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The role of the internet in the cancer experience: Synthesizing patient and provider views to forge new directions for care

by Kristen R. Haase

ABSTRACT

The CANO/ACIO Clinical Lectureship highlights an innovative nursing intervention or nursing-led study that aims to improve the quality of life for individuals on the cancer journey. People with cancer have high information and supportive care needs, and despite the best efforts of cancer care clinicians, these needs are sometimes left unmet. The advent of the internet has allowed for the democratization of cancer knowledge and the development of online cancer resources, applications, and communities. To date, little research explores the role of cancer-related internet information (CRII) in the cancer experience, particularly the role it plays in the healthcare professional relationships and the selection and use of healthcare services. In this lectureship, I present key findings from a mixed methods study exploring how the use of CRII informs the patient experience, with an emphasis on how oncology nurses, as integral members of the cancer care team, can incorporate these findings into their practice.

INTRODUCTION

A diagnosis of cancer is a life-changing experience that half of all Canadians are expected to experience in their lifetime (Canadian Cancer Society, 2018). Cancer is a multifaceted experience that brings both physical and psychosocial stress (Bultz & Carlson, 2006). When diagnosed with cancer, patients enter a complicated healthcare system:

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treatment choices, multiple new healthcare providers, and managing symptoms take their toll. Many people also face functional challenges—such as finances—during a period of unemployment, coping with altered levels of physical ability, and frequent travel related to health appointments. The burden of a cancer diagnosis is distressing, and patients and their families manage much of this burden on their own (McCorkle et al., 2011).

The use of internet information and support, as well as mobile-health (mHealth) applications, has become a lifeline for many individuals with cancer (Nasi, Cucciniello, & Guerrazzi, 2015). Patients can access information and support at their own choosing and on their own schedule without the input or mediation of their cancer care team (Ziebland et al., 2004). There has been growing awareness of the role of cancer-related internet information (CRII) in the cancer patient experience (Leykin et al., 2012; Ventura, Öhlén, & Koinberg, 2013), but less attention has been paid

to how clinicians and patients interact when discussing CRII, and how nurses. in particular. can support patients' online information-seeking efforts.

The purpose of this paper is to synthesize results from a mixed methods study exploring how people diagnosed with cancer use CRII to manage their cancer experiences and their interactions with the healthcare system. I present a practical model for oncology nurses to engage patients about their internet use, generated from a synthesis of study findings.

METHODS

This study was guided by an interpretive descriptive mixed methods approach (Cresswell, 2014; Thorne, 2016). The main findings of this study have been published elsewhere (Haase, Thomas, Gifford, & Holtslander, 2018a, 2018b, 2018c). Thus, I will provide only a brief overview of methods with summaries provided within the adjacent table (Table 1) and integrated into the findings section.

Table 1: Data sources and methods	
Data source	**Methods**
Websites	• 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.
People diagnosed with cancer	• 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.
Healthcare professionals	• Twenty-one healthcare professionals engaged in interviews (n=4) and focus groups (n=3) guided by an interpretive descriptive approach. • Data were analyzed via thematic analysis.

We chose an embedded concurrent design, where the dominant qualitative research methodology was complemented by a supplementary quantitative approach (QUAL+quan) (Cresswell & Plano Clark, 2011). We used several data sources to ensure we addressed the research objectives robustly. These data sources included: (1) a sample of commonly-searched cancer websites (n=20); (2) people newly diagnosed with cancer (n=19); and (3) health professionals (n=21) in cancer care. The study was conducted within the Saskatchewan Cancer Agency, a university-affiliated cancer treatment centre in Western Canada, approved by the relevant research ethics board, and by the cancer agency. To ensure trustworthiness, we followed the guidelines for rigour presented by Thorne (2016). These steps included (1) ensuring epistemological integrity by choosing a design congruent with the research question, methods, and approach; (2) demonstrating credibility and believability of the findings by using multiple data sources and triangulating said data and member checking; (3) ensuring analytic logic by keeping audit trails and memoing throughout the study; and (4) enabling interpretive authority through the use of exemplary quotes.

FINDINGS

We triangulated data from commonly searched cancer websites, conducted interviews and surveys with people newly diagnosed with cancer, and conducted interviews and focus groups with healthcare professionals. Together the study findings contribute to a better overall understanding of how people with cancer use CRII, what types of information are accessible on the most commonly searched websites, and how CRII informs their interactions with healthcare professionals and healthcare services. The findings start to build a framework for understanding where and how patients use the internet in the cancer experience. Specifically, these results provide an understanding of: which patients are looking for information; what information they look at online; what they are looking for, which might be different than what they are looking at; and how CRII fits into the patient-nurse relationship.

Website analysis

In the qualitative review of websites, we 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 Barbara 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 laid out by Carper.

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 diagnosis, as patients make sense of their illness, make decisions, and/or enter treatment. However, the dominance of biomedical information overshadowed other types of information. For example, information about death and dying was very difficult to locate (even when specifically searching these terms within websites), as was information to support self-management, or information accounting for diverse sociopolitical backgrounds. These findings are significant, as they raise questions and concerns about the information that people with cancer find when searching independently, as well as the information that is deemed important enough to be easily accessible. They also have implications in numerous domains 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 consult with their healthcare professional, next they would gather the information from their healthcare professional and consult the internet. Using both data sources they would triangulate the information to gain a better 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. Patients felt that the internet could be very useful to guide decision-making, especially when they were weighing two options. 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 explored 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 with members of the multi-disciplinary team at the cancer centre including nurses, physicians, dietitians, social workers and a pharmacist (n=17) and four individual in-depth interviews (n=4).

Healthcare professional participants acknowledged that many of their patients rely upon CRII to understand and process their diagnosis. Most healthcare professionals found that their patients would go to the internet to learn about their illness and to help them understand the information provided by their healthcare professional. Healthcare professionals also felt that there were key transition points in the cancer trajectory where people were more likely to feel heightened uncertainty, and, therefore, look for more information on the internet. Those two points were: at the time of diagnosis before they had received their consult at the cancer agency, and when discharged from cancer care back to their primary care provider. Healthcare professionals

felt that these times were especially stressful and anxiety-provoking for patients, and that CRII could help them to process their concerns in the absence of actual (or perceived) healthcare professional support.

Healthcare professionals acknowledged and supported patient use of CRII, but they also expressed hesitations. Some of these hesitations related to the concerns that patients would access information they were unable to understand or that was wholly inaccurate. Healthcare professionals felt that even if patients could find 'good quality' information, they were skeptical that most patients (i.e., with no prior medical knowledge) would be able to understand and apply what was applicable to their specific diagnosis. Information about complementary and alternative approaches/medicines was also commonly cited as topics of concern.

DISCUSSION

Together, the findings from this mixed methods study begin to clarify the role of CRII in the cancer experience and patient interactions with healthcare professionals and services. We have drawn upon multiple data sources, including the perspectives of both patients and healthcare professionals. 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. The discussion will focus on the practice implications of this study, and how oncology nurses can integrate an awareness of CRII into practice.

Nursing practice encompasses practical care for the whole person, their family, and their environment (Bottorff, 1991; Carper, 1978; Fawcett, Watson, Neuman, Walker, & Fitzpatrick, 2001; Thorne, 2019). As a practical profession with a holistic focus that goes beyond care of the physical body,

the findings from this study have multi-faceted implications for nursing. 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. Following a nurse-led model of patient navigation may proactively address patients' priority concerns during the transition into cancer care (Fillion et al., 2006; Pedersen & Hack, 2010). An oncology nurse navigator is well situated to assess what information patients want and address the gap with the acknowledgement that CRII may be an important source of cancer information.

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; McCorkle et al., 2011). Information needs are present across the trajectory of cancer, especially at diagnosis (Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 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. Nurses can tailor care to encourage patients to bring CRII into the nurse-patient relationship so it is complementary rather than 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 study have 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 shifted over time from a top-down approach to a collaborative partnership model (Gottlieb, Feeley, & Dalton, 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, the landscape has evolved to include patients finding their own information and engaging in independent learning about their illness (Lustria, Smith, & Hinnant, 2011). The desire for more exchange about CRII between patients and healthcare professionals has relevant repercussions for nurses.

In interviews with patients, we found that they used CRII to learn about their illness and to engage in self-management. 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 being judged could be a reason for patients not to disclose their CRII. 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 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.

In 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) entitled, '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 (e.g., 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 our research, we would elaborate these guidelines by encouraging nurses to

be catalysts to start conversations about CRII 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). We believe this model poses several attributes for generating discussions about CRII, but can be tailored based on findings from this study.

Drawing on the study findings, we propose the following approach to begin conversations about CRII: Ask, Listen, Engage, Reflect/Reorient, and Time (ALERT) (Figure 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.

(1) Ask patients and their families about their use of CRII and whether this is a source of information on which they rely. Although the RNAO fact sheet encourages patients to start this conversation, patient participants in this study clearly felt they wanted healthcare professionals to broach the topic first. Healthcare professionals emphasized that asking patients about what information they were looking for was an important way to understand what patients were interested in knowing. Starting from this simple question, nurses can then assess their patient's information needs, and make a plan to address them. This process mirrors the first step in the nursing process—assessment—which is the foundation of clinical reasoning in nursing (Alfaro-LeFevre, 2014).
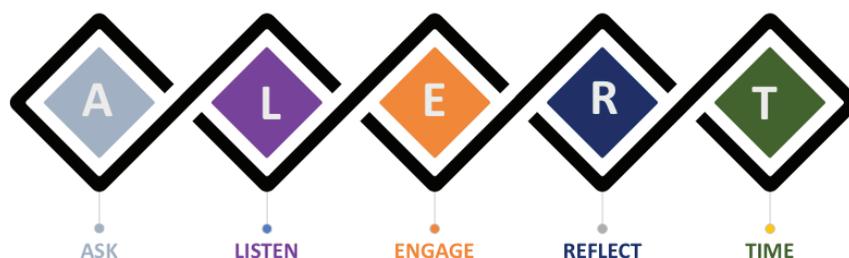

Figure 1: The ALERT model

(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). Listening includes effectively using empathy, acceptance, silence, verbal and non-verbal communication (Shipley, 2010). Listening allows nurses an opportunity to understand their patients' information needs and creates an environment where they can 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 these exchanges as a simple linear transaction creates opportunities for patients to feel like empowered partners rather than passive subjects (Sanford, 2000).

(4) Reflect upon and/or reorient what patients share with you. The idea of reflection was discussed amongst nurses as a means of essentially paraphrasing for patients their concerns, or simply repeating it back, using words you like: Here is what I think I hear you say. Nurses felt this was the first step to really understand if they knew what patients were looking for, or finding. By reflecting, nurses can also provide context for the information the patient has found, and apply it to their patient's specific needs.

The idea of reorienting goes one step further than reflection. Nurses discussed the idea of reorienting patients when they share information that might be partially but not completely factual or applicable. The nurse, having heard what information the patient has found, identifies any concerns and, if necessary, redirects the person 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).

(5) Time and timing relates to the importance of incorporating discussions of CRII throughout the cancer trajectory. Many healthcare professional participants identified a reluctance to engage in discussions about CRII at the first meeting with a client, as they may not have developed a rapport at that time, 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, we 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' can be a reminder that each time we interact is an opportunity to use ALERT, and engage on this topic. Nurses in this study also mentioned that many patients used their phone or iPad to pass the time between or during chemotherapy, 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, we believe it is the role of the nurse to initiate discussions about CRII, and should not be the sole responsibility of 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, nurses can reflect and reorient the concerns of the patient by listening to the information they have uncovered and putting it into a holistic context that applies to the patient. Finally, given the nature of cancer, nurses in all domains working with people with cancer can 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.

CONCLUSION

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. This paper presents a blueprint for nurses to proactively engage in conversations about CRII with their patients. Oncology 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. 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 later concerns related to ill-suited information and allow nurses the opportunity to provide holistic cancer information. Nurses also embody the multifaceted knowledge described by Carper (1978) and bring this holistic approach to their patient care in ways that CRII cannot.

Through research, we should continue to explore the implications of CRII, be critical about its implications in practice, and cautious about over-investment in unnecessary technology. This study also generates many new questions about older adult engagement with technology to manage their cancer diagnosis, 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 potentially using healthcare services or efficiently or effectively, and thus future research must explore whether this has direct effects on healthcare costs.

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