al. 2001, Lambert and Loiselle 2007). Needs assessments of individuals with cancer indicate patients require information about their illness at the time of diagnosis and across the cancer trajectory (Matsuyama, Kuhn et al. 2013). Patients may experience distress when information needs are unmet (Bultz and Carlson 2006) and, when in distress, may require health services that would be unnecessary if informational support had been provided proactively (Carlson 2004). Due to the important role that health information plays in an individual’s ability to cope with their illness, and the potential strains unmet

information needs may put on the healthcare system, finding efficient and accessible solutions to meet information needs is imperative.

The internet has become a key resource for individuals with cancer as they search for information to manage their illness (Ziebland, Chapple et al. 2004). However, patients and healthcare professionals have differing perspectives about how cancer-related internet information (CRII) relates to patient use of healthcare services and relationships with their providers (Haase, Strohschein et al. 2016). Some authors report oncology professionals with open attitudes to CRII (Shen, Dyson et al. 2015), whereas others have found professionals have misgivings about the potential harm of self-sought CRII (Newnham, Burns et al. 2005).

Patients report using CRII for a number of reasons, including preparing for consultations with providers and corroborating information from their healthcare professional (Loiselle, Peters et al. 2013). Reliance on CRII as a key source of information for patients seems to have some important benefits, as it allows patients to be more prepared and more knowledgeable for consultations (Salonen, Ryhänen et al. 2014), potentially reducing time spent with healthcare professionals. Regardless of the reasons for CRII use, it is the most preferred source of information if a patient's healthcare professional is unavailable (James, Daniels et al. 2007, Shea-Budgell, Kostaras et al. 2014). However, poor communication with healthcare professionals around CRII may lead to increased uncertainty and anxiety, and lead to decreased sharing of information with their healthcare professional (Xiao, Sharman et al. 2014).

To date, the intersections of CRII use and interactions with healthcare professionals and services have not been explored in-depth. The purpose of this article is to document the findings of a qualitative exploration of cancer healthcare professionals' views about the role of CRII use

in the ways patients interact with healthcare professionals and services. Data were gathered from interviews and focus groups conducted with cancer healthcare professionals.

Theoretical Frameworks

This study was informed by the behavioral model of health service utilization (BMHSU) (Andersen 1995). The BMHSU provides a means to understand the reasons why individuals use healthcare services. This model was used as a sensitizing framework and as foundational literature about the process of using and interacting with the healthcare system. The BMHSU considers four key factors: (1) environment, the physical, economic, social and political environs that can influence HSU; (2) population characteristics, the personal characteristics of individuals which influence their use of health services; (3) health behavior, the behaviors that individuals engage in which promote or limit health; and (4) outcomes of health service use.

The concepts of environment and population characteristics resonate with the practical and theoretical knowledge of the authors of this paper regarding patient use of CRII. These concepts were used to inform the development of the interview and focus group guides as well as the analysis. Environment is defined as the physical, economic, social, and political surroundings of a person, which influence their use of services. For example, professionals were asked whether they found people living in rural or urban areas used CRII differently. Population characteristics are described as predisposing (access to services, i.e., education, gender, age), enabling (logistical aspects, e.g., support), and perceived need factors. Such factors were explored through questions about patient access to services, supports, and their perceptions of health related to patient use of CRII.

Methods

This study is part of a broader constructivist mixed methods project exploring the role of CRII use by individuals newly diagnosed with cancer. This inquiry was guided by a qualitative interpretive descriptive approach. Interpretive description is a non-categorical naturalistic qualitative research method intended to be practical, reflexive, and make meaningful contributions in clinical and practical disciplines, particularly nursing science (Thorne 2016). This approach is characterized by epistemological coherence, the use of multiple data sources, and concurrent analysis. The goal of an interpretive descriptive study is to contribute meaningfully to the discipline by creating a structure that makes sense of the phenomena under study (Thorne, Reimer Kirkham et al. 2004, Thorne 2016).

Setting and sample

This study took place at a University-affiliated western Canadian cancer treatment center. During recruitment of patients in the broader study, healthcare professionals shared many valuable insights and perspectives on how they saw patients using CRII. Therefore, a purposive and theoretical sample of cancer healthcare professionals (social workers, pharmacists, nurses, dietitians, and physicians) was approached to take part in this study.

Procedures

Ethics approval was sought and received from the University of the first author (KRH) as well as the University affiliated with the cancer center. Once obtained, the first author contacted healthcare professionals by email to assess their interest in participating in the study. Individual interviews were initially sought as the best way to gather healthcare professionals views, but the reality of coordinating these was challenging and somewhat impractical based on scheduling

challenges. Thus we expanded our data sources to include focus groups. Interviews were audio-recorded, lasted between 40-60 minutes, and were guided by a semi-structured interview template (see Table 5.1). Focus groups lasted between 50-70 minutes and were guided by the same interview template. The interview template was altered as salient themes emerged throughout the study in concordance with an emergent research approach. For example, the theme of complementary and alternative therapies was raised by a healthcare professional in the first interview. This topic generated rich discussion, and thus was added to subsequent interviews and focus groups.

Table 5.1: Focus group and interview template

1. Can you tell me about what type of information your patients want when they are first diagnosed, or on their first visit?
 - Can you describe any particular sources of information you suggest?
 - Tell me about these
2. Can you tell me your thoughts on patients using the internet to find cancer information?
 - For what purpose do you think the internet is most useful for individuals with cancer? (i.e., communication, information, social networking, etc.)
3. How would you describe the quality of the information about cancer on the internet, generally?
4. Do your patients discuss CRII with you?
 - Can you explain a time, good or bad, when a patient shared CRII with you?
 - i. What was your response?
5. What if any connection exists between patients using the internet and how they use health services?
6. Do you ever direct patients to particular websites?

If yes, which ones and why?

If no, why not, can you explain this approach?

Analysis

Data were analyzed concurrent with data collection using the qualitative software Atlas.Ti (version 7). The data analysis process described by Thorne was employed, wherein an analytic framework of emerging themes was structured and subsequently established in an

ongoing and iterative process throughout data collection and analysis (Thorne, Reimer Kirkham et al. 2004). To develop the analytic framework, the first author (KRH) conducted all interviews and focus groups. This provided familiarity with the data and evolving themes. During and following interviews and focus groups, field notes were kept on salient and emerging themes and concepts, which formed the initial framework. Next, verbatim transcripts of these interactions were reviewed. An initial reading allowed the first author to revisit salient themes and cross-reference fieldnotes. The second stage involved an in-depth reading where codes were applied and the developing analytic framework was populated. As subsequent interviews were conducted and coded, comparisons between and across transcripts occurred, and prominent and recurrent themes were added to the emerging analytic framework. Throughout analysis, key themes were discussed with co-authors to verify and test the boundaries of the emerging analytic framework. A process of back and forth discussion took place until all authors were satisfied with the fit of all aspects of the analytic structure.

To ensure trustworthiness, the four strategies identified by Thorne (2016) were used. First, epistemological integrity was maintained by using reflexive methods, cogent with the overall inductive methodological approach. Credibility was ensured by member-checking (Carlson 2010), using multiple data collection strategies and concurrent analysis. Concurrent analysis allowed for revision and redoubling of efforts to answer the research question by bringing salient emerging themes to subsequent interviews and focus groups. Analytic logic was sought through the use of memoing and keeping an audit trail of decisions. Finally, interpretive authority was achieved by grounding the data in participant quotes and an acknowledgment by all authors that what is presented here are not facts, but truths constructed by the participants and interpreted by the authors of this paper (Thorne, Reimer Kirkham et al. 2004).

Results

A total of 21 healthcare professionals (see Table 5.2) took part in three focus groups (n=17) and four interviews (n=4). The findings present an initial understanding of healthcare professionals' views about the intersection of patient use of CRII in cancer care. The resulting analytic framework is comprised of two thematic categories: *Pragmatic concerns and priorities* and *Processes and practices*. These themes encompass the following subthemes: tailored information; holistic and whole person information; cancer types and available information; impressions of judgment and concern; bridging gaps in information; sharing to manage uncertainty; and decision-making. These categories represent a synthesis of the thoughts and stories of healthcare professionals about how CRII alters, informs, or modulates patients' cancer experiences and relates to their actions and interaction with healthcare professionals and services.

Table 5.2: Sample Characteristics

Health Profession	Number of participants	Gender
Physician	2	F=1 M=1
Social Worker	3	F=2 M=1
Dietician	3	F=3 M=0
Pharmacist	1	F=1 M=0
Registered Nurse	12	F=12 M=0
	Total N=21	Total F=19 M=2

Pragmatic concerns and priorities: The role of CRII in the patient experience

In this theme, participants described how they felt patients used CRII to address the priorities related to illness management, and the pragmatic concerns that arise on a daily basis. Discussion centered on the need for tailored information, how information (and needs) vary by

cancer type, the importance of holistic information, and concerns about reliance on CRII. This category represents the participants' desire to ensure patients are well cared for and have the best information possible.

Tailored information

Healthcare professionals described CRII as useful, but felt it is often too vague and untailored, making it potentially confusing for patients. Healthcare professionals identified reputable websites, such as the Canadian Cancer Society, as being a 'safe place' to find information, but felt patients would not know which information applied to their specific situation without medical expertise. One dietician referenced another reputable national cancer website, suggesting that the information it provided was good but not tailored to each specific patient

"It's very general and usually people need information a little bit more specific or tailored towards them."

Healthcare professionals also felt patients had differing needs for CRII; hence the need for tailoring. Age, education level, and whether a person was from an urban or rural area were suggested as factors that determined, to some degree, how much CRII a patient would want or need.

"Well there's some patients that come from up north or even just rural Saskatchewan who just go with what you told them and they're happy with that, and then others have looked into it to the nth degree and they come with preconceived ideas with what they should be doing or not doing." (Nurse)

“Some patients are very educated. They’re pretty much aware of everything- they have some information and they just need some guidance to make a decision. The other patients are very content with what you tell them. And sometimes they want you to make decision on their behalf.” (Physician)

“You have to have so many pieces of information to put together prognosis information.”
(Physician)

Healthcare professionals felt some patients were likely to use CRII and request additional information from their healthcare professional, some were more likely to independently navigate the complex information, and some might just defer to their healthcare professional.

Holistic and whole-person information

Many healthcare professionals felt the focus of CRII rested squarely on medical treatment, such as surgery, chemotherapy, and radiation, but did not address the needs of the whole person. For example, dieticians felt that patients often did not get specialized nutrition information support, either in person or online, unless they were struggling or very eager to find the information and specifically sought out professional support; the average patient would only be given information about their treatment and procedures and not nutrition information. This was problematic because patients would be left to find their own information unless they asked for a referral. The dieticians felt that this was problematic and the reason many patients ended up finding poor nutrition information or engaging in harmful diets.

“I think people have a hard time identifying what’s a good website. Like if people ask us what a good website is to go to, we give them a list. We have a whole list of websites for

nutrition and information ...it's hard for them to determine what is a good source of information.” (Dietician)

A similar concern was presented by social workers, who found that information for introspection and existential concerns or interventions such as meditation were not easy to locate online. Both groups would provide websites for this information when patients asked for it, but noted they were seldom asked and did not provide this information proactively.

Nurses in the focus group described information provision and patient education as a central nursing responsibility in oncology, but felt their role was broader than simply sharing information.

“We might offer something based on what we know about the patient and their social life and their home life and all these things, and specifically about their disease and what we see when we look at them and the internet has no way to capture that. It’s sort of general.”
(Nurse)

Nurse focus group excerpt:

P8: “Yeah the internet stuff would be very broad, whereas when they come and see us we know exactly what stage they’re at, what is a suitable treatment for them, it’s more succinct so if they want to go search then they at least have the details.”

P2: I was just going to say that also, nobody is perfect, but I think your chance of getting accurate information is probably a lot more guaranteed when you’re getting it from your nurse or your healthcare provider versus the internet right, because it’s so broad and there’s no filter to say “okay, this is correct” versus “this is wrong” so there’s definitely that aspect. It’s safer, more accurate.

P8: And a human face.

P2: Yes, absolutely.

Nurses described the importance of being present and providing support for patients and families. Therefore, nurses felt that when asking a question of CRII, patients could only capture a portion of what their healthcare professional -familiar with both the patient and their illness- could provide. One pharmacist also described how she saw CRII fitting into the patient-healthcare professional relationship, which she saw as not just about symptoms or treatment questions but something larger; specifically, she saw the role of the nurse or pharmacist was to address the patient question, and to understand what might be behind the concern. She argued that patient use of CRII in isolation does not address their needs as a whole person.

“The human element – that’s the part that’s missing... sitting across the table from you, the questions that they’re asking about drugs, are more than just questions about drugs. What they’re asking is, ‘I read on the internet that this is going to save my life’ I mean that’s an extreme case, right? Or ‘I’ve read on the internet that this will, totally prevent my nausea.’ They’re not just saying that; they’re saying, ‘I don’t want to throw up.’ ‘I’m morally afraid of having to puke my way through the day’ like it’s different. It’s more personal than the questions appear when they’re being asked.” (Pharmacist)

Thus, some professionals indicated that patients require broader, more holistic care and attention than CRII provides. Therefore, CRII was described more as a complement to healthcare professional knowledge, rather than a substitute. CRII was also seen as a bridge to greater discussion when CRII would contradict what they had said, or suggested.

Cancer types and available information

In terms of age, gender, and cancer type, many providers had varying opinions about how sociodemographic factors impact patient use of CRIL. Many participants identified that women with breast cancer, women in general, those with earlier stage cancer, and younger people were more likely to request and seek CRIL.

“I would say women with breast cancer tend to be more knowledgeable. They have more information about various treatments. Younger women of course, not the elderly women. For other cancers again I would say younger women more educated, they tend to have more information.” (Physician)

Other participants mentioned age as well; although most healthcare professionals mentioned that not all elderly patients were averse to using the internet, a common belief was that older adults were more likely to defer to their healthcare professionals for information.

“Age factors in. Sometimes if you know you’re eighty years old coming in, you might not be – I can’t blanket it – but you might be less inclined to be on the internet than somebody who is in their thirties, you know?” (Nurse)

Healthcare professionals also felt that the type of disease impacted the nature and amount of information that patients were able to find. For example, people with breast cancer and prostate cancer were seen as more knowledgeable than those with ‘other’ cancers. These notions about who would be more likely to use CRIL were based on participants’ practice experiences about observations of patient preferences for information.

Dietician focus group excerpt:

P1: “I definitely agree with the breast cancer like I’m going to research and advocate and rah rah, you know?”

P2: Prostate cancer to some extent, there are some men, maybe not the really older ones, but prostate men have information needs, too.

P1: Yeah, the less – I feel evil for calling them this but the less glamorous cancer like rectal or anal canal, nobody’s –

P2: Or even head and neck– or esophagus, like they’re not asking us about websites and fad diets and stuff like that.

P3: It’s more like we’re seeking them out because we can see that they’re having problems and it’s like we can help you.”

Impressions of judgment or concern

When the topic of patients’ sharing information with their healthcare professionals was raised, many participants suggested that this did not happen on a regular basis. When probed further, healthcare professionals suggested patients might hold back sharing CRII for fear of being judged or viewed as challenging their healthcare professional. However, healthcare professionals described feeling concerned for patients possibly finding harmful or misleading information on the internet. Providers also expressed concern about patients searching for videos of procedures, watching them, and then becoming extremely fearful.

“The other thing that sometimes helps, sometimes hurts I think with patient use of the internet or things like YouTube in terms of some of the procedures that we book for people. Particularly, I’m thinking of bone marrow biopsies. People come in absolutely terrified because of what they YouTubed and what they saw for a bone marrow biopsy and that sort of thing. So they’re using not just information sites but video sites as well.” (Nurse)

Most participants described how they would try to gently redirect patients to more tailored and reputable CRII if problematic information was brought forward. Healthcare professionals also noted the prevalence of harmful or inaccurate CRII and that most patients were ill-equipped to sift through it.

“So it’s not really quality literature and they don’t have the knowledge ...that’s why we try to say, at the new patient appointments that this is the sites that we would recommend if you want to do some searching because these are websites that we subscribe to as well and we pull your information off of it. But I would say it’s a bit of a crap shoot to be honest.” (Nurse)

Another concern expressed by all healthcare professionals related to complementary and alternative medicine (CAM) information that patients found on the internet. Providers did not discuss the use of CAM as an alternative to treatment, but did discuss apprehensions around the use of, or preponderance of the use of, CAM alongside traditional biomedical treatment.

“And sometimes too, once they get that Google search information in their head, it doesn’t really matter what we say. They just believe that it’s true knowledge. We try to bring up that “no, we are doing this” especially if it’s alternative therapy sort of thing, well we’re not saying “you can’t do it” but at the same time we can’t dissuade our way of treatment

because it's scientifically proven and you know that sort of stuff. So sometimes that comes up in conversation that they're convinced that this alternative treatment is the way to go."

(Nurse)

The pharmacist described patients coming in with numerous pages of printouts from the internet, whereas one social worker described receiving phone calls from patients telling them that the cure for cancer had been found and citing information from the internet. One nurse described how patients repeatedly discussed reading on the internet about the power of antioxidants, which led to having to educate the patient about the counteractive properties of such therapies alongside oxidizing chemotherapy. Although healthcare professionals described trying to keep an open mind about CRII in these situations, they remained concerned about how this information would impact their patients' wellbeing. Healthcare professionals were troubled when patients found information about a supplement or alternative treatment promising to cure their cancer, when this was not accurate information, and could provide false hope, counteract their medical treatment regimen, or have other deleterious effects.

Processes and practices

Healthcare professionals spent a great deal of time in interviews and focus groups sharing their thoughts on the dynamic role of CRII in the processes and practices of patient interactions. In this category, healthcare professionals viewed CRII as filling information gaps considered critical to the patient and healthcare professional, during the patient experience. Themes also included patients' sharing CRII with their care team as a means to manage uncertainty and to clarify important decisions.

Filling gaps in information

Despite some concerns with potential misinformation online, participants described CRII as an important source of information for patients that served to complement information provided by healthcare professionals. Most participants agreed that patients were likely to have limited to no information about their diagnosis when waiting for their first visit to the cancer clinic (after being referred). Participants identified a second critical gap when patients finished treatment and were ‘handed off’ to their primary care physicians. During these critical times, healthcare professionals described patients as being adrift with little to no information, a situation that would likely lead them to CRII.

“But it seems to me that there is a gap between us [the cancer center] and the referral point in terms of just really not having much to go off of and so there’s a real search there for anything that they can find to, maybe help them feel little bit more in control.” (Social worker)

A similar challenge arose for patients who encountered complications or concurrent health problems. For example, one nurse described a situation where a patient had an illness seemingly unrelated to his cancer, but it created huge challenges for him navigating the system and a situation where the patient was left without much information from either his oncologist or his primary care provider. In short, the patient was faced with a huge information gap and would be likely to rely on CRII to manage this shortfall.

“It’s very hard with patients that are on chemo, and we’re managing their oncology care, but this doesn’t sound like an oncology issues. I’m not trying to pass them off; I’m trying to make sure they get the care they need.” (Nurse)

Healthcare professionals also discussed how easy it was for patients to ‘ask’ questions on the internet without judgment or feeling embarrassed. For this reason, the internet was positively appraised in terms of accessibility; healthcare professionals acknowledged that, although it has limitations, CRII would always be more accessible than them.

Nurse focus group excerpt:

P7: “I think patients are more open to asking questions on Google instead of asking questions to our providers. Just for some patients, they are embarrassed to even ask a question or it’s easier to just type their question in and get many answers and I guess they just don’t feel comfortable about the interaction between them and the provider.

P2: And they’re scared too because it’s easy to go onto Google when you’re sitting at home at three in the morning having a panic attack when you can’t talk to your nurse or your physician or you haven’t yet come to see us yet and you’ve been told “you have lymphoma” but you don’t know the exact details because you haven’t actually come to see us as a new patient.

P3: And I think they’re aware of our time constraints, unfortunately. I mean, we get fifteen minutes to do it all and they can be on the internet as long as they want so they have to prioritize what they’re talking to us about.”

Sharing to manage uncertainty

The topic of patients sharing CRII with their healthcare professionals generated discussion around redirecting patients, level of comfort with, and timing of introducing CRII. With respect to redirecting, one physician emphasized that patients sharing CRII, even if inaccurate, gave her an opportunity to address the information and open lines of communication.

“I think they’re good starting points for discussion...it’s actually nice to see what are they thinking about what are they wondering about. From a discussion point of view it’s nice when they bring things because it shows they’re thinking and that they respect your opinion.” (Physician)

Many providers echoed this sentiment, stating that they would rather be open and have a dialogue about what CRII their patients are finding rather than express judgment and have patients engage in troublesome or potentially harmful self-care behavior.

Participants emphasized the importance of timing their discussions about CRII. Although the healthcare professionals saw patients at many different time points along the cancer trajectory, many talked about not finding the ‘right time’ to engage in a conversation about CRII. For example, if a nurse saw a patient before the patient saw the oncologist or had a treatment plan, the nurse felt it imprudent to discuss treatment information from CRII, if the patient did not have a treatment plan. Conversely, if they saw patients after treatment had already been selected, then they did not feel patients would have as many information needs, and directing to CRII may be redundant.

“People might specifically say ‘well where can I look for something’ but so much of our consult is based on the anxiety and just being diagnosed and us just providing that counseling at that moment that might not involve even talking about where to look for information at that moment.” (Social worker)

Also related to timing, some professionals felt that if patients did not feel comfortable, and if they were not specifically asked about CRII, they likely would not volunteer that information unless they had concerns.

“If there’s little connection you’ll be told a minimum [by the patient] and you will ask a minimum because you’re not necessarily assured of a non-judgmental or impartial response right? If you’re sort of made to feel that – and you’re vulnerable right? You’re at your most vulnerable I mean you may as well be sitting naked in front of that person which, at some point if you’re in front of an oncologist you are, and so you’re at your most vulnerable and if you don’t feel that that person is... if there is no connection there will be very little information exchanged or given or offered.” (Pharmacist)

These latter two factors—timing and level of comfort—were particularly interesting as points for reflection given the number of professionals patients see in a short time across their cancer trajectory. Consequently, as patients move through the cancer experience they may not spend a great amount of time with any one healthcare professional, and there may never be a ‘right time’.

Decision-making and uncertainty

All participants discussed how the level of uncertainty and severity of disease impacted patients’ ability to cope and manage their illness. Nurses felt that patients with less clear treatment choices, which required patients’ personal input, experienced more uncertainty. Nurses felt that patients in this situation were more likely to seek, find, and discuss CRII with their providers, but the influence of these resources often required “reorienting”.

“Most often they just want us to say “you should do this” or “you should do that.” But it’s not that easy. Then they have the influences of these blogs or this [internet] information that isn’t from reputable sources. That’s where I’ve had -- not issues, but -- kind of having to re-orient their thinking after they’ve been exposed to that.” (Nurse)

This idea of reorienting patient thinking resonated with many nurses in the focus group. Nurses emphasized how they acted to help their patients understand and clarify their options. As discussion ensued, nurses also discussed clarifications being more frequent when patients had decisions to make about their treatment.

“If the treatment is left up to the patient, you know where it’s not necessarily cut and dry...I think sometimes they want to talk to other patients [online] who are in similar situations.” (Nurse)

Concerns around uncertainty were also echoed regarding the stage of the disease. Healthcare professionals felt that patients were more likely to want and need more information to cope with their current situation, and prepare for what was coming next, in cases where treatment options had been exhausted.

“Early stage patients [have] pretty much been told that the cancer has been taken care of by their surgeon...But for advanced cancer in general it’s pretty dynamic because when the treatment finishes and things change and the options run out then people might be looking for more support as well as for potential trial or other options, alternate therapy; like they may be using the internet as a tool for all those access to knowledge, access to alternate therapy, access to more support.” (Physician)

Discussion

Healthcare professionals shared their views on the many ways patients’ use of CRII informs interactions with healthcare professionals and services. The diverse sample of participants all demonstrated openness to patients using CRII, and felt it enhanced the patient experience. CRII use seemed to play a central role in several aspects of the patient-healthcare

professional relationship and interactions with healthcare services. Healthcare professionals felt CRII was a necessary resource for patients that could address critical gaps in information and support. Healthcare professionals described patients using CRII to support information from their healthcare professional, particularly when they were required to make a decision about their medical treatment or surgery. CRII was identified as a central informational support for patients as they transitioned between primary care and cancer care services.

Participants indicated CRII is an important source of information to support decision-making for patients with cancer. Some discussion centered on certain populations being more likely to use the internet than others; however, a key point of consensus amongst almost all healthcare professionals was that patients who had no clear-cut treatment path and were faced with making a decision were more likely to use CRII, bring it to patient consultations, and want to discuss it. These are promising findings for patients, as those who use the internet for health information are able to be more engaged and active participants in healthcare decision-making (Lee, Gray et al. 2010). Furthermore, whilst some professionals may have overlooked the pervasiveness of CRII as a key tool for patients at all ages, they generally expressed openness to patient use of CRII.

Participants were also quick to address the fact that the provision of cancer care is not always streamlined and that patients encounter uneasy transitions in their cancer experience where more information is needed. The need for information along numerous points on the cancer trajectory, and closer connections from diagnosis to survivorship, resonates with much of the extant literature (Wells, Battaglia et al. 2008, Matsuyama, Kuhn et al. 2013). Despite some concerns about the accuracy of CRII, participants also described how CRII could fill information gaps and provide support when patients feel little else is available.

An area of CRII concern that was consistently raised amongst participants, relates to patient use of CAM and the internet as the main source for this information. This is reiterated elsewhere, where patients report finding most of their CAM information online (Turhan and Bör 2016). Furthermore, a recent study of CAM use by individuals with cancer and their carers found patients wanted more information about CAM, but providers rarely discussed it with them (King, Balneaves et al. 2014). That CAM is such a common area of interest for patients, and of concern to healthcare professionals, necessitates preventatively directing patients to more reputable CAM resources and engaging patients in discussions about their CAM information needs.

Involving dieticians in this study demonstrated a potential deficit with respect to information regarding diet and nutrition. All healthcare professionals in this study discussed diets and fad diets amongst their patients with cancer, and indicated that most of the harmful diet-related information patients presented was from the internet. This is corroborated in the broader literature, where a recent analysis of over 30 websites of cancer diet information found discrepancies between for-profit and not-for-profit websites, highly variable information, and information that is difficult for patients to sift through (Herth, Kuenzel et al. 2016). Clearly, patients need assistance finding the right information, particularly given the concerns raised by numerous professionals.

Limitations

Although this qualitative study does not have a prohibitively small sample, all healthcare professionals were recruited from the same clinic. Therefore, some homogeneity may exist as a result of a common overall philosophy and orientation of participants. However, the sample does represent a diversity of voices from various members of the interdisciplinary team.

Implications

The healthcare professionals interviewed for this study spoke of the information needs of people with cancer, and how CRII could meet these needs, but they also felt strongly that CRII could not replace the holistic knowledge and care of a skilled clinician. This has implications for nurses and other healthcare professionals involved in the practice of cancer care related to how they approach and collaborate with patients who use the internet. Despite the varying disciplines represented in this study, the healthcare professionals all seemed to agree that the essence of their role goes beyond the provision of information. Instead, their approaches to care are holistic, and include expressive and personal elements. These findings resonate well with nursing, where disciplinary knowledge has been theorized to be inclusive of several key types of knowledge. The seminal work of Barbara Carper (Carper 1978), and subsequent expansions (Munhall 1993, White 1995, Chinn and Kramer 2011), have offered that nursing knowledge includes ethical, aesthetic, empirical, personal, sociopolitical, and emancipatory components that reflect the need to care for the whole person. This study emphasizes that other disciplines share the view that the value of disciplinary knowledge transcends linear sharing of empirical information.

What this means for healthcare professional in cancer care, is that knowledge gleaned from the internet needs to be assessed and incorporated into consultations on a regular basis. As some of the participants suggested, the time when patients introduce CRII is an opportunity to start a conversation about the information they want, need, and have already found. However, healthcare professionals also need to be aware of the power dynamics in patient-healthcare professional relationships, and acknowledge that not all patients will feel comfortable raising CRII. In these cases, healthcare professionals have a responsibility to ask all patients about their information needs, and can then address CRII needs and recommend appropriate sources. These

actions require minimal time, virtually zero investment from the broader healthcare system, and serve to validate patient concerns and strengthen the patient-healthcare professional relationship.

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Chapter 6: Integrated Discussion

For this mixed method dissertation research, I sought to explore the role of CRII in peoples' cancer experience, and specifically their interactions with healthcare professionals and the healthcare system. I collected data pertaining to cancer websites, conducted interviews and surveys with people newly diagnosed with cancer, and conducted interviews and focus groups with healthcare professionals. Findings of this mixed methods dissertation contribute to a better overall understanding of how people with cancer use CRII, what type of information is accessible on the most commonly searched websites, and how CRII informs their interactions with healthcare professionals and healthcare services.

In this chapter, I summarize study findings from the entire dissertation. I provide an integrated discussion of all findings, alongside reflections on the process and outcomes of this dissertation. Finally, I present implications for practice, education, and future research. In Table 6.1, the dissertation findings are presented and grouped by manuscript (including the supplement).

Table 6.1: Summary of Dissertation Findings

Dissertation Objective Dissertation chapter	Tailored Manuscript Objective	Methods	Analytic Framework and Themes		Study Findings & Implications
1. To qualitatively explore the content of the most commonly searched CRII from a critical nursing perspective. <i>Chapter 3</i>	To explore and critique the content of the internet cancer milieu to better understand CRII from a nursing perspective.	Guided by an interpretive descriptive approach. A review of 20 websites was conducted using a two-step approach: websites selected using a consensus search strategy and by asking patients (n=19) which websites they most commonly used. Data were analyzed using inductive and deductive thematic analysis.	Empirical Medically focused language Medical focus Complementary and alternative medicine Up-to-date Information sources Empirical Pain management Palliative Personal Support services Life narrative Informed decision-making Person-led information seeking FAQ Survivorship Patient-provider communication Ethical Holistic health Attribution Palliative care Ethics End of life Socio-political Gender Economic challenges Culture Work concerns Second language Returning to work Aesthetic Togetherness Gendered Strength Clear and concise Multi-media		The dominant discourse focused on empirical information about treatment, prognosis, and cure. In contrast to the holistic, nuanced, and patient-specific knowledge that may be provided by nurses and other healthcare professionals, a lack of sociopolitical, ethical, personal, and esthetic information was noted in the reviewed websites. When seeking CRII online, patients predominantly found empirical and biomedical information. Findings highlight the importance of information diversity, and the need for nurses to be aware of the information that is available and that patients report accessing. Implications focus on the need for dialogue around pervasive technologies and the nursing role in assessing and directing patients to holistic information.

Dissertation Objective Dissertation chapter	Tailored Manuscript Objective	Methods	Analytic Framework and Themes		Study Findings & Implications
2. To explore the prompts to use CRII and how CRII informs the ways in which patients interact with healthcare professionals and healthcare services. 3. To document which CRII websites are accessed and the patterns and frequency of use. <i>Chapter 4, including Manuscript & supplement*</i>	To create an understanding of CRII use by people newly diagnosed with cancer, and how it shapes their patient experience and informs their interactions with healthcare professionals and healthcare services.	Guided by an embedded mixed design, interpretive description was the overarching methodology. Nineteen people with cancer were interviewed twice (n=38). Each participant also completed a survey about CRII use. Qualitative data were analyzed using thematic analysis. Quantitative findings were analyzed using descriptive statistics.	Person in context	Age	Three key themes emerged based on patient interviews: (1) person in context, (2) management of information, and (3) managing relationships with healthcare professionals. The three themes relate to personal factors that seem to shape how individuals come to use CRII and how patients mobilized CRII to manage their patient experience. Patients described CRII as an important resource as they sought to manage and make decisions about their illness and make sense of their disease. Patients also sought CRII to complement and reinforce information provided by healthcare professionals. Implications focus on the need for healthcare professionals and healthcare organizations to consider the broad implications of CRII and engage patients in discussion about their use of CRII.
				Gender	
				Rural communities	
				Education level and access to information	
				Family support	
			Management of Information	Symptom management	
				Physician reviews and second opinions	
				Guiding decision-making	
				Self-navigation	
				Knowing where to look and when to stop	
			Managing relationships with healthcare professionals * (supplement)	Filling the gaps	
				Timing	
				Being prepared and making use of valuable time	
				Choosing not to share information	

Dissertation Objective Dissertation chapter	Tailored Manuscript Objective	Methods	Analytic Framework and Themes		Study Findings & Implications
2. To explore the prompts to use CRII and how CRII informs the ways in which patients interact with healthcare professionals and healthcare services. <i>Chapter 5</i>	To document cancer healthcare professional views of patient use of CRII, and how this informs the ways patients interact with healthcare services and professionals.	Twenty-one healthcare professionals engaged in interviews (n=4) and focus groups (n=3) guided by an interpretive descriptive approach. Data were analyzed using thematic analysis.	Pragmatic concerns and priorities	Tailored information	Two key themes describe healthcare professionals' views of CRII use. These themes relate to healthcare professionals' perceptions of patient use of the internet to manage their pragmatic concerns and priorities. Healthcare professionals also felt patient CRII modulates their interactions with the healthcare system. Healthcare professionals were supportive of patient use of the internet to meet health information needs. Healthcare professionals also acknowledged key points in the cancer trajectory where information may be lacking or patients may have less informational support; participants felt that CRII served as a beneficial resource to address these gaps. Oncology healthcare professionals are well situated to take the lead in talking to patients about their CRII use. Communication about patient use of CRII may also strengthen areas of patient education that are lacking, and encourage healthcare professionals to raise key topics of interest, such as CAM.
				Holistic and whole picture information	
				Cancer types and available information	
				Judgment & concern	
			Processes and practices	Filling critical gaps in information	
				Sharing	
				Decision-making and uncertainty	

Summary of findings

Website analysis

In the qualitative review of websites, I explored the online milieu in an effort to understand the types of cancer information and content available, and what patients find when seeking information on the internet. I used two different methods to determine which websites I would analyze. Initially, before recruiting people with cancer to the study, I used a consensus search strategy to ascertain the most common websites that a patient might encounter. This method did not constrain website use by region or country, and allowed inclusion of a sample of the most commonly searched websites by keyword. The second sampling strategy included asking people with cancer which websites they used, and subsequently including these in the sample of websites.

I used Carper's fundamental patterns of knowing as a guiding framework for the website review (Carper, 1978). Carper's approach is consistent with my worldview as a nurse, and encompasses a holistic conceptualization of knowledge. I used deductive and inductive thematic data analysis, first analyzing the website content inductively and applying codes, and then grouping these into the overarching themes that reflected the multiple types of knowledge.

Findings from this review enable an understanding of the types of cancer content and information that an individual can expect to find when they search online. The most abundant is biomedical and empirical information about diagnosis, treatment, and medical management of cancer. This is vital information, and very important during the initial stages of diagnosis as patients make sense of their illness. However, the dominance of biomedical information did seem to overshadow information of equal importance. Specifically, information addressing strategies towards personal management of illness, sociopolitical factors, death and dying, and

existential challenges was difficult to find. These findings are significant as they raise questions and concerns about the information that patients find as well as the information that is deemed important enough to be easily accessible. They also have implications in numerous domains of the discipline of nursing and provide insight for future research. Furthermore, these findings raise questions about how nurses may address the limits of CRII in their nursing practice.

Patients

In the qualitative study with patients, I sought to understand CRII use by people newly diagnosed with cancer, how it shapes their cancer experience, and how it informs interactions with healthcare professionals and healthcare services. I used an embedded mixed methods design (Cresswell, 2014), guided by an interpretive descriptive approach (Thorne, 2016). I conducted two in-depth individual interviews and a short survey of CRII use with 19 people newly diagnosed with cancer (n= 38 interviews), over a period of 10 months. Qualitative data were analyzed using thematic analysis, and quantitative data were analyzed using SPSS.

The findings from this study demonstrate that patients feel CRII is an important resource during their cancer experience. From the time of diagnosis, patients describe CRII as their most important source of information, next to their healthcare professional. Patients felt that CRII complemented the information provided by their healthcare professional, and allowed them to have a better understanding of complex cancer and medical information. Many patients described a staged approach to CRII use. First, they would obtain information from their healthcare professional, and then they would consult CRII—at their own pace and on their own terms—to gain a comprehensive understanding of their diagnosis. Patients also described using CRII to manage their symptoms and to assist them as they navigated the complexities of the healthcare system. CRII was used to guide decision-making, particularly when two or more

choices were available to the patient. Clearly, CRII played a crucial role in multiple facets of patients' understanding of their diagnosis and the cancer experience.

Perhaps the most notable finding from this study was the diversity of the sample. The average participant age was 62, within a range from 43 to 87. Older adults described using CRII in much the same way as the younger adults in the study, although several older adults relied on family members to instruct them about which websites to use. Furthermore, many participants did not have advanced education, but this was not seen as a barrier to using the internet and navigating health information. Individuals from rural and remote communities described using CRII to manage the intricacies of accessing healthcare services in urban areas. The rural participants also felt that they relied on CRII more, because they did not always have local access to healthcare services and could not readily access their doctor or emergency services. Thus, rural participants' use of CRII seemed to be based more on necessity compared to those living in urban areas. Together, the participant findings point to interesting opportunities for future research and present implications for nursing practice and cancer care.

Healthcare professionals

In the qualitative study with healthcare professionals, I documented healthcare professional views of patient use of CRII, and how healthcare professionals see CRII use informing patient interactions with the healthcare system. I conducted three focus groups and four in-depth interviews with various healthcare professionals working at the cancer clinic, including nurses, physicians, dietitians, social workers, and a pharmacist (n=21). Data were analyzed using thematic analysis (Thorne, 2016).

Healthcare professional participants acknowledged that many of their patients rely on CRII to understand and process their diagnosis. For instance, upon receiving their diagnosis, patients would go to the internet to learn about their illness and to process information provided by their healthcare professional. Healthcare professionals identified two transitions where they felt information was needed to bridge the gap between cancer care and primary care: first, when entering cancer care at the time of diagnosis and, second, when discharged from cancer care back into the care of the primary physician. Healthcare professionals found that patients often experienced undue stress and anxiety around these times, and likely relied more on CRII to process their concerns in the absence of the appropriate healthcare professional or other support. However, healthcare professionals postulated that, even once in the cancer care system, patients may feel unsure about asking certain questions and, moreover, that clinic conditions do not always permit engaging with all patients.

Although healthcare professionals acknowledged and supported patient use of CRII, they also indicated associated challenges. Participants expressed concern about patients accessing information that they were ill-equipped to understand or that was wholly inaccurate. Healthcare professionals indicated that even when patients found what they called ‘good quality’ information, they were skeptical that the average patient (i.e., with no prior medical knowledge) would be able to parse through that information and identify what was applicable to their specific diagnosis. The case of CAM was also cited as a main topic of internet information that patients shared with healthcare professionals that generated concerns.

Overall, this study presents important conclusions for healthcare professionals to reflect upon. When triangulated with the findings from the additional data sources, these findings pose thought-provoking directions for future research and nursing practice.

Discussion

Together, the findings from my dissertation research begin to clarify the role of CRII in the cancer experience and patient interactions with healthcare professionals and services. To address the overarching objective of this dissertation, I have drawn on multiple data sources, including the perspectives of both patients and healthcare professionals. Specifically, patient and healthcare professional perspectives highlight the numerous ways that CRII is mobilized at diagnosis and throughout the cancer trajectory. The use of CRII supports patients as they interact with key healthcare professionals, and informs decisions around treatment and service use. These findings present a robust picture of the role of CRII in many aspects of the cancer experience.

Patient use of CRII to meet information needs

Across the findings from all objectives, a common theme is that patients need information to cope with a diagnosis of cancer. This is reinforced in the literature, where information is seen to be a key resource for individuals as they manage the demands of their illness (Lambert & Loiselle, 2007; Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Although it has been documented that information needs of people with cancer are often unmet (Faller et al., 2016), patient participants in this study readily used CRII to address information gaps. Patients were candid about their use of CRII and how it augmented information from their healthcare professional and strengthened their understanding of their illness. This enhanced understanding supported their decision-making abilities and enabled them to manage their symptoms. Patients provided several examples where they had limited information or sought more information to complement what their healthcare professional provided. For instance, when positive biopsy results were delivered over the phone or when an unexpected symptom arose, CRII was seen as a user-friendly resource that could be easily accessed. Unrestricted by office hours or having to

disclose their concerns to another person, the internet served as an unbiased alternative source of information.

Both patients and healthcare professionals held the view that people rely on CRII more when patients are required to make treatment decisions involving uncertainty as to the best available options. Patients explained that gathering and understanding information on all available options was necessary to make such a decision. For instance, several women talked about the need to decide between a mastectomy and breast-conserving surgery, and how they used CRII to bolster their decision-making abilities. Prior research comparing information needs by diagnosis type found that women with breast cancer prefer an active role in decision-making compared to those with colorectal and gynecological cancer (Beaver, Bogg, & Luker, 1999; Beaver & Booth, 2007). In this study, I observed that patients with breast cancer, esophageal cancer, and prostate cancer all used CRII to support their decision-making.

Many patients also described needing to take time ‘to sit with’ the information from their healthcare professional, to reflect upon it, and then come to a decision. Patients did not see this process as something that could be rushed. Although patients positively appraised the information they received from their healthcare professional, they felt CRII complemented and enhanced that knowledge. This was corroborated by healthcare professionals who felt that patients facing a decision that was even marginally ambiguous or uncertain—requiring the patient to choose some aspect of treatment or surgery—needed more support to make that decision. Healthcare professionals described patients relying heavily on CRII when such decisions were required.

Healthcare professionals were generally understanding and supportive of patients’ CRII use and their need for information. However, professionals did raise concerns about patients’

ability to filter and apply—or tailor—information relevant to their own diagnosis. The notion of tailoring information was important to healthcare professionals, but not generally raised by patients. This could be related to the healthcare professionals' extensive knowledge of cancer, the spectrum of potential complications, and their clinical experience observing the ramifications of misinformation. Comparatively, most patient participants did not have prior medical knowledge, in general or related to cancer, possibly making them less aware of information ill-suited to their diagnosis. However, in this study, patients described comparing information from multiple websites and other strategies to ensure they were getting information they felt was suitable. This relates to a recent study of online information use in which patients report using a process of searching and comparing multiple search results with the intent of getting the best information to solve their query (Fiksdal et al., 2014).

Regarding types of information, many patients expressed an affinity for watching videos or viewing pictures online to clarify what would take place during certain procedures or to confirm the anatomical location of their disease. People approached their illness in this way in order to be prepared and better informed. For them, cancer was no different than other unknown or foreign situations. For example, one man felt better prepared when he was able to watch videos of radiation, and a woman with claustrophobia felt less anxious after seeing a video of a CT scan. Prior reports reiterate patient sentiments appraising YouTube and social media as valuable sources of information during treatment and survivorship (Chou, Hunt, Folkers, & Augustson, 2011; Kressler, 2014; Sugawara et al., 2012).

From the website study, the information analyzed predominantly focused on treatment, surgery, and cure or was empirical in nature. I would assert that empirical information in isolation is limited and one-dimensional, particularly when compared with the multi-faceted

knowledge nurses can provide to patients, as conceptualized by Carper and others (Carper, 1978; Holtslander, 2008; Silva et al., 1995). However, the examples described above demonstrate how viewing a video that pertains to the empirical, e.g., the video of a CT scan, has multidimensional effects on the person, in this case lessening anxiety about that treatment the individual was anticipating. Her experience of that empirical piece of information is not limited or one-dimensional. Thus, each individual's subjective experience of online information may not be easily categorized into the five knowledge types; there is overlap, interaction, and interconnectedness. When patients apprehend CRII within the context of their own illness, sociopolitical context, and health information needs, it becomes part of their whole experience rather than simply empirical or one-dimensional. For example, someone looking for information about pain management may look at empirical information about pain medication, but perhaps this relates to a past experience where pain was poorly managed. This example demonstrates how that empirical information is actually interconnected to the patient's interest in obtaining ethical care, and relates to her personal experience. Thus, the website analysis presents a useful understanding of the information that is available, but patients' experience of using online information seems much more nuanced. Furthermore, nurses may have a practice role in addressing patients' CRII and complementing it with their holistic knowledge.

When patients found CRII online that supported their self-management and decision-making, they described feeling relieved; this presents a stark contrast to the concerns of healthcare professionals. Nurses and doctors cited many examples of patients watching procedures online and becoming extremely upset or anxious about a given procedure. Healthcare professionals were particularly concerned about the harm of watching videos that could be posted by anyone, which may unnecessarily induce fear and anxiety. Similar concerns around

information quality on YouTube—related to inaccuracy of information about cancer information and related treatments—have been documented in the literature (Martini et al., 2016; Steinberg et al., 2010). Remarkably, in this study, these concerns did not lead healthcare professionals to caution patients about watching videos of procedures or accessing information online. I believe their hesitance to caution patients speaks to the openness of the healthcare professionals and their regard for the importance of the patient-healthcare professional relationship.

Patients in this study described using CRII in numerous ways and, although supportive of its use, healthcare professionals' misgivings remain (Bylund et al., 2015; Newnham et al., 2005). It seems that this tension—patients finding CRII useful but healthcare professionals concerned about the repercussions—may remain unresolved. That is, healthcare professionals may remain scared and fearful of their patients using CRII as this continues to be a readily accessible source of information for patients. Furthermore, CRII will likely continue as a dominant source of self-sought information for patients, as healthcare professionals and the healthcare system show few signs of becoming more nimble in their information provision (Crowley & Speer, 2016). Perhaps future research can explore this tension, and specifically how healthcare professionals grapple with patients' autonomy and ability to access CRII, as well as the implications for both the healthcare professionals' practice and patient care.

CRII and health service interactions

Regarding interactions with healthcare services, patients report using CRII to learn more about their diagnosis and to prepare themselves for treatments, procedures, and travel related to managing their illness. Patients also described using CRII as a means to learn about their illness and regain control and to cope with their illness. In many instances, patients reported turning to CRII rather than phoning a nurse or visiting a hospital. Sometimes this meant gathering the

information to determine if they needed to seek further care, but this initial step in self-management is meaningful. These steps towards self-management decrease the use of healthcare services or may lead to more effective service use, as patients only use healthcare services when they feel they need them (Andersen, 1995). By using CRII to become informed about how to self-manage, patients rely less on their healthcare professional yet also have information about when it is necessary to contact them. This was well illustrated by the exemplar in Chapter 4, where a man with colorectal cancer used CRII to manage a complication of his treatment and identify when he should seek care. Although healthcare professionals were quick to comment that CRII could not replace the knowledge, skills, and judgment they provide patients, they also noted that patient information needs would often go unmet if they relied solely on healthcare professionals. Thus, CRII can bolster patients' knowledge of when to use health services and possibly create more efficient service use.

The notion that CRII could not be a substitute for the knowledge of healthcare professionals was clearly made by both patients and healthcare professionals; this was also confirmed in the analysis of websites. Whereas nurses (and to some extent other healthcare professionals) have holistic practice knowledge, the website analysis indicated CRII was very heavily focused on empirical information and biomedical treatment. Websites tended to focus on treatment, surgery, and medical management, and the importance of these topics should not be dismissed. The need for biomedical and treatment information resonated with both patients and healthcare professionals, particularly related to the decision-making process. However, both patients and healthcare professionals expressed that the information and support patients need is broader than just textual and medical. Some domains that were unaddressed or difficult to locate related to end-of-life topics, CAM, diet, return to work, and existential issues. These findings

reiterate the notion that CRII should serve as a complement to information provided by healthcare professionals rather than a substitute (Institute of Medicine, 2001).

The topic of patients sharing CRII with their healthcare professionals, and how it shapes patient-healthcare professional relationships, was also a key aspect of this inquiry. Many patients seemed uninterested in sharing CRII with their healthcare professionals. Even those who did report sharing information did not see it as an important step or something that they did deliberately. However, healthcare professionals seemed to feel that this was a great place to start dialogue and conversation about patient information needs.

Healthcare professionals explained that patients bringing CRII forward was an opportunity to assess the information they were using and what they were looking for. Interesting, then, is the fact that so few healthcare professionals actually initiated these conversations despite feeling that discussions of CRII were important. This was corroborated by patient participants, who indicated that few (if any) healthcare professionals offered information from the internet or discussed with them where and what to search. These findings point to a need for ongoing guidance and engagement from healthcare professionals in relation to CRII, as this study reiterates that CRII is now a main source of health information for patients (Shea-Budgell et al., 2014). The value proposition of sharing CRII within the context of patient-healthcare professional relationships seems to be more than giving or receiving information. That is, patients also benefit when they discuss CRII with their healthcare professional due to questions that arise or having to explain what type of information they are looking for. Thus, sharing and discussing CRII within the patient-healthcare professional relationship also creates opportunities to add nuance and depth to the empirical information patients may be seeking.

On the topic of sharing information, some patients described not sharing information—particularly information related to CAM—for fear of how their healthcare professional would react. Patients described feeling concerned that their nurse or doctor might judge them for seeking alternative information or for asking questions about something outside of the biomedical system. Interestingly, the dearth of CAM on the websites reviewed may also be linked to patient perceptions that this information is ‘off limits’. When healthcare professionals did express concern about CRII, the example of CAM was referenced most often. Healthcare professionals expressed genuine concern for the well-being of their patients, sharing stories of patients who found CAM information online that led them to problematic diets, emptying their bank accounts to buy expensive herbs, or simply believing their illness was curable. The literature reiterates that CAM is an area of interest for patients with cancer and that healthcare professionals can do more to engage patients on the topic (Maloney et al., 2015). In a study by Maloney and colleagues (2015) with 70 women with breast cancer, CAM was a key topic for CRII searching alongside such pivotal information as treatment and side effects. Thus, despite what healthcare professionals may think, patients want this information and are clearly capable of finding it if not provided. Thus, conversations initiated by healthcare professionals could cover these topics in a way that permits patients to ask questions without feeling judged.

Research on innovative technologies to support people with cancer continues at an impressive speed. Of particular note is the adaptation and testing of the Advanced Symptom Management System (ASyMS) with Canadian cancer patients (ASyMS-Can) (Clinical Trials.gov, 2017). This intervention was designed in the United Kingdom as a means for patients to electronically monitor and report their chemotherapy related toxicities (McCann et al., 2009), and is currently being adapted and testing in the Canadian context. ASyMS is a smartphone-

based symptom management system, emphasizing self-management via clinician telephone triage and symptom self-monitoring prompts. These types of interventions are very promising for individuals with cancer as they hold two key benefits emphasized by participants in this study: (1) They are mobile, easy to access, and readily available, and (2) they are connected to healthcare providers. Although I would contend that self-sought CRII will always be an important source of information for people with cancer, the nature of the ASyMS and similar interventions address some of the key issues identified by patients in this study; how they change the landscape of the patient experience with cancer should be closely observed.

Implications for Nursing

My dissertation research lends itself to understanding the role of CRII in the patient experience of cancer. Although these findings have implications for all of the disciplines providing frontline cancer care, I will focus on the multifaceted implications for the discipline of nursing. Insights gained from this dissertation research will add to the knowledge base of nursing in the domains of education, practice, and research. The limitations of this dissertation relate to the scope of the project and time, both of which relate to resources associated with conducting doctoral research: with more funding and more time, I could broaden the scope of this project, diversify sampling strategies, and increase the sample size. More specific limitations pertain to the absence of health service utilization measures in relation to CRII, for instance, using methods of economic analysis. In addition, the sample was not diverse in terms of ethnicity and culture, and in particular lacked Aboriginal participation. These limitations, along with strategies to address them through future research, are discussed in greater detail in the research implications section.

However, there are also several strengths to this study, including the breadth of data sources that included patients, healthcare professionals, and websites; the diversity of the patient sample, including people with various cancer types, those living in rural and urban areas, and a near equal gender split; and the mixed methods approach. Having discussed the limitations of each manuscript in Chapters 3, 4, and 5, I will now move into a discussion of the implications for how the findings, limitations, and insights can be addressed through nursing practice, education, and future research.

Practice

Nursing practice encompasses practical care for the whole person, their family, and their environment (Bottorff, 1991; Carper, 1978; Fawcett, 1984). As a practical profession with a holistic focus that goes beyond care of the physical body, the findings from this dissertation have multi-faceted implications. Cancer nurses face a particular challenge as they support patients during existential crises and the associated fatalistic stigma of cancer (Powe & Finnie, 2003). Cancer nurses also provide information and support for the physical demands of illness (Marbach & Griffie, 2011). Thus, these study findings should motivate nurses to reflect on the information patients require to manage their diagnosis. Insights about where patients are finding information and how both patients and healthcare professionals (including nurses) view the role of CRII in the patient-professional relationship warrant further discussion.

Oncology nurses and other healthcare professionals identified key points on the cancer trajectory when patients require more information: at diagnosis, when entering cancer care, and at discharge from cancer care. At the cancer centre where this research was conducted, patients were contacted by a social worker as soon as their referral was received. This phone call would be an ideal opportunity to assess and intervene, by providing websites and asking about relevant

questions or gaps in information. Making a connection to an oncology nurse at this point may also alleviate patient concerns. Some patients, particularly those with prostate cancer, were connected very quickly with an oncology nurse. These patients described feeling relieved and reassured by the information provided by the oncology nurse, who was able to refer them to other information sources. Whereas the expert care provided by a social worker should not be overlooked, the model of registered nurse as patient navigator has been thoroughly supported in the literature (Fillion et al., 2006; Pedersen & Hack, 2010). Following a nurse-led model of patient navigation may proactively address patients' priority concerns during the transition into cancer care. An oncology nurse navigator is well-situated to assess what information patients want and address the divergence between it and what is currently provided in order to bridge this gap.

People with cancer used CRII to manage their symptoms, including anxiety related to the numerous unknowns of their diagnosis. This is relevant to nurses, as our professional role includes significant support for symptom and self-management (Dodd et al., 2001). Information needs are present across the trajectory of cancer, especially at diagnosis (Matsuyama et al., 2013). Furthermore, past research on chronic disease management has found that the design of the care system is more important than the specialty training of healthcare professionals (Rothman & Wagner, 2003). Therefore, translating these findings into practice may include raising nurses' awareness of how and where patients are finding information and what they feel is missing. This is not a high technology, resource heavy solution, but my findings raise questions about whether or not there is a need for complex computer applications or elaborate multi-step interventions. In our current healthcare system of budget scarcity (Sutcliffe, 2011), where creating new interventions essentially means taking money away from something else,

nurses need to question the use of funds to develop new technologies that may be redundant. Given the ubiquity and ease of use of the internet, I believe patients will likely default to CRII use despite the development of expensive interventions and applications. Nurses can tailor care to encourage patients to bring CRII into the nurse-patient relationship so it is complementary versus supplementary. The findings from this study suggest that the relationship would be strengthened if patients and healthcare professionals discussed CRII openly, an approach that does not necessitate more technology.

Strategies for practice implementation.

The findings from this dissertation have educational implications for oncology nurses in practice and suggest that nurses could interact more with patients about their use of CRII. Patient teaching, patient education, or information exchange between nurse and patient by any other name has over time shifted from a top-down approach to a collaborative partnership model (L. N. Gottlieb et al., 2006). The growing accessibility of information on the internet, alongside the current focus on patient-centred care (which advocates for patients taking part in their own healthcare), has jointly shifted power dynamics (Wald, Dube, & Anthony, 2007). Whereas in the past patients typically learned about cancer from their healthcare professional, nurses now need to understand that patients find information and engage in independent learning about their illness (Lustria, Smith, & Hinnant, 2011). The desire for more exchange about CRII between patients and healthcare professionals has relevant educational repercussions for nurses.

In interviews with patients, I found that they used CRII to learn about their illness and to self-manage. Furthermore, patients reported that sometimes they did not mention CRII because they were concerned about judgment from their healthcare professional; healthcare professionals agreed that fear of judgment could be a reason for patients to keep their CRII secret. Thus, these

results highlight a need to develop capacity amongst nurses and healthcare professionals to discuss patient use of CRII. Developing capacity might include interventions focused on increasing nurses' awareness of patient CRII use and presenting tangible strategies to do so. As nurses are the healthcare professionals who spend the most time with patients, and for whom patient education is a key responsibility (Smith & Zsohar, 2013), these implications should resonate and be a call to action.

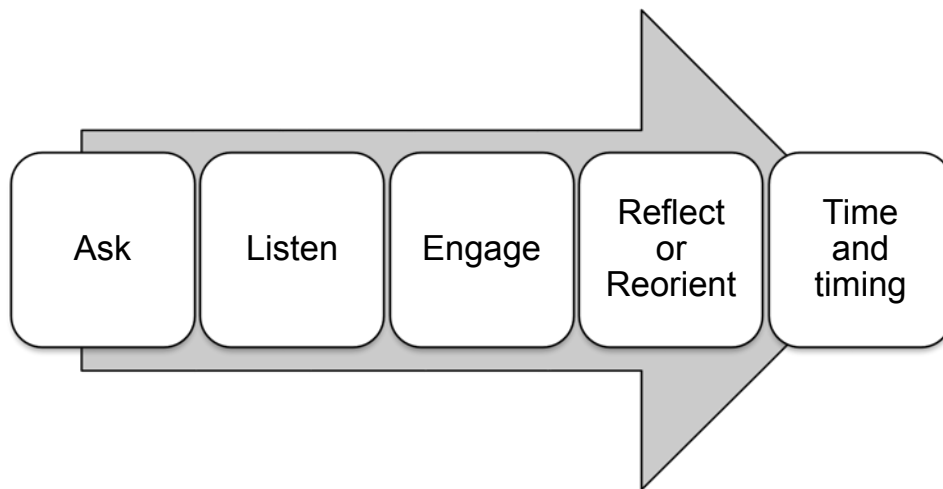
For nursing, there has been some discussion of how to involve patient-sought CRII into the nurse-patient relationship, but guidelines and strategies vary in their patient-centredness. For example, a health education 'fact sheet' from the Registered Nurses Association of Ontario (RNAO) titled 'Nurses and the use of computer technology: from nurses for you' (Registered Nurses Association of Ontario, 2008) refers to several ways technology functions in healthcare. The fact sheet suggests that patients may use internet health information to learn about their illness, that there are many websites of varying quality of which patients should be skeptical, and that patients should ask their nurse or healthcare professional for help in interpreting their internet information. Furthermore, the RNAO best practice guidelines on facilitating client-centred learning (Registered Nurses Association of Ontario, 2012) cite the need to create a safe space, assess patient learning needs, tailor education to patient needs, and use a combination of approaches (citing print, telephone, computer, etc.). Combined, these two approaches—encouraging patients to discuss CRII with their healthcare professional and encouraging nurses to create a safe space to talk about CRII—generate a pathway to integrate these findings into practice through patient education.

Based on the findings of my research, I would also encourage nurses to be the catalysts and to start such conversations about CRII use rather than waiting for patients to broach the

subject. The RNAO best practice guidelines emphasize the LEARNS Model, which draws on the nursing process by encouraging nurses to Listen, Establish, Adopt, Reinforce, Name, and Strengthen (Registered Nurses Association of Ontario, 2012). I believe this model poses several strong attributes for generating discussions about CRII, but can be tailored based on findings from this study.

Drawing on the study findings, I propose the following approach to begin conversations about CRII: Ask, Listen, Engage, Reflect/Reorient, and Time (ALERT) (Figure 6.1). This approach and the requisite nursing strategies are within the scope of practice of an oncology nurse, and are relevant to multiple other areas of nursing where patients use online information for self-management and to guide their use of health services.

Figure 6.1: ALERT to CRII



(1) Ask patients and their families about their use of CRII and whether this is a source of information they rely on. Although the RNAO fact sheet encourages patients to start this conversation, patient participants in this study clearly felt that they wanted healthcare

professionals to broach this topic first. Furthermore, providers seemed to feel that having this conversation, regardless of what patients told them, was a good way to initiate an important discussion and understand patient questions about their illness and what they wanted to know. Asking relates to assessment, which is the first step of the nursing process and the foundation of clinical reasoning in nursing (Alfaro-LeFevre, 2014).

(2) Listen to what your patient tells you. Listening and the accompanying non-verbal skills are an essential component of the patient-nurse relationship (McCabe & Timmins, 2013). Active listening skills allow nurses to understand their patients' information needs, and permit the patient time to share their needs or what they have already found on the internet.

(3) Engage with your patient. As laid out by the RNAO best practice guidelines, engage your patient to establish a therapeutic partnership, ensure that they feel comfortable sharing, and ensure they understand your desire for them to have the best possible information (Registered Nurses Association of Ontario, 2012). Developing rapport and dialogue with the patient, rather than viewing patient education as a simple linear transaction, creates opportunities for patients to feel like empowered partners rather than passive subjects (Sanford, 2000).

(4) Reorient or reflect on what patients share with you. Nurses put forward the idea of reorienting and reflecting what patients tell them as a means of affirmation. The nurse, having heard what information the patient has found, identifies their concern and, if necessary, redirects them to different or better CRII. This intervention positions nurses to acknowledge patient resourcefulness as a strength, thereby validating their information-seeking efforts (Feeley & Gottlieb, 2000). By reflecting, nurses can also take the empirically focused CRII and put it in a holistic context.

(5) Time and timing refers to the importance of incorporating discussions of CRII throughout the nurse-patient relationship and cancer trajectory. Many healthcare professional participants identified a reluctance to engage in discussions about CRII at the first meeting with a client for lack of rapport, whereas others expressed that there is no perfect time. However, patients may pass through the care of a medical oncology nurse and a radiation therapy nurse in a matter of one or two visits; thus, nurses need to capitalize on the opportunity to address patient concerns at every visit and in every interaction (Thomas-MacLean et al., 2008). The notion of ‘Time’ should be a reminder that every time patients interact with their nurses, nurses should use ALERT. Nurses also mentioned that many patients used their phone or iPad to pass the time, which can also serve as a prompt to have discussions about patient information needs and CRII questions.

The ALERT approach draws directly from the findings of this research, and is unique from LEARNS in several ways. First, I believe it is the role of the nurse to lead discussion about CRII, not the patient. Thus, the ALERT model starts with the nurse asking the patient about their use of CRII. Second, the website analysis indicated that CRII is predominantly empirical. And, from the patients and healthcare professionals, we know that patients do not always understand the CRII they find. Thus, it is the role of the nurse to reflect and reorient the concerns of the patient by listening to the information they have uncovered and putting it into a holistic context. Finally, given the nature of cancer, nurses in all domains working with people with cancer need to ask these questions in interactions at all stages of the cancer trajectory, even in primary care. To summarize, the ALERT model is a practically derived model that can guide oncology nurses’ discussions with patients about their use of CRII.

Education

Nursing education needs to be dynamic and responsive to the changing landscape of healthcare and society in general (Jensen, Meyer, & Sternberger, 2009). As such, nursing curriculum experts advocate that nursing curriculum should be: (1) context-relevant, (2) evidence-informed, and (3) unified (Iwasiw, Goldenberg, & Andrusyszyn, 2014). Whereas the evidence-based movement has gained a solid footing in both practice and education (Canadian Nurses Association, 2010), the need for context-relevant education warrants discussion in relation to these dissertation findings.

Although technology and informatics in nursing education are a growing area of curriculum focus, the emphasis typically rests on the use of electronic health records, nurse-centred applications, and integration of high- or medium-fidelity simulation teaching approaches (Ehnfors & Grobe, 2004; Ruchala, 2014). However, there remains an opportunity to act on patients' use of technology and teach our future nurses to incorporate this into their practice. Importantly, these dissertation findings reiterate that use of CRII allows patients to feel a sense of control, autonomy, and greater ability to manage their illness; all of which emphasize a strengths-based approach to nursing. Furthermore, a tension amongst healthcare professionals around patients' use of CRII emerged in interviews and focus groups. We can address these tensions in our nursing curriculum, thereby preparing students as they may encounter these dilemmas in their own practice. For instance, developing case studies on the issue of patient-sought internet information may allow nursing students to reflect upon how this makes them feel, and how they will approach this in practice. Nursing students would also benefit from the ALERT schematic discussed above, as a simple reminder in practice. Together, these actions in

nursing curriculum can prepare a future generation of nurses to be more equipped to approach patients' self-sought internet information.

Another key aspect of the challenges surrounding patient education and CRII, pertain to the lack of care coordination amongst interprofessional cancer care teams (Lamb et al., 2010). With the context of a growing push toward interprofessional education (Khalili et al., 2013), the ALERT model may act as an important learning tool for educating students about CRII across all disciplines. Due to some of the concerns around 'timing' conversations about CRII, educating multiple members of the team about the importance of CRII, may serve as a proactive measure to ensure patients are asked about their needs at multiple time points, and by multiple members of the cancer care team.

Future research

This dissertation research uncovered many possible future directions for research and areas for reflection pertaining to the complex methodology. The impetus of future research arises from the diversity of the patient sample, the sample size, and the numerous findings that signal the need for further exploration.

The sample size of this study was small, and the survey of CRII would bear more valuable results if a larger sample were drawn. A brief follow-up survey of a larger patient population at the same clinic, to ascertain CRII use amongst a greater number of patients in this setting, would bolster data on the types and amounts of internet use within this population. A larger sample size for the quantitative survey would also permit conclusions about the generalizability of these findings to other populations. Of particular interest is whether the use of CRII by older adults was a function of the study criteria, or if this level of engagement with the

internet is common amongst older adults with cancer more generally. This warrants exploration as it has the potential to impact frontline care and challenge stereotypes about older adults and their use of the internet for health information.

Patients in this study described using CRII for self-management purposes, to manage symptoms, and to augment information from their healthcare professionals. Further exploration of self-management, and its impact on cancer care, is relevant given the nature of the illness as it occurs across a continuum from prevention to survivorship and usually over a period of years (McCorkle et al., 2011). I feel confident in my initial understanding of the ways in which CRII informs interactions with healthcare professionals and services, but further work might explore this relationship more closely. A study using health service utilization as an outcome, or chart review, may be one way to test the hypothesis that patients use less health services when CRII supports their self-management. This hypothesis could be further extended to explore sub-groups of the population, including those in rural areas and older adults, to understand any variations based on geographic location, age, and access to health services. One further area for future exploration pertains to the applicability of this research to those with other chronic diseases, and whether there are differences between people with cancer, in how they use CRII.

Further research is also needed with those living in geographically rural and remote areas. The stories told by rural participants about the differing nature of their CRII use, in addition to their perception that they needed to use CRII more because they lacked access to services, is an interesting path for future exploration. Prior research has documented the needs of rural dwellers with cancer, including a greater need for information, supportive care services, and challenges related to their distance from cancer care services (Bettencourt, Schlegel, Talley, & Molix, 2007; Engelman et al., 2005). However, links to rural patients' use of CRII have not been documented

to date. In future research, I plan to explore how patients mobilize CRII and other technologies to manage their illness when living in rural areas, and how this compares to urban populations.

On the topic of populations and diversity, it is noteworthy that no Aboriginal men or women were involved in this study. This is certainly a drawback, but also an area for future research. This was not a deliberate aim of sampling; given that the province of Saskatchewan has the highest percentage of Aboriginal persons in Canada (Statistics Canada, 2016), it was reasonable to assume at the outset that some of the participants in this study might identify as Aboriginal. Furthermore, Aboriginal populations are known to experience unique logistical and cultural challenges participating in cancer treatment, and thus their experiences of using CRII may present contrasts to non-Aboriginal populations (Shahid, Finn, Bessarab, & Thompson, 2011). Future research might explore how Aboriginal populations use CRII to meet their specific health needs and whether this differs from non-Aboriginal populations (Hammond et al., 2016).

However, challenges have been documented related to non-Aboriginal researchers conducting research in Aboriginal communities (Maar et al., 2011). Some of the notable challenges include community exhaustion related to continued requests for involvement in research and project work, the need for culturally sensitive research approaches that favor oral methods, and the need to involve community stakeholders. Thus, future work might benefit from the involvement of Aboriginal patient representatives and stakeholders from Aboriginal communities. Such involvement would align with the need for patient involvement in health research design, which is a cornerstone of the Canadian Institutes of Health Research (CIHR) strategy towards patient-oriented research (Canadian Institute for Health Research, 2016).

Several participants in this study discussed the role of family members in guiding or supporting their use of CRII. This surrogate CRII support was notable, particularly amongst

older adults. Prior studies have documented cancer caregivers' need for information (Glajchen, 2003; Molassiotis, Wilson, Blair, Howe, & Cavet, 2011), but the family role of supporting patient use of CRII has not been documented. Several theoretical approaches to nursing care encourage nurses to take a family approach to care, for example the Calgary Family Assessment Model (Wright & Leahey, 2012) and the McGill Model of Nursing (Gottlieb & Rowat, 1987). These models emphasize that people experiencing health challenges exist within the structural, developmental, functional, and environmental dimensions of their family (Gottlieb & Gottlieb, 2007). Thus, the goal of nursing care should be to partner with patients and their families to better understand their strengths and vulnerabilities to work towards health and wellness (Feeley & Gottlieb, 2000; Gottlieb et al., 2006). This opens the door to exploring and documenting the shared approaches to CRII use amongst patients and their families in future research. Mostly older adults reported support from their families when using CRII, but the use of CRII and its role across the family lifespan might be a particularly worthwhile area of investigation. For example, how does the use of CRII differ for parents of young children or young adults compared to older adults? These research findings would again contribute to nursing practice and generate a greater understanding of the supportive care and information needs of patients. One important caveat here is to emphasize the importance of ensuring older adults' agency is maintained, in light of such research approaches. Specifically, the consent of older adults should always be sought when conducting research alongside their family member or caregiver to ensure these endeavors remain patient-centered and respectful of older adult autonomy.

In this dissertation research, I also employed the use of various models and theories to guide specific aspects of this work. In the first manuscript -the review of websites- I used the philosophy of technology to guide a critical approach to assessing the content of commonly

searched websites from a nursing perspective. The philosophy of technology provided an important theoretical approach to underpin the discussion of cultural and social implications of CRII content on the patient experience with cancer, specifically from a nursing perspective. This philosophy provided an insightful lens to illuminate the contrast between holistic and nuanced nursing knowledge, versus the predominance of empirically and technically focused information found on the most commonly searched websites. This research demonstrates that CRII clearly plays a key role for individuals with cancer, and using the philosophy of technology as a theoretical approach demonstrated that CRII benefits from critical interrogation. The philosophy of technology may serve as a useful framework for future research around CRII as it becomes even more entrenched in the daily lives of those with cancer.

A final comment pertains to the mixed methods design used in this study. I chose this design as I felt that the quantitative data would help to illustrate the types and amounts of CRII patients used, whereas the qualitative data would allow for an in-depth examination of the problem. Despite the small sample size, and the fact that few conclusions can be drawn from an analysis of such a small number of respondents, the survey data did add another dimension to the research problem. For example, it was beneficial to quantitatively confirm that half of participants chose to share information with their healthcare professional, whereas half did not. It was also valuable to ascertain that participants used CRII across the cancer continuum: from pre-diagnosis until after treatment. Thus, the quantitative data further illuminated many of the themes that were discussed in the interviews with participants. Together, triangulating data obtained through mixing methods provided for a rich multidimensional description of the research problem, which is a strength of this dissertation.

In the context of broader discussions about mixed methods research (Giddings and Grant, 2007), I feel it is also important to note that the addition of the quantitative data was not a casual decision or an afterthought. Instead, this was a deliberate and well-planned attempt to provide the best data to address the research objectives. As such, I tried to be true to mixed methods design by explicitly describing the purpose and intent of using both quantitative and qualitative data (Cresswell & Plano Clark, 2011; Morse & Niehaus, 2009). A plan for integration of the data (discussed in Chapter 2) was instructive as I developed the table to converge all findings (Farmer et al., 2006) and summarize the whole of the study results. Furthermore, I have engaged in thoughtful reflection about the use of data from paradigms often described as incommensurable, and have addressed these issues by using a constructivist stance to interpret all data, regardless of paradigmatic origin. In future work, I believe mixed methods designs can be useful to address research problems where both depth and breadth are desired, but are not a replacement for a well-designed study that is either strictly qualitative or quantitative (Giddings & Grant, 2007).

Conclusion

In 2015 and 2016, I conducted a mixed methods study to explore the role of CRII in peoples' cancer experience, and their interactions with healthcare professionals and healthcare services. The key finding from the analysis of websites was that most provide abundant information about cancer treatment and diagnosis but less information that is holistic. In the patient sample, CRII was seen as an invaluable resource that complemented the information provided by healthcare professionals. CRII supported patient self-management abilities and informed when and how they used healthcare services. The healthcare professional participants acknowledged and supported patient use of CRII, while balancing concerns about patient capacity to self-tailor medical information and select websites appropriate to their specific

diagnosis. Altogether, this dissertation research presents the content of commonly searched websites, how patients use CRII to manage and understand their illness, and healthcare professionals' views on how CRII fits into the patient-professional relationship. The study findings generate an understanding of how people mobilize CRII to support their needs, and how this influences and shapes interactions with healthcare professionals and the healthcare system.

More broadly speaking, the tension between healthcare professionals' desire to be supportive, despite misgivings about CRII, will not be resolved without action. Nurses are leaders in healthcare, which includes consideration of where patients get their informational support. As such, nurses can be catalysts for change by demonstrating an open and non-judgmental approach to CRII in interactions with patients, healthcare professionals, and decision makers. In research, we can continue to explore the implications of CRII, be critical about its implications in practice, and cautious about over-investment in unnecessary technology.

This dissertation research generates many new questions about patient and family use of CRII and the direct effects on healthcare systems and services. Patients described using CRII to support their self-management, thereby more effectively using healthcare services, and thus future research must explore whether this has direct effects on healthcare costs. In consideration of the concerns of healthcare professionals, strategies that involve proactively engaging patients regarding their use of CRII should be emphasized. Using the ALERT approach, nurses are especially well-situated to ask patients about their CRII use and provide appropriate direction, particularly as these actions further support patient self-management. Intervening early to support CRII use might mitigate some concerns related to ill-suited information and allow nurses the opportunity to provide holistic cancer information, little of which is available online. Nurses

also embody the multifaceted knowledge described by Carper (1978) and bring this holistic approach to their patient care in ways that CRN cannot.

Chapter 7: Contribution of Collaborators

In this chapter, the contributions of collaborators and their role on each manuscript are outlined, as per the guidelines of the Faculty of Graduate and Post-doctoral Studies at the University of Ottawa. Decisions about authorship were based on the International Committee of Medical Journal Editors Uniform Requirements (2016). In accordance with these guidelines, manuscript authors must make substantial contributions to the conception and design of the research, acquisition of data, or analysis and interpretation of data; draft or critically revise the manuscript for important intellectual content; and approve the final version.

As the primary researcher, I am responsible for the entirety of this dissertation and the veracity of each manuscript (Table 7.1). I am a Registered Nurse (RN), and am currently a lecturer at the University of Saskatchewan. I began my PhD at McGill University and was supported by the following fellowships and awards: A Canadian Institutes of Health Research (CIHR) Strategic Training Fellowship in Psychosocial Oncology, a Doctoral Fellowship from the Groupe de Recherche interuniversitaire en Interventions en Sciences Infirmières du Québec (GRIISIQ), and a two-year Leveque Doctoral Research Scholarship from the Jewish General Hospital/Hope and Cope. From McGill University, I received a Provost Award, University Principal Award, and Provost Graduate Fellowship and from the Faculty of Medicine at McGill University I received a Graduate Excellence Fellowship Award, the Eileen Peters Scholarship, an International Travel Award, and the Esther Cushing Fellowship. I was also the recipient of dissemination awards from the Canadian Association of Nurses in Oncology and the International Society of Nurses in Cancer Care, which supported the presentation of these dissertation findings at national and international conferences. This study was also supported by a research grant from the Canadian Association of Nurses in Oncology. The funders had no role

in study design, data collection and analysis, decision to publish, or preparation of the manuscripts or dissertation.

Table 7.1: Summary of Collaborator contributions				
	Chapters 1, 2, 6, 7	Manuscripts: Chapters 3, 4, 5		
		Chapter 3 Website Paper	Chapter 4 Patient Paper	Chapter 5 Healthcare professional paper
Conceptualize and design	KH	KH	KH	KH
Collect data	KH	KH	KH MB	KH MB
Analyze and interpret data	KH	KH RT WG LH	KH RT WG	KH RT WG
Draft content	KH	KH	KH	KH
Revise manuscript	KH	KH RT WG LH	KH RT WG LH DH	KH RT WG LH DH
Approve final version	KH RT WG LH DH	KH RT WG LH	KH RT WG LH DH	KH RT WG LH DH
Responsible for content	KH	KH	KH	KH

I was also supported by collaboration with my thesis supervisor, co-supervisor, and thesis committee members. These partners guided the development of the research proposal, provided support and consultation in the collection of data, participated in the analysis of data, and contributed to each manuscript (see Table 7.1 for a summary of contributions). My thesis supervisors, Dr. Roanne Thomas (RT) and Dr. Wendy Gifford (WG), and thesis committee members, Dr. Lorraine Holtslander (LH) and Dr. Dave Holmes (DH), provided instrumental

support. RT is a Full Professor in the School of Rehabilitation Sciences at the University of Ottawa and holds a Canada Research Chair in Creative Practices and Well-being. WG is an RN, an Associate Professor in the School of Nursing at the University of Ottawa, and Co-Director of the Nursing Best Practice Research Centre. LH is an RN, a Full Professor in the College of Nursing at the University of Saskatchewan, and Chair of the Graduate Program. DH is an RN, a Full Professor in the School of Nursing at University of Ottawa, and holds a University Research Chair in Forensic Nursing.

Several key people who were not members of my thesis committee collaborated in the conduct of this research. Denise Budz (RN) and Deb Bulych (MSW) assisted with developing recruitment strategies at the Saskatchewan Cancer Agency. Dr. Shahid Ahmed (MD), Barb Usher (MSW), and Allison Weber (MSW) assisted with recruitment of patients at the Saskatchewan Cancer Agency. Dr. Meridith Burles, a post-doctoral fellow in the College of Nursing at the University of Saskatchewan, provided research support and assisted with recruiting and interviewing participants; her contributions were greatly appreciated. Rachel Tang managed support for transcription at the Social Sciences Research Lab at the University of Saskatchewan.

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APPENDIX A
DISSERTATION PROTOCOL

Internet Cancer Information Use by Newly Diagnosed Individuals and Interactions With the Health System: A Mixed Methods Study Protocol

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Abstract

Nearly 40% of Canadians will be diagnosed with cancer in their lifetime, and people with cancer are increasingly turning to the Internet to bolster support and information received from health-care providers. However, little is known about the role of the Internet in patients' interactions with the health-care system. The goals of this study are (1) to qualitatively explore the content of commonly used websites from a holistic nursing perspective, (2) to explore the prompts to use the Internet and how it informs the ways patients utilize and interact with health services, and (3) to document the types of Internet resources and amounts of usage. This study is guided by a constructivist mixed methods design. Interpretive description will guide the overarching qualitative component, including an analysis of data from commonly used websites and interviews with 16 newly diagnosed individuals. Open-ended interviews will clarify, through exploration, the role of the Internet in participants' health system interactions. A survey of Internet use will add insight and depth about where, when, and how participants use the Internet. All interviews and website data will be analyzed using thematic analysis. Descriptive statistics will illustrate a summary of Internet usage. Triangulation of findings will provide oncology nurses and interdisciplinary team members with insight into how patients' use of the Internet informs their use of health services. Methodologically, this study advances the use of qualitative methods for websites analysis, on which relatively little has been documented.

Keywords

oncology, nursing, qualitative research, mixed methods, interpretive description

Introduction

Cancer is the most common disease in Canada, and 40 % of Canadians are expected to be diagnosed with cancer in their lifetime (*Canadian Cancer Statistics* [CCS], 2014). A cancer diagnosis involves complex treatment and surgeries leading to disturbances in normal bodily functions, body image, and basic eating habits (Beaver et al., 2010; McMullen et al., 2011). Although the physical consequences are profound, the psychosocial implications can be equally distressing (Carlson & Bultz, 2003). These pressing multidimensional needs frequently exceed the capabilities of health-care providers (HCPs), leaving individuals on their own to seek and find information (Harrison, Young, Price, Butow, & Solomon, 2009; James et al., 2007).

For many people, the Internet has become a key source of health information due to its accessibility and ease of use (Castleton et al., 2011; McHugh et al., 2011). Currently, it is

estimated that 8 of 10 Canadians have Internet access and average 45 hr of Internet use a month (Canadian Internet Registration Authority, 2012; Internet World Stats [IWS], 2014). For individuals with cancer, Internet Cancer Information Resources (ICIRs) are used for informational, community, networking, and communication purposes and can readily address their queries, whenever they require (Eysenbach, 2003a). However, little is known about how the reliance on ICIRs shapes

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patients' interactions with the health-care system and it requires further clarification.

Study Purpose

The growing reliance on ICIRs for health information and the frequently unmet information needs of individuals with cancer instigates a need to better understand the role ICIR plays when individuals with cancer interact with the health-care system. Guided by a mixed methods approach, the purpose of this study is to clarify the use of ICIRs by patients newly diagnosed with cancer and lend insight into the role it plays in interactions with the health-care system.

Literature Review

Cancer Information Needs and the Health-Care System

For most people, a diagnosis of cancer is highly distressing, given its life-threatening nature and complicated trajectory (Bowles et al., 2008; Hall, Gray, Browne, Ziebland, & Campbell, 2012). The potential for numerous treatments and multidisciplinary involvement adds further complexity to the experience of patients and families. Physically, cancer and its treatments can have debilitating physical side effects, including but not limited to severe nausea, loss of appetite, extreme fatigue, impaired sexual function, limited mobility, and pain (Gerber, Solomon, Shaffer, Quinn, & Lipton, 2007; Kirschning & von Kardorff, 2008; Urowitz et al., 2012). Equally pressing are the psychosocial concerns, including difficulty adjusting to bodily changes, fear of surgical complications, and feelings of vulnerability and inadequacy (Soerjomataram et al., 2012; Taylor, Richardson, & Cowley, 2010). Individuals with cancer also report a host of unmet needs in both of these domains, including those that are psychological, informational, and psychosocial. Unmet needs are also connected to disruptions in activities of daily living (Carlson, Waller, & Mitchell, 2012; Harrison et al., 2009; Puts, Papoutsis, Springall, & Tourangeau, 2012).

Simultaneously, access to information is a frequently cited source of concern for people with cancer (Carlson et al., 2012). At the time of diagnosis, individuals are likely to experience distress, anxiety, and frustration (Harrison et al., 2009; Holland & Alici, 2010), with informational needs among the most frequently left unmet (Harrison et al., 2009; Swash, Hulbert-Williams, & Bramwell, 2014). Furthermore, in a recent systematic review of over 770 patient-centered interventions, Coulter and Ellins found that access to high-quality information increased patients' acceptance, knowledge, and ability to cope with illness (Coulter, 2014; Coulter & Ellins, 2006, 2007). Furthermore, information needs are of particular interest as previous studies suggest that limited access to timely information can be distressing and lead to increased use, misuse, and avoidable reliance on health services (Dubois & Loiselle, 2009; Harrison et al., 2011). In turn, it has been suggested that attending to psychosocial and informational needs early (e.g., at the

time of diagnosis) may reduce health service use (HSU) throughout the trajectory of care, ultimately reducing health-care costs (Carlson & Bultz, 2004; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001).

Moreover, the context of the Canadian health-care system includes ongoing budgetary restriction, where HCPs are challenged to provide care that is patient centered and accessible (Milne, Sheeran, Holmes, Tidhar, & Aranda, 2012). This often leaves individuals to fill the gaps in supportive treatment and care (Sutcliffe, 2011). In this milieu, ICIRs are very promising, particularly with the growing ubiquity of Internet use (IWS, 2014; Murray, Burns, SeeTai, Lai, & Nazareth, 2005). Although there is growing interest in the multifaceted impact of ICIRs, to date, there has been little exploration of patients' perspectives about the ways in which ICIR informs their interaction with the health-care system.

E-health and ICIRs in Cancer Care

E-health is a term widely used to describe the use of technology in health care and can include the use of any interactive technology, from telephones to computers, in any aspect of health care intended to improve patient care (Cote, 2007; Oh, Rizo, Enkin, & Jadad, 2005). The Internet, as one modality of e-health that is particularly consumer focused, is now in the homes of 80% of Canadians (StatsCan, 2009). The open Internet differs from other types of tailored web-based interventions, which are designed to be structured, self-guided, or human-supported websites with the intention of supporting decision-making, symptom management, behavior change, or some other aspect of health or mental health (Barak, Klein, & Proudfoot, 2009). Alternatively, the open Internet provides information and support of the patients choosing, at their own pace and on their own terms.

Similar to the general population, the use of ICIRs by individuals with cancer is also growing. The popularity of Internet use by those with cancer is supported by numerous surveys, for example, a recent American survey found 63% ($n = 500$) used the Internet to search for health information (Castleton et al., 2011). In the Canadian context, a 2014 survey of 411 individuals attending a Canadian cancer clinic for posttreatment follow-up found that although their providers were the most trusted source of information, the Internet was the second most preferred source, with 80% reporting regular use (Shea-Budgell, Kostaras, Myhill, & Hagen, 2014).

Beyond unparalleled accessibility, there are numerous reports about what motivates patients to use ICIRs for health information. Some patients report turning to the Internet when their preferred source of information (their doctor or nurse) is unavailable (James et al., 2007), to prepare for/cross-check information from HCP consultations (Castleton et al., 2011; Haase, Strohschein, Lee, & Loiselle, in press; Loiselle et al., 2013), and to gain a sense of confidence around cancer information (Ziebland et al., 2004), whereas others report using the Internet when dissatisfied with HCP advice (Tustin, 2010). However, a great deal of information on the Internet is also

of questionable quality and relevance, which is a concern cited by HCP and patients (Deshpande & Jadad, 2009; Lam, Roter, & Cohen, 2013; Verma et al., 2006). Because of the ubiquitous dependence on the Internet, further study is required to explore patients' experiences using ICIRs and how it informs how they use health services (Eysenbach, 2003b; Leykin et al., 2011).

Although studies have sufficiently documented that ICIRs use is prolific among those with cancer, few studies go in-depth to illuminate the intricacies of ICIRs use from the perspective of the patient or its role in interactions with the health-care system. For example, in one eminent qualitative investigation into the role of Internet use by individuals with cancer, Ziebland and colleagues (2004) conducted a narrative analysis and interviewed 175 men and women aged 19 to 83. The authors found that participants used the Internet to become more competent and "make sense" about their disease. Participants described the rationale for Internet use as twofold, so they could display competence to their HCP and to validate the advice they were receiving from their HCP. A gender analysis of this study revealed that men were more fixated on using ICIRs to learn more about physical ailments, and women more interested in emotional and social support (Seale, Ziebland, & Charteris-Black, 2006). Thusly, men's use of ICIRs tended to focus on informational sources, whereas women relied upon networking or social support sites, which has been documented elsewhere (Dickerson, Boehmke, Ogle, & Brown, 2006; Dickerson, Reinhart, Boehmke, & Akhu-Zaheya, 2011). The role of ICIRs in interactions with the health-care system or relationships between types of health-care services used resultant of ICIRs use was not explored.

Role of ICIRs in Interactions With the Health-Care System

The role of ICIRs in interactions with the health-care system is of interest due to patients' growing use of the Internet and how this might impact the quality and quantity of their HSU (Cline et al., 2007). Several reports indicate physicians are anxious about patients' use of the Internet, the impact on patient consultations, and the ability for patients to discern appropriate and reliable information (Ahluwalia, Murray, Stevenson, Kerr, & Burns, 2010; Newnham et al., 2005; Urowitz et al., 2012). In consideration of these misgivings, providers' responses to Internet information seeking have been categorized in three ways: (1) feeling threatened (health professional centered), (2) collaborating with the patient by obtaining and analyzing the information (patient-centered approach), and (3) guiding patients to reliable websites (prescribing information; McMullan, 2006).

In the context of cancer, the use of ICIRs is growing. People with cancer report using the Internet to help facilitate encounters with HCP (Dickerson et al., 2011) and to verify information (Bylund, Gueguen, D'Agostino, Imes, & Sonet, 2009; Loisel et al., 2013) but will only discuss this information if they perceive sufficient trust with their provider and ample

time (Kirschning & von Kardorff, 2008). However, patients do expect HCP to acknowledge their information and assist them in making sense of it (Bylund et al., 2009). Furthermore, one frequently documented impetus for ICIRs seeking is a lack of informational support from providers (Dolce, 2011). Whereas patients may feel comfortable with sharing information (Newnham et al., 2006), many reported sometimes or never sharing ICIRs with their oncologist, due to fear of judgment from their oncologist (Bylund et al., 2009; Imes, Bylund, Sabee, Routsong, & Sanford, 2008).

Oncology health professionals have also reported mixed reactions to ICIRs. A survey of oncologists ($n = 226$) found most were accepting of patients' use of the Internet, with 91% believing it could cause harm, but 56% generally supportive of information seekers (Newnham et al., 2005). Furthermore, an in-depth qualitative analysis with multidisciplinary oncology team members ($n = 16$) found that several providers had concerns about ICIRs demanding too much of their time in patient consultations (Haase & Loisel, 2012). In a qualitative secondary analysis of patient and provider insights of the same ICIRs, the main point of divergence was on the patients' view that ICIRs would enhance patient consultations and relieve time pressures, whereas providers felt it would be too time-consuming (Haase et al., in press). This final point indicates a need for the research proposed—to further clarify and understand the role of ICIRs in interactions with the health-care system, particularly around how the use of ICIR informs the use of health services.

Conceptual Framework

This study is framed by Andersen and Newman's (1973) behavioral model of health service utilization (BMHSU) and Carper's fundamental patterns of knowing (1978). According to Andersen and Newman, HSU is defined as the process of seeking and obtaining health-care services with the intention of maintaining or improving health (Andersen & Newman, 1973; Schepper, van Dongen, Dekker, Deertzen, & Dekker, 2006). The general assumption of the model is that HSU is a function of both individual and societal influences. The model has been used extensively since its inception, for example, in chronic disease research, acute care, and in the evaluation of Internet evaluations (Babitsch, Gohl, & von Lengerke, 2012; Chiu & Eysenbach, 2011; de Boer, Wijker, & de Haes, 1997; McCusker, Karp, Cardin, Durand, & Morin, 2003; Townsend, Gearing, & Polyanskaya, 2012). The most recent iteration of the model (Andersen, 1995) delineates four main areas shaping HSU: (1) the environment, (2) population characteristics, (3) health behavior, and (4) outcomes. The model will be used mainly as a means of explicating sensitizing concepts of interest that will inform in-depth exploration of HSU.

Carper's Fundamental Patterns of Knowing

This study will be oriented within a holistic nursing perspective guided by the patterns of knowing, first discussed by Barbara

Carper (1978). This framework is appropriate to guide the classification of numerous sources from which knowledge is derived in nursing practice (Holtzlander, 2008). Specifically, the review of websites will be guided by Carper's original ways of knowing. Carper's original work emerged from a qualitative analysis of the concepts, structure, form, and patterns of nursing knowledge (1978). She identified the four patterns as: (1) empirical or scientific, (2) aesthetic or the art of nursing, (3) personal, what is learned through practice, and (4) ethics the moral aspect of nursing; later additions include sociopolitical knowing (White, 1995) and unknowing (Munhall, 1993). Carper accurately depicts the epistemological diversity of nursing knowledge and provides a practical framework to approach the analysis of online cancer information. Acknowledging that human experience and knowledge is shaped by sociopolitical contexts in which they are created, the concept of sociopolitical knowing will be embraced from a holistic perspective across all ways of knowing (Kagan, Smith, Cowling, & Chinn, 2009).

Goals and Objectives

The overarching goal of this mixed methods study is to clarify the ways in which the context and use of ICIRs by individuals newly diagnosed with cancer informs their interactions with the health-care system.

Specific objectives are:

1. to identify the content of the most commonly used ICIR from a holistic nursing perspective compared to sites most frequently visited by participants,
2. to explore the prompts to use ICIR and how ICIR informs the ways in which patients utilize and interact with health services and providers, and
3. to document which ICIRs are accessed and the patterns of usage.

Design and Method

An embedded mixed methods design will address the complexity of the research objectives and generate a comprehensive understanding of the research problem using inductive and deductive methods (Cresswell & Plano Clark, 2011). An embedded design mixes different types of data at the design level, but one type of data is embedded within the methodological approach of the overarching data type. The overarching methodology is interpretive description (ID) and will guide the collection and analysis of *qualitative data* and address Objectives 1 and 2. The ID will be comprised of two data sources: (1) a review of websites and (2) interviews with 16 individuals newly diagnosed with cancer. The supplemental *quantitative component* relies upon surveys completed by the 16 participants and provides further description of the research problem, thereby addressing Objective 3. Finally, *integrating and triangulating the data from the qualitative and quantitative components* will clarify the role of ICIRs in interactions with the

health-care system by individuals newly diagnosed with cancer, thereby addressing the *overarching goal*.

The overall paradigmatic thrust of this study ascribes to a constructivist epistemology (Guba & Lincoln, 1994), as such, the main methodological approach is ID (Thorne, 2008). Thorne describes ID as an appropriate method to generate a better understanding of complex questions that arise from practice-based disciplines, such as nursing, without sacrificing rigor or taking on overwhelmingly large studies with the risk of losing a practice focus. The goal of ID is to go beyond qualitative description in providing a detailed account of a phenomena of interest, to interpret the meaning and understand the relationships and patterns of said phenomena. Thorne encourages researchers to look below the surface of clinical issues via systematic exploration and thorough analysis of these issues particularly through the use of clinical knowledge and multiple data sources, which will generate new knowledge and understanding of the research problem under study.

Setting

Patients will be recruited from an urban university-affiliated cancer treatment center in Saskatchewan. This cancer center provides cancer treatment to the local and Northern populations of the province.

Sample

Cancer websites. Initially, a purposeful sample of websites was deductively selected by searching cancer-related terms on three of the most popular search engines (Google, Yahoo, and Bing; Experian, 2014) and ranking the findings, a method that is increasingly accepted in the study of websites (Kaicker, Debono, Dang, Buckley, & Thabane, 2010). Heretofore, the sample of representative general and cancer-specific websites included for analysis is: Canadian Cancer Society (general, colorectal, and lung), Breast Cancer.org, and Prostate Cancer.ca. Based on feasibility balanced with the need for depth, a sample of approximately 10 pages will be analyzed on each website. Websites mentioned during interviews will be added to the sample.

Participant sample. A purposeful theoretical sample of individuals newly diagnosed with cancer will be approached to take part in this study. A sample of maximum variation will be sought based on emerging variation in participants as well as equal gender representation.

Participants recruited must meet the following inclusion criteria: (1) a histologically confirmed, first diagnosis of cancer (all stages), (2) diagnosis within the last 20 weeks, (3) at least 18 years old, (4) fluent in English, (5) able and willing to take part in interviews and complete questionnaires, (5) have unrestricted access to the Internet, and (6) affirm the use of the Internet for health information. Participants will be excluded if they have been previously diagnosed with cancer.

Although the notion of data saturation is commonly relied upon in qualitative work (Caelli, Ray, & Mill, 2003), Thorne argues it is inappropriate as one cannot know whether new information will arise in subsequent interviews, especially within the context of nonrandom sampling strategies (2008). Instead, she urges researchers to expect a sample size based upon the anticipated number of unique patient profiles or cases, and what is feasible within the constraints of the study. Based on the desired profiles, a sample of at least 16 individuals will be sought, depending on the themes emerging in the concurrent analysis. If there are divergent findings that emerge around specific profiles, additional participants will be sought to explore these themes, should it be feasible and pertinent to the study objectives.

Participant Recruitment Procedures

Recruitment will be completed through three avenues: (1) physician and nurse referral, (2) the new patient intake coordinator, and (3) patient orientation sessions. First, medical oncologists and nurses will be asked to refer newly diagnosed patients fitting the study criteria. Second, all new patients at the cancer center are contacted by the new patient navigator and invited to attend a monthly orientation session. The study will be mentioned to patients during their new patient phone call, and, if interested, their information will be flagged and reported to the research assistant. Information about the study will also be provided at the monthly new patient orientation presentation. Interested participants will be asked to speak with a study representative after the presentation and be provided with further information.

Data Sources

This study has three data sources: (1) cancer websites, (2) qualitative interviews, and (3) quantitative surveys. The data sources and survey tools are described below.

Cancer Websites

Analysis of website data will address Objective 1 to identify the content of the most commonly used ICIRs from a holistic nursing perspective compared to sites most frequently visited by participants. Although a number of tools have been developed to determine quality, accuracy, and readability of websites and focus on rating or ranking quality (Kaicker et al., 2010), the goal of this analysis is to determine the informational context of ICIRs, from a holistic nursing perspective. Criteria from DISCERN (Charnock, 1998; DISCERN project, 2014), a tool designed to help patients and professionals assess the quality of health information online, will be used as a sensitizing framework, but the value proposition of the website data analysis intends to go beyond quantitative metrics. DISCERN presents a framework guided by three main questions: (1) Is the website reliable? (2) What is the quality of information on

treatment choices? (3) What is the overall rating or impression of this publication?

Qualitative Interviews

In-depth interviews will be a key source of patient-derived data. The initial interview guide (Appendix A) will address Objective 2 to explore the prompts to use ICIR and how ICIR informs the ways in which patients utilize and interact with health services and providers. The interviews will be semistructured, around a list of trigger questions, to facilitate exploration and description of the areas described above (Thorne et al., 2005). The trigger questions are informed by concepts from the BMHSU and the literature (Andersen, 1995). Examples of questions are tell me about the role of the Internet in your life since you've been diagnosed with cancer? What role has the Internet played in your use of health services? Due to the emerging nature of qualitative research, the trigger questions may be modified as interviews evolve, based on issues arising that beg further exploration (Thorne, 2008). All interviews will be digitally audio recorded with participant consent.

Surveys

Surveys with each participant will address Objective 3 to document the ICIR accessed and the patterns and frequency of use. Data on participants' age, gender, income, education, diagnosis, treatment, and existing medical conditions will be collected through a self-report questionnaire designed for the purpose of this study. Data on specific types of ICIRs used will be collected through a self-report questionnaire that draws on prior surveys of Internet use of by individuals with cancer (Eysenbach, 2003a; Kelly, Jenkinson, & Ziebland, 2013; van de Poll-Franse & van Eenbergen, 2008), for example, where is the Internet used, is the information discussed with HCPs, and what types of information are used. This survey information adds to the overall understanding of Internet use and creates a more robust picture of the research problem (see Appendix B for full survey).

Data Collection Procedures

Websites. Collection of the initial sample of website data will be completed prior to participant interviews, using a deductive approach. As participants are recruited to the study and discuss additional websites during their interviews, these sites will be added to the review.

Interviews. Participants meeting the eligibility criteria will be asked to identify a convenient time for the interview. Interviews will take place at a mutually agreeable and suitably private location, such as a clinic room at the cancer center or the participant's home. At the beginning of each interview, participants will be asked to read and sign a consent form to take part in the interview, be reminded that interviews are being audio recorded and that their participation is voluntary. Interviews are expected to last approximately 45 to 60 min.

Following completion of the first interview, the second interview will be arranged. Participants will receive a phone call 2 days before the second interview to confirm a suitable time and place.

Surveys. Before the interview is completed, participants will be asked to complete a questionnaire on their background and medical information and utilization of ICIRs.

Data Analysis

All qualitative data analysis will be conducted using Atlas.ti qualitative software, version 7, and will be concurrent with data collection. Thorne recommends that interpretive descriptive data analysis commence with immersion in the data, reading and rereading the data, and then attempting to gain an overall impression of the data by asking “what is happening here?” Subsequently, “synthesizing, theorizing, and recontextualizing” (Thorne, 1997, p. 175) of the data will commence via a step-by-step analytic strategy described below.

Websites. Website pages of interest will be screen capped and saved in Atlas.ti. Initially, these pages will be read with the guiding questions described above. Next, website data will be reviewed for examples of exemplary information tied to the DISCERN criteria and the patterns of knowing, which will be highlighted, documented, and preliminarily coded. Memos will be kept regarding researcher interpretations about codes. Codes will subsequently be grouped according to emerging themes. Themes will then be compared across websites and between the initial sample of website and those reported by participants. These themes will be assessed for their fit within each of the types of knowledge described by the conceptual framework. The goal of the analysis is to understand the content of the most commonly used ICIRs from a holistic nursing perspective; this goal will be revisited throughout the analysis.

Interviews. Interview recordings will be transcribed verbatim and analyzed according to the method of thematic content analysis described by Thorne (1997) and Thorne, Reimer Kirkham, and O’Flynn-Magee (2004). Following the initial reading described above, transcripts will be read with the goal of inductively deriving conceptual themes, first within and subsequently across transcripts. Detailed notes and emerging codes will be kept in Atlas.ti, and emerging codes and notes will be analyzed and grouped according to emerging themes. Next, conceptual themes will be organized into an analytic structure to guide exploration within and between individual cases. Once the analytic structure has been refined through the process of ongoing analysis and comparison, a circling back to the initial questions of “what is happening here?” and “what is the relationship between ICIR use and interaction with the health-care system?” will occur. Using a team approach, the authors will aim to abstract and interpret the meaning of the overall findings in relation to the research objectives through critique, dialogue, and refinement.

All quantitative data analysis will be carried out using Microsoft Excel. Data will be checked for accuracy and completeness to ensure the data attributed to each variable are valid and accurate (Clarke & Cossette, 2000). Descriptive statistics (means, medians, and frequencies) will be used to depict sample characteristics. Patterns of ICIR use will be documented by calculating summary scores of total ICIRs by type and frequency of use.

Integration of Qualitative and Quantitative Data

Integration of the quantitative and qualitative data will occur at two points: (1) Results from the quantitative analysis will be used to interpret participants ICIR use in greater depth and (2) data from interviews, website, and surveys will be triangulated to construct a robust and rich understanding of how ICIR informs service use. Interpretation of quantitative results will not take place in isolation, due to the limited sample size, but will provide essential data about the types and amounts of ICIR participants used (Morse, 2003). Together, these data provide a holistic picture of ICIR use and health-care system interactions.

Evaluation of Rigor

To ensure methodological rigor, Thorne urges researchers to reflect upon principles of epistemological integrity, credibility, analytic logic, and interpretive authority (2008). Principles of epistemological integrity have been respected by using an overarching inductive approach that relies upon responsive and reflexive methods. Representative credibility will be achieved by using multiple data sources and triangulating these sources to account for multiple angles of the research problem. Eschewing the concept of saturation aligns with a constructivist approach, as this acknowledges the impossibility of knowing all there is to know on a possible subject, through the attempts of one study, at one place in time. Analytic logic will be explicated throughout the research process by the use of memos and an audit trail of key decisions, so the research process can be independently evaluated. Interpretive authority aims to establish that the researchers’ interpretations are trustworthy and will be achieved by grounding the findings in the data and the use of supporting exemplary quotes.

Ethical Considerations

Conditional approval was received from the University of Ottawa and University of Saskatchewan Research Ethics Boards. All participants will be asked to read and sign a consent form explaining the study. Participants’ privacy will be preserved by coding their identity on all information collected and storing the data in password-protected electronic files on a password-protected computer, with restricted access to the participant coding key. Use of the interview data in publications will not be specific enough to permit the identification of individual participants (e.g., individual participants will not be identified by age, diagnosis, and treating center). All data

(electronic and paper) will be stored for a maximum of 10 years after which time it will be destroyed.

Limitations

The sample for this study is relatively small, is purposefully and theoretically derived, and may therefore be biased. Due to the small sample size and potential bias, the results of the quantitative analysis will be interpreted with particular caution. As well, providers are not included in this study and would provide a more comprehensive picture of how participants use ICIR, but it is not feasible to include them in the present study.

Significance and Implications

This study is important and novel because it seeks to address issues central to understanding how ICIR use informs patients' interactions with the health-care system—an area where there are significant gaps in understanding. Methodologically, situating the study within a qualitative review of websites presents a novel approach that is timely, given patients' increasing reliance on the Internet for health information. Moreover, understanding how patients' use ICIRs will provide insight into the type of information discussed in patient consultations and generate new knowledge about the role ICIR plays in patients' use of health-care services. Finally, and perhaps most importantly, these findings will provide oncology nurses and interdisciplinary team members with insight into how patients use ICIR to inform their use of health services, which is vital to the planning, tailoring, and delivery of patient-centered care.

Appendix A

Interview Guide

1. Can you tell me about the information that was important to you after you were diagnosed with cancer?
 - Probes
 - Where did you look for information?
 - Who did you talk to?
 - Can you describe any particular sources of information you found more or less useful?
 - Tell me about these
2. Can you tell me about the role of the Internet in your life since you've been diagnosed with cancer?
 - Probes:
 - When did you first use the Internet to look for health information?
 - What's the main purpose of your Internet use, with regard to cancer? (i.e., communication, information, social networking, etc.)
 - How would you describe the quality of the information about cancer?
3. What prompted you to go to the Internet?
 - Probes
 - a. Did something specific prompt this?
 - b. What kinds of things were you looking for? Did you find them?
4. Did you discuss Internet information with your doctor or nurse?
 - a. Can you explain a time when you shared information you found on the Internet with your provider
 - i. What was their response?
5. Tell me about a time when a concern arose related to your cancer and you weren't sure what to do.
 - Probes:
 - Where did you turn to find information about what to do?
 - How was the situation resolved?
 - Did you use the Internet, if yes, what role did it play?
 - How was the situation resolved?
6. Did you ever use the Internet to help you find a health service or to decide what kind of services you might need?
 - If yes, please describe the situation.
 - Did the Internet give you accurate information?
 - How did it influence your decision to use other health services?
 - How did you feel, or what was your reaction to this situation?
 - Does where you live (neighbourhood, town, part of the city, and proximity to hospital) play a role in how you used the Internet?
7. Can you tell me about a time when the Internet made you seek out specific care or services?
 - If yes, please describe the situation.
 - Did the Internet give you accurate information?
 - Did you tell your provider why you decided to seek care?
 - If yes, what was their response?
8. Was there ever a time where you wanted to speak to health-care professional but weren't able to?
 - What did you do?
 - Did you use the Internet instead? If yes, tell me about this.
9. Can you tell me about a time when you discussed the information from the Internet with your doctor, nurse, or social worker?
 - What about family members or friends?
 - If yes, what was their response?
 - If no, why not?

Appendix B

Survey Internet Use

1. To access the Internet, do you use (circle most appropriate):

Computer	Mobile device (phone or tablet)	Both
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2. If you use a computer to access the Internet, where do you *most frequently* use the Internet?

At home
At a friend or family member's house
At school
At work
Library, café, or other public space

3. How often do you access the Internet?

Once a month or less
Once a week
Several times a week
Every day
Several times a day

4. How many hours a week do you spend on the Internet?

Number of hours

5. Do you discuss cancer information from the Internet with your care provider?

No
Yes

6. Did you use the Internet to learn about your cancer:

Check all that apply

Before you met with your oncologist for the first time (prediagnosis)
Right after your diagnosis
During treatment
After treatment

7. Which of the following applies to your Internet use (related to cancer)?

Check all that apply.

Communication (e-mailing care providers or support people)
Community (support groups)
Content/information (learning about cancer, treatments, symptoms, etc.)
Commerce (buy things you need related to cancer diagnosis, medication, supportive devices, etc.)

8. Which types of information did you search for:

Check all that apply.

Type of cancer
Treatment
Treatment side effects
Fatigue
Fertility
Sexuality
Treatment guidelines
Trials
Research
Alternative medicine
Your hospital/cancer center
Your oncologist
Cancer support groups
Patient activities in your area
Financial support/information
End of life
Cancer genetics

Other

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APPENDIX B

RECRUITMENT DOCUMENTS

Internet cancer information use by individuals newly diagnosed with cancer: A mixed methods study of interactions with the health care system

WHAT?

My name is Kristen Haase, I am a registered nurse studying towards a PhD in nursing at the University of Ottawa. I am conducting my data collection at the Saskatoon Cancer Centre.

The purpose of this study is to explore how individuals newly diagnosed with cancer use the internet to help find and use healthcare services. Hopefully, this study will contribute to a better understanding of how patients use the internet to find care and its role in their use of health services. I'm hoping you will help with recruitment by referring eligible patients to me.

WHO?

I am looking for patients who fit the following criteria:

- First diagnosis of CRC, lung, prostate or breast cancer (all stages),
- Diagnosed within the last 20 weeks
- At least 18 years old
- Fluent in English,
- Willing to complete questionnaires and take part in interviews
- Use the internet for health information

CONTACT ME

You can refer patients to this study by contacting me via:
SMS text or phone:

Email:

Thank you for your assistance!

Kristen Haase, RN PhD(c)
University of Ottawa,
School of Nursing

Study Description and Eligibility Screening Script

Hello, my name is Kristen Haase and I am a doctoral candidate at the University of Ottawa. I am speaking to you today because your healthcare provider has determined that you are eligible to participate in the study I am doing.

Would you like to hear about this study?

If No:

Thanks for your time. I will give you a brochure and if you decide later that you are interested, you can contact me.

If Yes:

- The purpose of the study is to explore how you use the internet to help you find and use healthcare services. It is hoped that this study will contribute to a better understanding of what kind of information the internet is providing and how you use it to find care.
- Your participation will consist of filling out a questionnaire and taking part in two interviews, lasting about 60 minutes. The interviews will be audio-recorded. The questionnaire will take about 15 minutes to complete. The interview will be scheduled at a time that works well for you, in a convenient location.
- Your participation is voluntary, and you can answer only those questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research team.

Do you have any questions?

If participant does not agree:

Thanks for your time. I will give you a brochure and if you decide later that you are interested, you can contact me.

If participant agrees:

Screen for eligibility.

You must fit all of the following criteria:

- Confirmed first diagnosis of Colorectal, lung, prostate or breast cancer
- Have been diagnosed within the last 20 weeks
- Be at least 18 years old
- Be fluent in English,
- Able and willing to complete the questionnaires and take part in interviews
- Use the internet for health information.

You are invited to participate in a study about your use of healthcare services and the internet during your cancer diagnosis. This study is being completed as part of my PhD in nursing from the University of Ottawa, and is supervised by Dr.'s Roanne Thomas and Wendy Gifford of the University of Ottawa.



CONTACT INFORMATION

For more information about this study, please call or email me!

Kristen Haase, RN PhD candidate
School of Nursing
University of Ottawa

Study Supervisors
Roanne Thomas, PhD
Professor
School of Rehabilitation Science
University of Ottawa

Wendy Gifford, RN PhD
Assistant Professor
School of Nursing
University of Ottawa



Internet cancer
information and
interactions with
the health care
system

Your involvement in this study will help us better understand the needs of those with cancer.

What is this study about?

The purpose of the study is to explore how you use the internet to help you find and use healthcare services. Hopefully, this study will contribute to a better understanding of the kind of information the internet is providing, and how you use it to find care.



You can be involved in this study if you:

- Have a confirmed first diagnosis of colorectal, lung, prostate or breast cancer
- Have been diagnosed within the last 20 weeks
- Are at least 18 years old
- Are fluent in English
- Are able and willing to complete the questionnaires and take part in interviews
- Use the internet for health information

What is required?

Your participation will consist of filling out a questionnaire and taking part in two audio-recorded interviews, lasting approximately 60 minutes each. The questionnaire will take approximately 15 minutes to complete. The interview will be scheduled at a time that works well for you, in a convenient location

Are there risks or benefits?

This study poses no known risks to you. You may find that participating in this study helps you with the emotional aspects of your cancer experience. If you choose to participate, you have the right to withdraw at any time. If you have a strong emotional responses to participation in the study, I will provide you with the contact information for appropriate services.

Hello, my name is Kristen Haase. I am a doctoral candidate at the University of Ottawa, and a Registered Nurse (RN) working at the University of Saskatchewan, College of Nursing. I am emailing you today because I'm conducting a study with individuals newly diagnosed with cancer to explore how they use the internet to help find and use healthcare services.

I would like to conduct focus groups and interviews with healthcare professionals at the cancer agency to explore **their opinions** and perspective about patient use of the internet.

Your participation will consist of taking part in a focus group or interview, lasting about 60 minutes.

Your participation is voluntary, and you can answer only those questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research team.

If you're interested in taking part in this study, please email me or reply to this email.

Thank you in advance for your consideration,

Kristen Haase, RN, BN, MA PhD(c)
Doctoral Candidate
School of Nursing
University of Ottawa

APPENDIX C

DATA COLLECTION TOOLS

Background Information

1. Today's date:

(day) (month) (year)

2. Please indicate your gender: _____

3. Please enter the first three digits of your postal code:

--	--	--

4. What is your age? _____

5. What is your marital status?

Single (never legally married)
Married / common law (two people living together but not married to each other)
Separated / divorced
Widowed

6. Which of the following describes your usual work status?

Full time in the paid work force (30 hours or more per week)
Part time in the paid work force (less than 30 hours per week)
Self employed
Unemployed
Disability / Sick leave
Homemaker
Retired
Other (write in):

7. How many children do you have? (please circle)

0 1 2 3 4 5 6 7 8 9 10

8. How many dependent children or children under the age of 18 do you have living with you? (please circle)

0 1 2 3 4 5 6 7 8 9 10

9. What is the highest level of education you have completed? (please check one only)

Elementary school
High school
Technical or vocational school or pre-university degree
University (undergraduate: bachelor)
University (graduate: masters, doctorate, or post-doctorate)

10. What was your total family income from all sources before taxes last year?

Less than \$20,000	\$60,000 - \$79,999
\$20,000 - \$39,999	\$80,000 or more
\$40,000 - \$59,999	Don't know / Refuse to answer

1. What was your diagnosis:

--

2. When were you diagnosed?

Day	Month	Year
-----	-------	------

3. Do you know the stage of your cancer?

No					
Yes. If Yes, please circle the stage in the next box:	0	I	II	III	IV

4. What types of treatments did you receive or are still receiving now for your cancer?

Surgery
Radiotherapy
Chemotherapy (taken by mouth or injected using a syringe)

5. What additional services have you used or are still using in relation to your cancer? (check all that apply)

Acupuncture	Nutrition (e.g. special diets)
Art therapy	Relaxation
Cancer treatments or medicines from other countries	Visualization
Exercise	Vitamins
Homeopathic remedies	Yoga
Hypnosis	Other (please describe below):

Internet use

Internet Use

1. To access the internet, do you use: (circle most appropriate)

Computer	Mobile Device (phone or tablet)	Both
----------	------------------------------------	------

2. If you use a computer to access the internet, where do you most frequently use the internet?

	At home
	At a friend or family member's house
	At school
	At work
	Library, café or other public space

3. How often do you access the internet?

	Once a month or less
	Once a week
	Several times a week
	Every day
	Several times a day

4. How many hours a week do you spend on the internet?

	Number of hours
--	-----------------

5. Do you discuss cancer information from the internet with your care provider?

	No
	Yes.

6. Did you use the internet to learn about your cancer:
Check all that apply

☐	Before you met with your oncologist for the first time (pre-diagnosis)
☐	Right after your diagnosis
☐	During treatment
☐	After treatment

7. Which of the following applies to your internet use (related to cancer)?
Check all that apply.

☐	Communication (emailing care providers, or support people)
☐	Community (support groups)
☐	Content/information (learning about cancer, treatments, symptoms, etc)
☐	Commerce (buy things you need related to cancer diagnosis, medication, supportive devices, etc)

8. Which types of information did you search for:
Check all that apply.

☐	Type of cancer
☐	Treatment
☐	Treatment side effects
☐	Fatigue
☐	Fertility
☐	Sexuality
☐	Treatment guidelines
☐	Trials
☐	Research
☐	Alternative medicine
☐	Your Hospital /Cancer centre
☐	Your Oncologist
☐	Cancer support groups
☐	Patient activities in your area
☐	Financial support/information
☐	End of life
☐	Cancer genetics
☐	Other

Interview Guide

Thank you for taking the time to participate in this interview. The purpose of this interview is to talk to you about your experience using the internet and about the health services you have used since your diagnosis with cancer. The interview will take approximately 1 hour.

I want to remind you again that this interview will be audiotaped, and everything you say here will be confidential. If at any time you are uncomfortable or want to stop the interview, please let me know and I will turn off the recorder.

Do you consent to being recorded and participating in this interview?

(Proceed when participant responds)

We will start with some general questions about information you received when first diagnosed with cancer, and move on to some specific examples. Feel free to ask questions of me as we go along.

1. Can you tell me about the information that was important to you after you were diagnosed with cancer?
Probes
 - Where did you look for information?
 - Who did you talk to?
 - Can you describe any particular sources of information you found more or less useful?
 - Tell me about these
2. Can you tell me about the role of the Internet in your life since you've been diagnosed with cancer?
Probes:
 - When did you first use the Internet to look for health information?
 - What's the main purpose of your internet use, with regards to cancer? (i.e. communication, information, social networking etc)
 - How would you describe the quality of the information about cancer?
3. What prompted you to go to the internet?
Probes
 - a. Did something specific prompt this?
 - b. What kinds of things were you looking for? Did you find them?
4. Did you discuss internet information with your doctor or nurse?
 - a. Can you explain a time when you shared information you found on the

internet with your provider

i. What was their response?

5. Tell me about a time when a concern arose related to your cancer and you weren't sure what to do.

Probes:

- Where did you turn to find information about what to do?
 - How was the situation resolved?
- Did you use the internet, if yes, what role did it play?
 - How was the situation resolved?

6. Did you ever use the Internet to help you find a health service or to decide what kind of services you might need?

- If yes, please describe the situation
- Did the internet give you accurate information
- How did it influence your decision to use other health services?
- How did you feel, or what was your reaction to this situation?
- Does where you live (neighbourhood, town, part of the city, and proximity to hospital) play a role in how you used the internet?

7. Can you tell me about a time when the Internet made you seek out specific care or services?

- If yes, please describe the situation
- Did the internet give you accurate information
- Did you tell your provider why you decided to seek care?
 - If yes, what was their response?

8. Was there ever a time where you wanted to speak to health care professional but weren't able?

- What did you do?
- Did you use the internet instead? If yes, tell me about this.

9. Can you tell me about a time when you discussed the information from the Internet with your doctor, nurse or social worker?

What about family members or friends?

If yes, what was their response?

If no, why not?

That is the end of the interview questions.

Is there anything you would like to add, or questions you would like to ask?

Can we arrange a suitable time for a follow-up interview two weeks from now?

Healthcare Professional Interview Guide

Thank you for taking the time to participate in this interview. The purpose of this interview is to talk to you about your views on how your patients use the internet to find cancer information and their use of health services. The interview will take approximately 1 hour.

I want to remind you again that this interview will be audiotaped, and everything you say here will be confidential. If at any time you are uncomfortable or want to stop the interview, please let me know and I will turn off the recorder.

Do you consent to being recorded and participating in this interview?

(Proceed when participant responds)

We will start with some general questions about information you give patients when first diagnosed with cancer, and move on to some specific examples. Feel free to ask questions of me as we go along.

1. Can you tell me about what type of information your patients want when they're first diagnosed, or on their first visit?
 - Can you describe any particular sources of information you suggest?
 - Tell me about these
2. Can you tell me your thoughts on patients using the internet to find cancer information?
 - For what purpose do you think the internet is most useful for individuals with cancer? (i.e. communication, information, social networking etc)
3. How would you describe the quality of the information about cancer on the internet, generally?
4. Do your patients discuss cancer information from the internet with you?
 - Can you explain a time, good or bad, when a patient shared information found on the internet with you?
 - i. What was your response?
5. What if any connection exists between patients using the internet, and how they use health services?
6. Do you ever direct patients to particular websites?

If yes, which ones and why?

If no, why not, can you explain this approach?

That is the end of the interview questions.

Is there anything you would like to add, or questions you would like to ask?

Focus Group Guide

Thank you for taking the time to participate in this focus group. The purpose of this focus group is to talk to you about your views on how your patients use the internet to find cancer information and their use of health services. The focus group will take approximately 1 hour.

I want to remind you again that this focus group will be audiotaped, and everything you say here will be confidential by the research team. If at any time you are uncomfortable or want to stop the focus group, please let me know and I will address your concern as best I can.

Do you consent to being recorded and participating in this focus group?

(Proceed if there is agreement amongst all participants)

We will start with some general questions about information you give patients when first diagnosed with cancer, and move on to some specific examples. Feel free to ask questions of me as we go along.

1. Can you tell me about what type of information your patients want when they're first diagnosed, or on their first visit?
 - Can you describe any particular sources of information you suggest?
 - Tell me about these
2. Can you tell me your thoughts on patients using the internet to find cancer information?
 - For what purpose do you think the internet is most useful for individuals with cancer? (i.e. communication, information, social networking etc)
3. How would you describe the quality of the information about cancer on the internet, generally?
4. Do your patients discuss cancer information from the internet with you?
 - Can you explain a time, good or bad, when a patient shared information found on the internet with you?
 - i. What was your response?
5. What if any connection exists between patients using the internet, and how they use health services?
6. Do you ever direct patients to particular websites?

If yes, which ones and why?

If no, why not, can you explain this approach?

That is the end of the focus group questions.

Is there anything you would like to add, or questions you would like to ask?

APPENDIX D
ETHICAL APPROVALS AND CONSENT FORMS



Université d'Ottawa University of Ottawa

Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Monday, May 11th, 2015

Roanne Thomas

School of Rehabilitation Sciences
University of Ottawa

Kristen Haase

School of Nursing
University of Ottawa

Wendy Gifford

School of Nursing
University of Ottawa

Dear Professors Thomas and Gifford and Ms. Haase,

Thank you for submitting an application for ethics approval for your research project entitled: **"Internet cancer information use by individuals newly diagnosed with cancer: A mixed methods study of interactions with the health care system"** (Ethics file #H03-15-01).

The University of Ottawa Health Sciences and Sciences Research Ethics Board (REB), which operates in accordance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2nd edition)* and other applicable laws and regulations in Ontario, has examined your application and has granted a conditional approval for the above named research project. Full approval is conditional upon the submission of the ethics approval from the University of Saskatchewan REB.

Please note:

- i) This letter does not constitute full ethics approval of the project. Full approval can only be granted by the University of Ottawa REB.
- ii) Full ethics approval will be granted by the University of Ottawa REB upon receipt of the ethics approval from the University of Saskatchewan REB.
- iii) Consequently, recruitment and data collection should not begin until the University of Ottawa REB has granted full approval and issued the ethics certificate.

We also take this opportunity to remind you that any change to the protocol and/or other documents must be reviewed by the REB.

If you have any questions, please do not hesitate to contact the Ethics Office at 613-562-5387 or by e-mail at: ethics@uOttawa.ca.

Sincerely,

Riana Marcotte
Protocol Officer for Ethics in Research
For Barbara Graves, Chair of Social Sciences and Humanities REB



**UNIVERSITY OF
SASKATCHEWAN**

Behavioural Research Ethics

Certificate of Approval

PRINCIPAL INVESTIGATOR

Roanne Thomas-MacLean

DEPARTMENT

Health Sciences Operations
University of Ottawa

BEH#

15-144

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED

Saskatoon Cancer Centre
20 Campus Drive
S7N 4H4

SUB-INVESTIGATOR(S)

Wendy Gifford

STUDENT RESEARCHER(S)

Kristen Haase

FUNDER(S)

UNFUNDED

TITLE

Internet Cancer Information Use by Individuals Newly Diagnosed with Cancer: A Mixed Methods Study of Interactions with the Health Care System

ORIGINAL REVIEW DATE
04-Jun-2015

APPROVAL ON
30-Jun-2015

APPROVAL OF:
Application for Ethics Approval -
University of Ottawa
Recruitment Poster/Brochure
Study Description and Eligibility Screening
Script
Consent Form
Interview Guide
Background and Medical Information
Internet use Survey
Script for Professionals Referring Patients
to the Study
Supportive Contact Information

EXPIRY DATE
29-Jun-2016

Full Board Meeting ☐

Delegated Review ☒

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

Please send all correspondence to:

Research Ethics Office
University of Saskatchewan
Box 5000 RPO University, 1602-110 Gymnasium Place
Saskatoon SK S7N 4J8
Telephone: (306) 966-2975 Fax: (306) 966-2069

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month prior to the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: <http://research.usask.ca/for->

2

~~Scott~~ Tunison, Vice-Chair
University of Saskatchewan
Behavioural Research Ethics Board

Please send all correspondence to

Ethics Office
University of Saskatchewan
Room 306 Kirk Hall, 117 Science Place
Saskatoon SK S7N 5C8
Telephone (306) 966-2084 Fax (306) 966-2069



Consent Form

Université d'Ottawa

Faculté des sciences
de la santé

École des sciences de la
réadaptation

University of Ottawa

Faculty of Health
Sciences

School of Rehabilitation
Sciences

Title of the study: Internet cancer information use by individuals newly diagnosed with cancer: A mixed methods study of interactions with the health care system

Kristen Haase, RN BN MA PhD candidate
School of Nursing, University of Ottawa

Supervisors:

Roanne Thomas, Ph.D
Full Professor, School of Rehabilitation Sciences,
University of Ottawa

Wendy Gifford, Ph.D
Assistant Professor, School of Nursing, University of Ottawa

You are invited to participate in a study to document how you use the Internet for health information during your diagnosis and treatment for cancer. This study is being completed as part of my PhD in nursing from the University of Ottawa and is supervised by Dr.'s Roanne Thomas and Wendy Gifford at the University of Ottawa.

Purpose: The purpose of the study is to explore how you use the Internet to learn about your diagnosis of cancer, to help you find and use healthcare services and in your relationships with health care providers. It is hoped that this study will contribute to a better understanding of what kinds of information the Internet is providing and how you use it to find care.

Participation: Your participation will consist of filling out a questionnaire and taking part in two interviews, lasting approximately 60 minutes each. The questionnaire will take approximately 15 minutes to complete. The interviews will be scheduled at a time that works well for you, in a convenient and suitably private location, either at the cancer clinic or at your home. If the interview takes place at the cancer clinic, the clinic staff may know you are participating in the study, but anything you

☎ 613-562-5436
☎ 613-562-5428

451 Smyth
Ottawa ON K1H 8M5 Canada

www.uOttawa.ca

say will be kept confidential and your participation will not affect your care. The interviews will be recorded using a digital recording device.

Potential Risks and Benefits: You may experience emotional discomfort as a result of your participation in this study as you may be discussing frustrations around the type and amount of cancer information you have received. However, you have the right to refuse to answer any questions you do not wish to answer and can request that the recording device be turned off at any time. At the end of the interview, I will provide you with a list of support resources.

You may find that participating in this study helps you with the emotional aspects of your cancer as you will have the opportunity, during the interview, to speak about any challenges or frustrations with cancer information you have experienced since your diagnosis of cancer.

Right to Withdraw: Your participation is voluntary, and you can answer only those questions that you are comfortable with. There is no guarantee that you will personally benefit from your involvement. The information that is shared will be held in strict confidence and discussed only with the research team. You may withdraw from the research project for any reason, at any time, without penalty of any sort. Withdrawal will not affect your medical care or access to health services. If you choose to withdraw from the study, any data you have contributed will be destroyed beyond recovery at your request.

Confidentiality and anonymity: Any personal information you share for the purposes of this study will be kept strictly confidential. Personal information such as phone numbers, addresses and organizational affiliations will be kept confidential and any information that may identify third parties associated with participants will be deleted or altered (i.e. names of doctors, family members, etc.). Your identity will also be protected in future publications and presentations.

Storage of Data: All information collected for this study, including audio-recordings, transcripts of interviews and contact information, will only be available to the student and supervisors working on the study. The data will be stored in a locked filing cabinet and all records, including interview sound files, will be kept on password protected computers in a locked and secured area in my private office in the Health Sciences Building at the University of Saskatchewan, for a minimum of five years after the study is completed. After five years the data will be destroyed beyond recovery. All study documents and information will be scanned and saved on a password protected USB stick and stored in the locked private office of Dr. Roanne Thomas at the University of Ottawa five years.

Dissemination of findings: The findings of this research study will appear in reports to healthcare workers, in conference presentations and academic journal articles. If you have any questions concerning the study, please feel free to ask at any point; please do not hesitate to contact the researchers with any questions about the research or findings.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with the doctoral student, Kristen Haase or a Research Assistant. I have had my questions answered in language I understand. I understand the risks and benefits of the study. I believe that I have not been unduly influenced by any study team member to participate in the research study or by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be

given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time.

I understand that information regarding my identity will be kept confidential. I authorize the inspection of any of my records that relate to this study by the University of Ottawa Research Ethics Board, for quality assurance purposes. Ethical clearance for this study has been obtained from the University of Ottawa Research Ethics Board.

If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154,

Ottawa, ON K1N 6N5

Tel.: (613) 562-5387

Email: ethics@uottawa.ca

I, _____, agree to participate in the above described research study conducted by Kristen Haase, University of Ottawa, Supervised by Dr. Roanne Thomas and Dr. Wendy Gifford, University of Ottawa.

There are two copies of the consent form, one of which is mine to keep.

_____ (Participant's Name)

_____ (Date)

_____ (Signature of Participant)

_____ (Researcher's Name)

_____ (Date)

_____ (Signature of Researcher)



Université d'Ottawa

Faculté des sciences
de la santé

École des sciences de la
réadaptation

University of Ottawa

Faculty of Health
Sciences

School of Rehabilitation
Sciences

Provider Consent Form

Title of the study: Internet cancer information use by individuals newly diagnosed with cancer: A mixed methods study of interactions with the health care system

**Kristen Haase, RN BN MA PhD candidate
School of Nursing, University of Ottawa**

Supervisors:

**Roanne Thomas, Ph.D
Full Professor, School of Rehabilitation Sciences,
University of Ottawa**

**Wendy Gifford, Ph.D
Assistant Professor, School of Nursing, University of Ottawa**

You are invited to participate in a study to document how your patients use the Internet for health information during their diagnosis and treatment for cancer. This study is being completed as part of my PhD in nursing from the University of Ottawa and is supervised by Dr.'s Roanne Thomas and Wendy Gifford at the University of Ottawa.

Purpose: The purpose of the study is to explore how your patients use the Internet to learn about their diagnosis of cancer, to help find and use healthcare services and in their relationships with health care providers. It is hoped that this study will contribute to a better understanding of what kinds of information the Internet is providing and how patients use it to find care.

Participation: Your participation will consist of taking part in one interview, lasting approximately 60 minutes. The interview will be scheduled at a time that works well for you, in a convenient and suitably private location at the cancer clinic. All interviews will be recorded using a digital audio recorder.

☎ 613-562-5436
☎ 613-562-5428

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www.uOttawa.ca

Potential Risks and Benefits: You may experience emotional discomfort as a result of your participation in this study as you may be discussing frustrations around the type and amount of cancer information your patients receive. However, you have the right to refuse to answer any questions you do not wish to answer and can request that the recording device be turned off at any time.

Right to Withdraw: Your participation is voluntary, and you can answer only those questions that you are comfortable with. There is no guarantee that you will personally benefit from your involvement. The information that is shared will be held in strict confidence and discussed only with the research team. You may withdraw from the research project for any reason, at any time, without penalty of any sort. If you choose to withdraw from the study, any data you have contributed will be destroyed beyond recovery at your request.

Your right to withdraw data from the study will apply until the data has been combined. After this it is possible that some form of research sharing will have already occurred and it may not be possible to withdraw your data

Confidentiality and anonymity: Any personal information you share for the purposes of this study will be kept strictly confidential. Personal information such as phone numbers, addresses and organizational affiliations will be kept confidential and any information that may identify third parties associated with participants will be deleted or altered (i.e. names of doctors, family members, etc.). Your identity will also be protected in future publications and presentations.

Storage of Data: All information collected for this study, including audio-recordings, transcripts of interviews and contact information, will only be available to the student and supervisors working on the study. The data will be stored in a locked filing cabinet and all records, including interview sound files, will be kept on password protected computers in a locked and secured area in my private office in the Health Sciences Building at the University of Saskatchewan, for a minimum of five years after the study is completed. After five years the data will be destroyed beyond recovery. All study documents and information will be scanned and saved on a password protected USB stick and stored in my locked private office for a period of five years. All original documents will be couriered to Dr. Roanne Thomas at the University of Ottawa and stored in her locked private office for five years.

Dissemination of findings: The findings of this research study will appear in reports to healthcare workers, in conference presentations and academic journal articles. If you have any questions concerning the study, please feel free to ask at any point; please do not hesitate to contact the researchers with any questions about the research or findings.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with the doctoral candidate, Kristen Haase or a Research Assistant. I have had my questions answered in language I understand. I understand the risks and benefits of the study. I believe that I have not been unduly influenced by any study team member to participate in the research study or by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time.

I understand that information regarding my identity will be kept confidential. I authorize the inspection of any of my records that relate to this study by the University of Ottawa Research Ethics Board, for quality assurance purposes. Ethical clearance for this study has been obtained from the University of Ottawa Research Ethics Board.

If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154,
Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

This research project has also been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on (June 30th, 2015). Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office (966-306-2975). Out of town participants may call toll free (888-966-2975)

I, _____, agree to participate in the above described research study conducted by Kristen Haase, University of Ottawa, Supervised by Dr. Roanne Thomas and Dr. Wendy Gifford, University of Ottawa.

There are two copies of the consent form, one of which is mine to keep.

_____ (Participant's Name)

_____ (Date)

_____ (Signature of Participant)

_____ (Student Researcher's Name)

_____ (Date)

_____ (Signature of Student Researcher)