

2023-08

Untangling The Knitting Problem: An Exploration of The Interplay Between The Cancer Journey, Identity, Information, and The Internet

Thiessen, Maclean

Thiessen, M. (2023). Untangling the knitting problem: an exploration of the interplay between the cancer journey, identity, information, and the internet (Doctoral thesis, University of Calgary, Calgary, Canada). Retrieved from <https://prism.ucalgary.ca>.

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Untangling The Knitting Problem: An Exploration of The Interplay Between The Cancer
Journey, Identity, Information, and The Internet

by

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A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF DOCTOR OF PHILOSOPHY

GRADUATE PROGRAM IN NURSING

CALGARY, ALBERTA

AUGUST, 2023

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Abstract

Background: Information helps support the identity of individuals navigating the cancer journey. However, information is one of the most prevalent unmet supportive care needs of those living with cancer. The objectives of this thesis are to 1) characterize how tools for assessing the information needs of those living with cancer have been developed, 2) determine what characteristics make information useful for navigating the cancer journey, and 3) conceptualize why and how individuals use the internet to access information including what characteristics make online information content useful.

Methods: Objective 1 was addressed through a scoping review of the peer-reviewed literature exploring the development of information needs assessment tools for use in the cancer context. Objectives 2 and 3 were addressed using semi-structured interviews and classic grounded theory in two sequentially conducted studies.

Results: The scoping review identified 21 tools for assessing information needs. Development of the tools was primarily informed by healthcare professionals and pre-existing literature, not those with lived cancer experience. The first grounded theory ($n = 60$) defined high-quality information as that which was accessible, credible, applicable, and framed in a way that was empowering and provided hope. The second grounded theory ($N = 21$) described that individuals used the internet when high-quality information for a challenge they were facing was not available from healthcare providers to address the key orientation questions of: 1) why the challenge is happening, 2) what to expect from it, and 3) what options exist for managing it. Recommendations for better online content include, but are not limited to, clearly identifying the population the content is for and the placement of hyperlinks after the key orientation questions have been addressed.

Conclusion: Current understanding of what information needs are important for those living with cancer is highly influenced by what healthcare professionals consider important for patients to know - not necessarily the priorities of those living with cancer. Characterization of the challenges faced by those living with cancer is necessary to guide the development of information needs assessment tools and interventions. This work should be undertaken in partnership with those that have lived experience.

Preface

Copyright and Contributions of Author Statement

This thesis includes four manuscripts which involved multiple co-authors, each of which contributed to their completion. The manuscripts are presented in chapters 2, 3, 5, and 6. For the scoping review protocol (Chapter 2) and report of the findings (Chapter 3), Maclean Thiessen (MT) and Shane Sinclair (SS) were responsible for the design of the protocol. Data collection was performed by MT and Daranne Harris (DH). Analysis and development of the draft of both manuscripts was completed by MT. SS, Shelley Raffin Bouchal (SRB), and Patricia A. Tang (PT) were responsible for supervision and review of the resulting manuscripts. For the two grounded theory studies (chapters 5 and 6) MT, SS, SRB, and PT were responsible for study design. Data analysis and developing the initial draft was conducted by MT. SS, SRB, and PT provided supervision and suggestions for revisions of the initial draft manuscript.

The manuscripts presented in chapters 2, 5, and 6 have been accepted and published in peer-reviewed journals. They are all open access articles, distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium providing the original work is properly cited including complete bibliographic information, a link to the original publication, as well as the copyright and license information, which is listed below.

Copyright and citation information for the manuscript presented in Chapter 2:

Thiessen M, Harris D, Tang P, Raffin Bouchal S, Sinclair S Examining the Development of Information Needs Assessment Questionnaires in Oncology: Protocol for a Scoping Review JMIR

Res Protoc 2022;11(9):e35639 URL: <https://www.researchprotocols.org/2022/9/e35639> doi: 10.2196/35639 PMID: 36048517

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Copyright and citation information for the manuscript presented in Chapter 5:

Thiessen M, Sinclair S, Tang PA, Raffin Bouchal S Information Access and Use by Patients With Cancer and Their Friends and Family: Development of a Grounded Theory J Med Internet Res 2020;22(10):e20510 URL: <http://www.jmir.org/2020/10/e20510/> doi: 10.2196/20510 PMID: 33118940

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Copyright and citation information for the manuscript presented in Chapter 6:

Thiessen M, Raffin Bouchal S, Tang PA, Sinclair S. Navigating the Cancer Journey Using Web-Based Information: Grounded Theory Emerging From the Lived Experience of Patients With Cancer and Informal Caregivers With Implications for Web-Based Content Design. JMIR Cancer 2023;9:e41740. URL: <https://cancer.jmir.org/2023/1/e41740/> doi: 10.2196/41740 PMID: (pending)

©Maclean Thiessen, Shelly Raffin Bouchal, Patricia A. Tang, Shane Sinclair. Originally published in JMIR Cancer (<https://cancer.jmir.org>), 20.04.2023.

The manuscript presented in Chapter 3 has been submitted for consideration to a peer-reviewed journal and is currently under consideration, as such the manuscript is previously unpublished. It has been included in this thesis with permission from the authors. Appendix O provides a template that was used to obtain permission for this manuscript to be included in this thesis document. A version containing the co-authors signatures indicating their consent to include the manuscript in this thesis has been retained by the author of this thesis document.

Acknowledgements

Without the support of my supervisory committee, Dr. Patricia Tang, Dr. Shelley Raffin Bouchal, and Dr. Shane Sinclair, this work would not have been possible. Each contributed in a way that was timely and meaningful in helping me reach my destination. Thank you.

The support of Alberta Health Services, Wellspring, and the Patient Oriented Research Unit at the University of Calgary all were essential for assisting with recruitment and supporting my excitement/enthusiasm for this work. Each interaction was positive, supportive, and helped make this work successful.

Ruby and Natalie – thank you for your patience. I just have a few more sentences to finish and then I'll be in for bedtime. Promise.

Dedication

To the helpers - may you stay humble, honest, and hopeful.

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List of Abbreviations

AHS: Alberta Health Services

CGT: Classic grounded theory

CRD: Cancer-related data

HIA: Health information acquisition

HISB: Health information-seeking behavior

JI: Joanna Briggs Institute

MBSS: Miller Behavioral Style Scale

PDA: Patient decision aid

PROMs: Patient reported outcome measures

QI: Quality improvement

SEO: Search engine optimization

TV: Television

UFO: Unidentified flying object

US: United States of America

Chapter 1: Introduction

Chapter Overview

The body of work presented in this thesis is part of an ongoing journey I have been on to solve a clinical problem. At first, the problem seemed like a relatively simple one. But I have come to understand that it is complex, manifests itself in many forms, and raises important questions about contemporary cancer care.

This introductory chapter is intended to frame the subsequent chapters in terms of my own professional journey with the problem and introduce the concepts that I have found helpful for understanding it. In the following section, a narrative about the problem as I first recognized it in my clinical work is presented. Next, five key concepts that have been foundational for my understanding of the problem are defined and explored. Following this, a review of the problem as it relates to the oncology literature is presented. Lastly, an outline of the subsequent chapters is presented, including how the manuscripts, presented in Chapters 2, 3, 5, and 6, inform solutions to the problem that first brought me to this work.

The Knitting Problem

A little over ten years ago, I was working as a medical oncology resident and assessing a patient who had completed treatment intended to cure a colon cancer. I was reviewing the patient for signs of re-occurrence. The patient had undergone a surgery about a year prior. They then received six months of chemotherapy to reduce the chances of the cancer coming back (Gelibter et al., 2019). I asked the patient a few questions to find out how they were doing, examined them, and reviewed the investigations the patient had undergone just prior to our appointment including a CT scan, colonoscopy, and bloodwork (Rose et al., 2014). Then I shared the conclusion of my review with the patient which was that there was no evidence of cancer re-occurrence.

Despite the good news, the patient said they were angry and depressed. They shared how the chemotherapy had taken away one of the central things in their life. Because of the treatment, the patient had lost the sensation in their fingers and, consequently, the ability to knit. What the patient was describing was a common toxicity from the type of chemotherapy they had received called peripheral neuropathy (Kang et al., 2021).

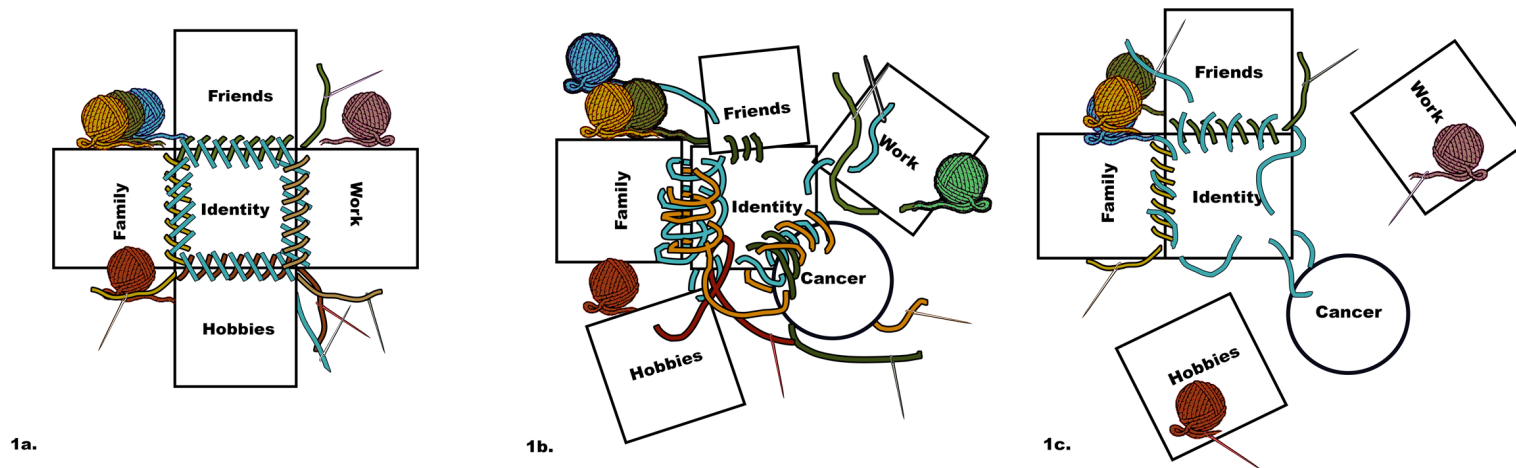
Prior to receiving chemotherapy, knitting was what connected this person to their social world. They had spent most of their free time knitting presents for family members, including their own children, nieces, nephews, and grandkids. They had also been part of several weekly knitting groups and lead the church knitting group. The patient described that because of the impact that the chemotherapy had on their ability to knit, they had lost their sense of purpose, place in the community, and one of the major ways they expressed love for their family.

Hearing stories from patients and those who love them about the losses experienced on the cancer journey was not new for me. At that time, I was - and continue to be - familiar with being a witness to the experience of loss that patients and their supporters suffer as the things they previously valued and gave them purpose (Little et al., 2022; R. Olson, 2014) are left behind along their cancer journey. But at that point in my career, my vantage point as an oncology clinician into the impact of the cancer journey was limited to a few brief interactions over the course of a month or two, as I rotated through various clinics as part of my training. What made the interaction with this patient stand out was that they told me that after embarking on their chemotherapy treatment, they had learned that an alternative version of the chemotherapy they had received was available that would not have impacted their sensation.

According to the patient, the trade-off with this alternative chemotherapy was a slightly smaller statistical benefit in terms reducing the risk of re-occurrence. I was familiar with the study

the patient referenced (Andre et al., 2004), but what got my attention was how eloquently this patient demonstrated an understanding of the relevant statistics and the consequences of this alternative treatment. They said that if they knew that they were risking their ability to knit, and that an alternative treatment was available, they would have chosen the less toxic treatment despite less reduction in the risk of recurrence.

This interaction was the beginning of my journey with what I refer to as the knitting problem, in recognition of the patient I met many years ago. The knitting problem describes when the life of someone experiencing cancer, either as a patient or support person, is impacted in a negative and irrevocable way due to the receipt of cancer care. Specifically, where the negative impact is due to conflict between what is entailed with receiving treatment and the unique way that the individual makes their way in the world. From my own clinical experience, I believe the knitting problem is quite prevalent as I have seen it manifest itself in many ways including loss of employment, divorce, estrangement from friends and family members, and even untimely death. Since I first recognized it, my understanding of the knitting problem has developed primarily from encountering five concepts that relate to the biomedically focused nature of contemporary cancer care and the resulting dehumanizing effects. A model of the knitting problem, including the five concepts and how they are inter-related, is presented in Figure 1. The next section presents these five concepts and how they informed my understanding of the knitting problem.

Figure 1.*Model of the Knitting Problem*

Note. The knitting problem describes a persistent undesirable alteration of an individual's identity resulting from the receipt of cancer care. Understanding of the knitting problem is informed by five concepts: 1) contemporary cancer care is biomedically focused; 2) biomedically focused care can be dehumanizing; 3) dehumanization is problematic through the lens of contemporary medical ethics; 4) identity defined as the sum of an individual's social roles; 5) identity is harmed by dehumanization, making supporting identity an important goal for evolving cancer care. Figure 1a provides a model of pre-diagnosis identity. Figure 1b illustrates the impact of cancer care receipt and treatment, fracturing previously stable identity. Figure 1c provides a model of persistent loss of pre-diagnosis social roles following the receipt of care.

Key Concepts For Untangling The Knitting Problem

Concept #1: The Historical Context of The Knitting Problem

Contemporary western medical practice has its origins in ancient Greece (Toombs, 2001). The two ancient schools of medicine that are considered to have had the largest influence are the Cnidian and Coan schools (Toombs, 2001). The Cnidian school is named after the town of Cnidos (Vaisrub, 1971). The Coan school being named the island of Cos, birthplace of Hippocrates (Vaisrub, 1971).

Importantly, a tension in the practice of medicine has existed between the ethos reflected in the teachings from the Cnidian and Coan schools (Toombs, 2001; Vaisrub, 1971). The Cnidian school of medicine focused on taxonomizing disease, with the underlying belief that disease and the patient were separate entities (Vaisrub, 1971). On the other hand, the teachings originating from the Coan School did not separate the patient from their disease conceptually. Instead, the Coan school considered the patient in their unique life context, and focused on restoring or maintaining the patient's function in their unique context, regardless of whether the disease could be cured (Toombs, 2001; Vaisrub, 1971).

A lot has changed since Greek antiquity in the world of medicine. This is in large part due to the development and introduction of the scientific method as a basis for medical practice (Toombs, 2001; Vaisrub, 1971). Key ideas emerged from the latter half of the last millennium from scientists and scholars such as Francis Bacon and Thomas Sydenham shifting medical practice away from unproven theory, myth, and magical thinking (Toombs, 2001). Instead, practice began to be guided by rigorous scientific exploration, including systemic observation and rational thought (Toombs, 2001). Emerging technology has also been an important part of this evolution. For instance, the early 19th century brought with it the stethoscope which enhanced the

ability of clinicians to create medical knowledge by linking symptoms and signs obtained from clinical exam with post-mortem findings (Toombs, 2001). The shift of medical practice away from magic and myth towards a logical and rational approach incorporating new technology has continued up to this day (Toombs, 2001).

While the advances in medical practice over the last few hundred years have undoubtedly had immeasurable benefit for the world's population, an important question is whether there has been a hidden cost to this evolution? Some scholars (Crookshank, 1926; Toombs, 2001; Vaisrub, 1971) suggest that the evolution of medicine over the last number of centuries has resulted in a loss of connection with ethos of the Coan school of medicine (Toombs, 2001) and that currently we are living in an era where the Cnidian ethos prevails – where treating disease is prioritized over caring for the wellbeing of the person living with it (Toombs, 2001).

There are certainly examples to support that contemporary medical practice is not always well aligned with the Coan ethos. The Flexner report, and its lasting impact on medicine and medical education, supports this assertion. The Flexner Report entitled “Medical Education In The United States and Canada” was published in 1910 (Duffy, 2011). It was commissioned by the Carnegie Foundation for the Advancement of Teaching who had hired a former high school teacher and pedagogical expert named Abraham Flexner to survey the quality of medical schools in the United States and Canada (Stahnisch & Verhoef, 2012). Interestingly, some scholars suggest that Abraham Flexner was hired primarily to be a “hatchet man” (Duffy, 2011, p.271), delivering a predetermined agenda designed to sweep clean the medical system (Duffy, 2011). As part of the report medical schools were evaluated primarily based on admission standards, physical facilities, laboratories, and the amount of instruction available from physician scientists (Duffy, 2011). This evaluation processes resulted in many schools being closed that did not meet the standards outlined

in the report (Duffy, 2011), as well the elimination of curriculum not based on empiric science (Stahnisch & Verhoef, 2012). Additionally, it firmly positioned medical education within institutions that prioritized biomedical scientific discovery, in part by promoting the full-time model where physician scientists received financial compensation for research activities to make up for income that would have been otherwise generated through patient care.

The new model of academic medicine that was introduced was not without critics. For instance, the famous Canadian physician, Dr. William Osler, raised concerns that the proposed system of medicine would detrimentally narrow the focus of physicians, and result in an elitist group of physicians disconnected from both their colleagues outside of teaching centers and the realities of their patients (Duffy, 2011). Furthermore, Dr. Osler was concerned that by prioritizing scientific discovery in teaching centers, the welfare of patients, and the education of students in how to care for patients would suffer (Duffy, 2011).

Despite protests from Dr. Osler and others, the Flexner Report led to the transformation of academic medicine and medical education promoting the full-time model in teaching centers. This model promoted biomedicine and its evolution through scientific discovery based in the natural sciences (Duffy, 2011; Stahnisch & Verhoef, 2012). Decades later, the impact of the Flexner Report is clear, as it not only catalyzed an era of significant biomedical discovery and breakthrough, but also created a medical education system where topics critical to the wholistic care of patients, such as communication and information sharing, continue to receive lesser priority (Stahnisch & Verhoef, 2012).

Perhaps reflecting the impact of the Flexner report on the education of those who implement policies and administrative practices that guided my education, my own clinical practice provides evidence for how contemporary medical practices reflect the ethos of Cnidian

school. For instance, my productivity as a clinician is measured, at least on an administrative level, by how many patients I see and how much biomedical treatment I prescribe. In support of this, the tariffs I bill for communicating with patients and their families are capped at a relatively small maximum per year for each patient, yet there are no such caps for the tariffs related to treatment administration (The Minister of Health, 2022). As a result, I am primarily remunerated for diagnosis and treatment, not how well I meet the non-biomedical needs of my patients and their informal caregivers.

The peer-reviewed scientific literature also supports that contemporary medicine is misaligned with the Coan ethos. For instance, one study explored barriers to implementing patient centered interventions at a veterans affairs hospital (Bokhour et al., 2018). A total of 108 employees – 22 senior leaders, 42 middle managers, 47 front-line providers, and 7 staff – were interviewed. Barriers were found at all levels. A nurse who shared the experience of having limited time to focus on duties other than the ones that were essential to providing biomedically focused care is illustrative: “How can I really be patient-centered, and how can I really sit there and listen deeply when I’ve got about [eleven seconds] to do it?” (Bokhour et al., 2018, p. 8).

The historical perspective outlining the significant influence of the Cnidian school of medicine on contemporary medical practice provides a constructive framework for exploring the knitting problem for two reasons. First, it supports that blaming an individual person or party for the outcome of the patient who helped me identify the knitting problem is not appropriate. In fact, in the historical context outlined above, the patient’s care went as planned. It was in keeping with recommended guidelines, no error was committed, and the key goals were achieved; eradication of disease was prioritized (Toombs, 2001; Vaisrub, 1971). Second, the historical perspective suggests that the knitting problem is occurring on a global scale and likely will be for the

foreseeable future. This is because the knitting problem is not a phenomenon occurring at a specific cancer center. Instead, it is a consequence of a healthcare culture evolved to focus on employing technology and scientific principles to diagnose and eradicate diseases – potentially at the expense of caring for the global wellbeing of the individual (Toombs, 2001; Vaisrub, 1971). Given that the focus of western medicine appears to continuously be shifting further towards the Cnidian ethos (Toombs, 2001), the knitting problem is likely here to stay.

Concept #2: Freire On Being Human

The historical context (Toombs, 2001) is helpful for understanding the origins of the knitting problem and developing a stance that is empathic towards healthcare professionals. However, this perspective does not provide an understanding of how the knitting problem might manifest itself outside of the specific context of a needle-work enthusiast who is experiencing chemotherapy induced peripheral neuropathy. Nor does the historical perspective inform what alternative outcomes may be more desirable. To begin to address these issues, this section will explore the knitting problem using Freire’s understanding of what it means to be human and his conceptualization of dehumanization (Freire & Ramos, 1970/2014).

Paulo Freire (1921 – 1997) was a Brazilian philosopher, educator, and a foundational figure in the development of critical education theory (Elias, 1975). In one of his most important works, *Pedagogy of the Oppressed*, Freire defined essential characteristics distinguishing animals and humans (Freire & Ramos, 1970/2014). Freire describes animals as existing in an ahistorical reality, where there is no “here, now, there, tomorrow, and yesterday” (Freire & Ramos, 1970/2014, p. 99). Additionally, Freire describes animals as not able to participate in shaping their own world. He argues that animals are not in dialogue with their reality, lacking an ability to reflect and take

action to transform it - being “as animal-like [in the forest] as they are in the zoo” (Freire & Ramos, 1970/2014, p. 98).

In contrast to animals, Freire describes that humans exist in active dialogue with their world. They are aware of the reality in which they exist, their relation to it, and that they exist both separately from their environment and in a relationship with it (Freire & Ramos, 1970/2014). Additionally, unlike animals, humans are capable of reflecting on their relationship with their reality and setting objectives and planning action to transform it (Freire & Ramos, 1970/2014). These characteristics of being human are what it means to be human and what is lost when individuals are oppressed, for both the dehumanized individual and their oppressor (Freire & Ramos, 1970/2014). According to Freire, a person’s true ontological vocation (i.e., true purpose) is to become more fully human (Freire & Ramos, 1970/2014).

Freire’s educational philosophy and approach was grounded in real world context. His work in Brazil occurred during a time when the literacy rates in Brazil were some of the lowest in the world, especially among farmers and other low socio-economic groups in the northeast part of the country (Elias, 1975). Education in Brazil was primarily focused on helping individuals succeed in the professional world (Diaz, 2022) and obtaining it was a luxury that was out of reach for the populations that Freire worked with. Additionally, only people who were literate were eligible to participate in voting (Diaz, 2022), limiting participation in the democratic processes that could lead to change in public structures, such as the education system, to those of upper classes.

Freire’s approach to teaching literacy reflected his understanding of what it meant to be human. His approach involved customizing literacy curriculums for communities around the social issues that the students in these communities faced (Freire & Ramos, 1970/2014). This approach

involved first engaging with the members of the communities where he would be leading literacy education to understand the issues that were important to them (Elias, 1975; Freire et al., 1973). The curriculum was then developed to build literacy around the words central to the challenges the members of the community faced. This process involved exploring the reading and writing of the syllables involved in the words central to the challenges faced by the members of the community. For instance, *favela*, the Portuguese word for slum, would be first broken down into its syllables with the learners (Freire & Ramos, 1970/2014). Then, using these syllables, the learners would learn about other words related to the *favela*, eventually moving onto to broader themes related to poverty, such as oppression, and imperialism (Elias, 1975; Freire & Ramos, 1970/2014).

This approach not only provided impoverished Brazilians with an education around reading and writing; it promoted community building and empowering the students to envision social change (Diaz, 2022; Elias, 1975; G. Olson, 1997). The result was an educational program that proved to be incredibly efficient in helping individuals gain reading and writing skills. Some sources report that individuals were able to gain the ability to read and write in less than 45 days (Elias, 1975). More importantly, Freire's approach helped communities maintain their social and cultural identities by uniting them around shared social challenges, through dialogue, reflection, and action (Diaz, 2022; Elias, 1975).

Freire explored humanization and dehumanization in terms of cultural groups and communities (Diaz, 2022; Freire & Ramos, 1970/2014), but his ideas about what it means to be human are helpful for understanding the knitting problem. For the populations that Freire worked with, the lack of literacy and the resulting social challenges the communities faced were mechanisms of oppression and dehumanization. Similarly, the patient I met many years ago

described relative illiteracy at the beginning of their cancer journey, identifying challenges with understanding many of the words, processes, and concepts that were related to the treatment decision making processes. As a result, the patient was unable to advocate for their own interests in the decision-making process and was unable to participate in making decisions that would have protected their way of life. In this way, the patient lost the human capacity to reflect, set objectives, and meaningfully participate in transforming their reality (Freire & Ramos, 1970/2014). Additionally, once the treatment toxicity arose, further dehumanization resulted, as the patient experienced further loss of their ability to participate (Freire & Ramos, 1970/2014) in the social reality they had participated in before receiving treatment.

Freire's understanding of what it means to be human is rooted in the social world, not in biology. Specifically, it is related to a person's ability to observe their reality, reflect on it, and take action to transform it (Freire & Ramos, 1970/2014). Using Freire's terminology, the knitting problem occurs when dehumanization occurs at the expense of receiving cancer treatment intended to protect a patient's biology. Freire's understanding of what it means to be human provides a deeper appreciation of a hidden consequence of the contemporary medical paradigm dominated by the Cnidian ethos (Toombs, 2001), where care of the person is reduced to biomedical interventions. Importantly though, while Freire's terms are helpful for further articulating the knitting problem, they do not necessarily provide an imperative or guidance for how to address it – or whether it needs to be addressed at all.

Concept #3: An Ethical Argument for Humanization

Freire's conceptualization of what it means to be human (Freire & Ramos, 1970/2014) does not inform what, if anything, should be done about the knitting problem. In the specific instance of my encounter with the patient who introduced me to the knitting problem, I was empathetic to

their suffering and wished that their circumstance was different. But experiencing empathy, and identifying instances where dehumanization (Freire & Ramos, 1970/2014) has occurred does not, in and of itself, identify a need for change or inform a prescription for what that change should be. Instead, what is considered to be right or wrong in medical practice is informed by widely recognized ethical principles (Beauchamp & Childress, 2009/1985), not necessarily reflective of what empowers individuals to meaningfully participate in the transformation of their own reality (Freire & Ramos, 1970/2014).

In contemporary medical practice, Beauchamp and Childress (2009/1985) provide what is widely considered to be a standard in terms of an ethical framework for guiding decisions and conduct. Since the first publication of *Principle of Biomedical Ethics* (Beauchamp & Childress, 2009/1985) in the mid-21st century, their framework has guided decision making at all levels of healthcare delivery, informing medical decision making at the clinical and administrative level as well as guiding the education of healthcare trainees. Their framework is based on four moral principles: beneficence, non-maleficence, autonomy, and justice (Beauchamp & Childress, 2009/1985). Exploring the knitting problem using these principles is helpful for understanding its ethical implications, and for better understanding if, and how, it should be addressed.

Over the last century, autonomy has emerged as an important guiding principle in biomedical ethics (Beauchamp & Childress, 2009/1985). Autonomy entails respecting the rights of individuals to make choices, hold beliefs, and take actions. For the healthcare professional, autonomy presents an associated obligation to assist patients in making autonomous choices, and to mitigate situations which “destroy or disrupt autonomous actions” (Beauchamp & Childress, 2009/1985, p. 63). The principle of autonomy can be linked to the philosophies of Immanuel Kant

and John Stuart Mill, who argued for both the value of the individual, and the right of individuals to make their own decisions (Beauchamp & Childress, 2009/1985).

Autonomy is relevant to the knitting problem in the instance where I first recognized it because there was an alternative chemotherapy option that the patient claimed was not presented to them. As the patient described, the alternative chemotherapy option may not have impacted the sensation in their hands, and therefore their ability to knit in the same way (Andre et al., 2004). As I was not present at the initial physician visit when the treatment plan was made with the patient, I cannot be certain how this conversation unfolded, however a few possibilities are likely. These include that a) the alternative treatment was not presented as an option or b) the alternative treatment was presented, but not in a way that supported the patient recognizing the different impact the two treatment options would have on their wellbeing (Politi et al., 2012). Importantly though, Beauchamp and Childress (2009/1985) identify that healthcare professionals have an obligation to assist individuals in making autonomous decisions. In practice this assistance may manifest itself by taking steps to help patients understand their options, therefore fostering their capacity as autonomous agents (Politi et al., 2012). Therefore, supporting autonomy by helping patients understand how treatment options will impact their lives is important from a contemporary ethics perspective and will likely prevent some instances of the knitting problem – but the knitting problem is not exclusively limited to autonomy in relation to treatment decision making.

As a reminder, the definition of the knitting problem is when the receipt of biomedically focused care results in harm due to long lasting interference with the idiosyncratic way that an individual makes their way in the world. While providing the patient with the tools to explore multiple different treatment options at the time of decision making may have helped them be in a better position to shape their reality, it is possible that, without the benefit of hindsight, they may

have agreed to the very same treatment that had led them to be so frustrated in my encounter with them. Additionally, there are certainly examples from my clinical practice where the knitting problem has occurred, but not due to a direct toxicity of a specific treatment. For instance, through my clinical work, I have been involved with patients who, in contrast to others receiving the same treatment, have experienced financial hardship (Fitch & Longo, 2021), lost their jobs (Shim et al., 2021), or have had to relocate across the country to be better supported by friends and family. These occurrences are also representative of the knitting problem – as they are instances where the consequences of receiving healthcare were disproportionately interruptive to how the individuals were living their lives.

While the principle of autonomy regarding treatment decision making is certainly relevant to the knitting problem in some instances, the ethical principles of non-maleficence and beneficence may be more central. Non-maleficence reflects the obligation of healthcare professionals to not do harm whereas beneficence is the principle of contributing to the welfare of others (Beauchamp & Childress, 2009/1985). In the context of cancer care, especially in contemporary medical practice (Toombs, 2001), the benefits of cancer treatment are relatively easy to define as they relate to either cure or life sustaining treatment. In contrast, harm is defined by Beauchamp and Childress as “thwarting, defeating, or setting back some party’s interests” (2009/1985, p. 116). Based on this definition, harm is broadly defined and includes outcomes beyond what can be defined biomedically such as death, pain and suffering, incapacitation, offense, to the deprivation of the goods of life including happiness, rewarding relationships, knowledge, and achievement (Beauchamp & Childress, 2009/1985; Campbell et al., 2021).

As Beauchamp and Childress (2009/1985) outline, what is ethical is often evaluated by weighing the harm that would, or has occurred, against the benefit to the wellbeing of the patient.

In the context of the patient I met in clinic, and the knitting problem in general, the harm appears to be with regards to deprivation of the goods of life, as the relationships, happiness, and ability to achieve that was facilitated by knitting were all impacted by their cancer treatment (Campbell et al., 2021). On the other hand, while the specific chemotherapy medication that impacted the patient's sensation could have potentially been eliminated, sparing the patient from developing peripheral neuropathy, there is a small but real possibility that the treatment saved the patient's life (Politi et al., 2012). The challenge with looking for ethical guidance by comparing harm and benefit in this situation is that both are occurring simultaneously and are of two distinct types making the relative weight of each challenging to compare.

Justice is the final of the four principles in the framework of medical ethics presented by Beauchamp and Childress (2009/1985) and specifically refers to distributive justice and problems with resource allocation as opposed to criminal or rectificatory justice (Beauchamp & Childress, 2009/1985). In general, problems with justice are guided by the Aristotelian principle that "equals must be treated equally, and unequals must be treated unequally" (Beauchamp & Childress, 2009/1985, p. 227). Of the four principles, justice – and the idea of equal treatment among equals – is perhaps the most helpful in terms of informing solutions to the knitting problem.

Beauchamp and Childress (2009/1985) limit their discussion of justice to its application across large, relatively easily identifiable population groups. For instance, justice as it relates to those with specific health conditions such as AIDS, physical impairments (i.e., deaf), and those with and without health insurance are discussed in relation to the application of the principle of justice (Beauchamp & Childress, 2009/1985). For these problems, the principle of justice supports that additional resources should be allocated to help individuals enjoy the same quality of life as other individuals in their community. In contrast, the knitting problem describes a certain type of

problem that occurs because of a unique characteristic of an individual, not a group. It is the interaction between this characteristic and healthcare delivery that leads to unravelling of the individual's identity. As a result, the knitting problem can be seen as a consequence of a just distribution of resources (Beauchamp & Childress, 2009/1985) whereby the physician who was involved in making the treatment decision with the patient likely spent the same amount of time with the patient as they would have with any other patient. If asking about knitting was not part of the clinician's routine, it is easy to imagine how identifying the potential risk to the patient's wellbeing of peripheral neuropathy could have been missed. It is also easy to imagine that, like looking for a needle in a haystack, if clinicians were responsible for identifying and navigating every potential idiosyncratic interaction between a patient's social world and biomedical treatment that the healthcare system would become less efficient. While this may result in less dehumanization it may also result in, simply, less humans.

In terms of working towards solutions to the knitting problem, the discussion above outlines how the four principles that guide contemporary medical ethics (Beauchamp & Childress, 2009/1985) inform what the ideal solution to the knitting problem should involve. First, in keeping with the ethical principles of non-maleficence and beneficence, solutions should minimize the negative impact of biomedical care on the goods of life the individual experiences, without impacting the good of medical care. Second, the solution should be capable of assisting shared decision making in terms of treatment decision making, when possible, in keeping with the ethical principle of autonomy. Lastly, due to the nature of the knitting problem being one that does not impact identifiable groups, solutions should require a relatively low allocation of resources, in keeping with the ethical principle of justice.

Concept #4: Identity As The Sum Of Social Roles

The historical context of healthcare delivery, Freire's concept of dehumanization, and the ethical framework provided by Beauchamp and Childress (2009/1985) have helped me develop a high-level understanding of the knitting problem. But what helped me move to a lower-level understanding of the mechanics of the knitting problem was learning about identity theory (Burke & Stets, 2009). This is because identity theory (Burke & Stets, 2009) provides an explanation, rooted in the empiric and theoretical literature, for why the knitting problem can be so devastating for the wellbeing of an individual.

Identity theory is a body of work primarily originating from the discipline of sociology and informed by symbolic interactionism (Burke & Stets, 2009). Symbolic interactionism is an important sociological theory, originating from the work of Scottish moral philosopher Herbert Blumer, and subsequently developed by a number of others including Cooley, Dewey, and Mead (Schwartz et al., 2011). It links the motivation for the actions that individuals take in their social roles to the meaning they place on both the social role itself, as well as the expected outcome. Identity theory builds on symbolic interactionism by considering the sum of the roles and relationships an individual has in society and how the evolution and performance of these roles over time impacts an individual's wellbeing (Burke & Stets, 2009; Schwartz et al., 2011). According to identity theory, an individual has many unique social identities (or social roles), and their performance and commitment to these roles has psychological consequences. Importantly, while Freire's work centered on social groups and their collective humanity (Freire & Ramos, 1970/2014), identity theory can be viewed as a conversation about an individual's collection of social identities, and the consequences of success and failure of these social roles on the individual's wellbeing.

Identity theory outlines that throughout the human life cycle, individuals go through phases of acquiring, maintaining, and transitioning between social roles (Burke & Stets, 2009). Individuals entering adulthood typically explore multiple different social roles, eventually making long term commitments to engaging in social roles that reflect their values (Schwartz et al., 2011). When an individual receives an extrinsic or intrinsic reward for engaging in a social role, their commitment to the roles increases (Burke & Stets, 2009; Schwartz et al., 2011). On the other hand, when they are not rewarded despite engaging in the role, or barriers to participating in that role exist, commitment to the role decreases (Burke & Stets, 2009; Schwartz et al., 2011). As a simple example, identity theory would predict that an employee who performs poorly in their job would be more likely to leave their job compared to one that is doing well and is being rewarded by their employer.

According to identity theory, transitions into, maintenance of, and abandonment of social roles are not benign processes for an individual's well-being. The quality of fit between an individual's values, their social roles, and role performance can have a profound impact on an individual's emotional and psychological health. In general, poor performance in and loss of the social roles an individual values has been linked to anxiety, depression, and pessimism (Burke & Stets, 2009). On the other hand, acquisition of, and good performance in valued social roles, can be linked to positive emotional and psychological states (Burke & Stets, 2009).

Multiple factors can influence which social roles an individual values, the social roles they engage in, and their role performance (Burke & Stets, 2009). First, the values an individual has are not static and can change over time – and as they change, so does the value they place on different social roles (Hitlin, 2003; Rokeach, 2008). For instance, post-secondary education has been identified as having the power to influence the value systems that students have over the course of

their education (Rokeach, 2008; Schwartz et al., 2011). As a result, a student is likely to value different sources of employment, and associated social roles, pre-university as opposed to when they have graduated. Second, an individual's ability to find social roles that are a good fit with their values is influenced by the social roles that are available to the individual (Burke & Stets, 2009). For instance, the individual's geographic location, skill set, previous experiences, and knowledge of available social roles are examples of factors specific to an individual that could potentially limit their interest in a social role. On the other hand, racism, ageism, sexism, and other forms of discrimination and prejudice are examples of factors external to the individual that may limit their ability to engage in social roles that they may otherwise value.

Identity theory facilitates a deeper understanding of the knitting problem by providing a framework for viewing how the cancer journey affects an individual's ability to navigate multiple social roles and the impact this has on their identity. As outlined earlier, an individual's identity is a conglomerate of many unique social identities performing in multiple social roles (Burke & Stets, 2009). Importantly, social identities are expressed one at a time, resulting in allocation of the individual's resources, including their time and energy, among their social identities. An individual's social identities are expressed in an order described as a salience hierarchy, which predicts the probability that a given role will present itself in a situation when given the opportunity (Burke & Stets, 2009). In an individual's salience hierarchy, the identities at the top are those: 1) with limited opportunities for being expressed; 2) that represent a greater source of overall support for the individual; or 3) that the individual is more committed to. The key being that both the expression and place in the salience hierarchy of a given social identity result from the social structure that the individual is in. As a result, how open a social structure is, in terms of opportunity

and flexibility for individuals to express their various social identities, has a significant influence on the identity of the individual.

Examples of how individuals prioritize social roles, depending on social structure, comes from two studies involving college freshman during their first semester (Serpe, 1987). The college where the studies took place was located in a small US city that most of the students had left homes in other cities to attend, leaving behind the social structures that supported the social identities they had established pre-college (Burke & Stets, 2009). The first of the two studies explored the level of freedom that the freshman believed they had in terms of how they engaged in five different identities categorized as: coursework, athletics/recreation, extracurricular, personal relationships with friends and family, and dating. A total of 631 freshman students enrolled in an introductory psychology class in the fall semester were asked to rate the five identities in terms of their ability to freely choose how they would participate in them from 1 (no freedom to choose) to 7 (complete freedom to choose). The relative freedom to choose was lowest for the academic/coursework identity and had the lowest standard deviation suggesting little variation (Men: $M = 2.2$, $SD = .84$; Women: $M = 1.9$, $SD = .81$). In contrast, the participants rated the other identities as providing more choice by a large margin. The next identities with the least choice had an average freedom score that was higher by a margin of over 2. In other words, the participants identified that there were limited options for successfully engaging in their coursework identity, presumably related to the traditionally rigid structure of coursework, involving scheduled classes, assignments, and examinations.

The second study was performed in a subsequent fall semester and included 320 freshmen enrolled in the same introductory psychology class (Serpe, 1987). The students completed a self-administered questionnaires three times over the course of the semester (September, October, and

December). The questionnaires captured specific data related to the same five identities explored in the first study, but this time it asked questions related to identity salience and commitment instead of about freedom (Serpe, 1987). Importantly, the coursework identity, which was found to be the most restrictive in terms of social structure in the previous study, exhibited no significant change in identity salience over the course of the study (Serpe, 1987). For both men and women, it consistently received the highest salience score. In contrast, except for extracurricular activities, the other identities demonstrated change over the course of the study. According to the authors this was because, similar to coursework, extracurricular activities were less open than dating, interpersonal relationships, and athletics/recreational activities (Serpe, 1987) because they were dependent on the structure of the organizations coordinating and sponsoring them.

The authors came to several conclusions (Serpe, 1987) that are important for understanding the knitting problem. First, they concluded that identity commitment impacts salience, and not the other way around (Serpe, 1987). In other words, it is the level of commitment to an identity, such as being in romantic relationship (i.e., dating) or being a leader in student government (i.e., extracurricular) that defines how likely an individual is to prioritize participating in that role in a given situation (Serpe, 1987). Second, in the setting of a restrictive social system, where opportunities for participation in the role are limited, this relationship does not hold true (Serpe, 1987). In other words, even if an individual is more committed to a specific role identity, an identity role with limited opportunity to participate may be chosen preferentially when opportunities to participate in it arise. For instance, if an individual is less committed to coursework than to athletics, the coursework identity may be higher in the individual's salience hierarchy than the athletic identity if opportunities for participation in coursework are limited in ways that require its prioritization over other identities.

In terms of the knitting problem, the patient I met clearly had been committed to several identities prior to the cancer diagnosis – including with her family, friends, church, and community. Importantly, the patient had developed their performance in these social roles to depend on the activity of knitting. Because of the patient's cancer journey, their ability to participate in their previously established roles was lost, being overshadowed by their new identity as a cancer patient. This suggests that the social structure that their pre-diagnosis social identities developed in was highly restrictive, as there were limited ways that the individual could participate in their social roles (Serpe, 1987). Similarly, the role opportunities as a patient were also restrictive. This is likely due to the fact that at the time of treatment decision making, the perception was that receiving the recommended chemotherapy (Andre et al., 2004), with its long-term toxicities (Kang et al., 2021), was the only option available to the patient for participating in the patient role. Therefore, the knitting problem can be seen as one that is influenced both by the social structures which an individual exists in as well as the social structure of the cancer care system itself. In particular, it is a problem that occurs when an individual's identity is principally maintained through performance in a few specific social roles that are ultimately lost or severely compromised due to the demands of receiving cancer care.

To summarize the concepts presented so far, identity theory adds to the understanding of the knitting problem and how to solve it in several important ways. First, it helps to quantify the harm that was done to the patient as a result of chemotherapy toxicity, as the patient's entire identity structure (Burke & Stets, 2009), including multiple relationship roles, collapsed. When considered from the perspective of the Coan ethos for the practice of medicine (Toombs, 2001), this represents significant harm to the patient, as their ability to function in their social world was negatively impacted. Second, combining identity theory with Freire's concept of dehumanization

(Freire & Ramos, 1970/2014), supports that being able to participate effectively in social roles through planned action is an important part of being human. When the patient lost their ability to knit, they experienced dehumanization as they lost their ability to take action and participate in their social context (Freire & Ramos, 1970/2014). Third, when identity, as defined by identity theory (Burke & Stets, 2009) is considered alongside the ethical framework provided by Beauchamp and Childress (2009/1985) it can be concluded that interventions to address the knitting problem should primarily be focused on reducing harm to individuals social roles in ways that preserve a just allocation of resources.

Concept #5: The Important Link Between Identity, Role Performance, and Emotion

The concepts of closed and open social structure, identity commitment, and identity salience are helpful for understanding how the identity and wellbeing of the patient who introduced me to the knitting problem was impacted by their cancer journey. Additionally, identity theory also is useful for understanding some of the emotions (Burke & Stets, 2009) the patient expressed in clinic because it links emotional states to role performance (Burke & Stets, 2009; Schwartz et al., 2011). This is important as emotional states may be helpful in identifying when cancer care is interfering with identity, which is important for guiding clinical practice and intervention development.

According to identity theory, the emotions people feel are a response to whether or not they have met the standard for performance in an identity role (Burke & Stets, 2009; Schwartz et al., 2011). When an individual fails to meet a standard, whether it is because they recognize that they have not met one they have set for themselves or they receive signals from others that they have not performed well, they are likely to experience negative emotions (i.e., feel bad). On the other hand, when role identity standards are met or exceeded, the individual is likely to experience

positive emotions (i.e., feel good). Importantly, the relationship between emotions and role performance creates a feedback loop, with the positive emotions from good performance resulting in verification of the identity role (Burke & Stets, 2009). If verification occurs the individual is likely to continue to put effort into maintaining the identity role – but may begin to abandon the role, seeking other roles to replace it, if the role is not verified (Burke & Stets, 2009; Stets, 2005).

To illustrate, if a parent expresses disappointment in a child for uncharacteristically poor performance on a high-school math test, the child's behaviour and their identity may change in a number of ways (Burke & Stets, 2009). First, the child may put more effort into their identity as a math student in an effort to meet the identity standard they had previously set for themselves, which may align with their parent's expectations. Overtime, this may result in improved performance on future math tests, and the parent affirming the child's identity status as a good math student, resulting in the student feeling pride (or the primary emotion of happiness resulting from mastery). On the other hand, the child may re-evaluate their identity roles. They may reconsider their role in the child/parent dyad and what feedback from their parent about their role performance as a student means (Burke & Stets, 2009; Stets, 2005). For instance, if they had been struggling with a particular topic, or had been facing some personal challenges that had been distractions from studying, they may begin to reject their parent's evaluation of their performance as unfair or even feel anger toward their parent for an unfair evaluation. These negative emotions are likely to impact the value that the child puts on their identity role as part of the parent/child dyad, possibly leading to the relationship they have with their parent becoming a lower priority over time. Alternatively, if the student has been struggling, or continues to struggle, to achieve good grades in the class, they may begin to put less energy in to maintaining their identity as a

math student, instead focusing on other identity roles which they are able to perform better in – which may or may not be related to academics.

The link between emotion and identity verification was explored in one study that simulated receiving feedback on role performance (Burke & Stets, 2009). Paid student volunteers (n=282) from a university class performed three simple clerical tasks. Each participant received initial feedback on their performance indicating that they had completed the task at an average level (Stets, 2005). They were then evaluated by an individual acting as a manager, who evaluated them as either performing the three tasks above, below, or at an average level. The participants were then asked to rate, on a scale of 0 to 10, the intensity of specific negative emotions (i.e., anger, fear, sadness, and disgust) and positive emotions (i.e., satisfaction, and gratefulness) in response to the evaluation. Compared to participants that received feedback from the manager that they had performed average, those that received feedback that they had performed above average reported more positive emotions (Mean emotion score for above average feedback = 0.48, SD = 0.50; Mean emotion score for average feedback = 0.16, SD = 0.62; $p = .05$). Conversely, feedback that performance was below average was associated with more negative emotion (Mean emotion score for below average feedback = -0.08, SD = 0.76; Mean emotion score for average feedback = 0.16, SD = 0.62; $p = .05$). What is important about this study (Stets, 2005) is that each participant was initially given feedback that their performance was average, thereby establishing an identity standard for the performance in their worker identity. The study results showed that when the participants received the feedback from the manager, after initially being told they had performed average, they had predictable emotional responses. These results support that emotion can be a useful gauge for understanding whether individuals perceive that they are succeeding in their identity roles.

Another study explored how verification of role performance over time impacts identity salience and commitment in incarcerated individuals (Asencio & Burke, 2011). Inmates at a medium security prison in the United States (US) who were participating in a six-month substance treatment program were invited to volunteer for the study. The study involved completing a survey at three different time points which were eight weeks apart. The survey was confidential, with responses being accessible only to the research team. The survey explored how the inmates viewed themselves and believed others viewed them as a drug user, criminal, and worker. Regarding how the inmates viewed themselves, they were asked to rate themselves using 5-point Likert scales in terms of the role. For instance, for the role of drug user, they ranked themselves on a scale from 1 (being a non-drug user) to 5 (being a drug user). For how they were viewed by others, the inmates were asked to rank how they believed they were perceived by significant others (including spouses or important family/friends), peers (other inmates), and guards at the jail. The rating system involved the same 5-point Likert scales as they used for the self-ratings. A total of 124 inmates participated in the study (Asencio & Burke, 2011). Of the three identities, the worker identity had the highest scores in terms of how the participants viewed themselves as participating in that role. Unlike the scores for the criminal and drug user identity, which demonstrated a statistically significant linear trend of decreasing in score (both with $p \leq .01$), the score for the worker role did not demonstrate a statistically significant trend in any direction over the course of the survey.

These findings fit with what is suggested by identity theory in two ways (Burke & Stets, 2009). First, the inmates in the study (Asencio & Burke, 2011) were able to frequently verify their worker identity role as they regularly conducted chores and other work in the prison. However, as they were incarcerated and enrolled in a substance abuse rehabilitation program, they were not able to participate in criminal activity or drug use. Therefore, as verification of these roles was not

possible, the participants identified less strongly with these roles over time. Second, the participants' perceptions of what others thought of them also impacted how they viewed themselves in the three identities (Burke & Stets, 2009). For all three identities, a statistically significant association (criminal: $p \leq .01$, drug user: $p \leq .01$, worker: $p \leq .05$) was found between what the inmates believed their peers thought of them and their self-appraisals.

The findings from these studies are helpful for better understanding the interaction with the patient that first brought me to the knitting problem. First, the patient both described and expressed a number of negative emotions, including feeling depressed and angry (Burke & Stets, 2009; Stets, 2005). Through the lens of identity theory, these emotions reflect the patient's inability to meet the identity standards they had set for themselves in their social roles as a friend, parent, grandparent, and leader of the church knitting group. Second, as a result of the loss of the patient's ability to verify a number of the identity roles maintained through knitting, their relationship with these roles changed, as some were abandoned, like leadership of the knitting group, while others were likely re-defined over time (Asencio & Burke, 2011; Schwartz et al., 2011).

The link between role performance and emotion (Asencio & Burke, 2011; Stets, 2005) is an important one that builds on the other four concepts previously discussed (Burke & Stets, 2009; Freire & Ramos, 1970/2014; Toombs, 2001). This establishes emotion as both an interpretable and logical response to how individuals are performing in the social roles that make up their identity. Applying the concepts of non-maleficence and beneficence to identity and the social roles an individual has, as well as their ability to reflect on and take action to transform their reality (Freire & Ramos, 1970/2014), can be guided by the information that emotions provide making them very valuable for aligning care delivery with the Coan ethos (Toombs, 2001). On an administrative and health services delivery level, data about the emotional states of the patient population as they

proceed through care is likely to be useful for informing how healthcare delivery is interfering with the social roles of the individuals being served – informing service change and intervention development. On a clinical level, expressed negative emotions can be seen as an important signal that a patient, or care partner, may be experiencing non-verification of an important social role (Stets, 2005). Such instances may represent opportunities to improve the patient experience by exploring how the care plan is impacting social role performance, and how this can be remedied.

Identity and Cancer Care: The Cost of Trust

After my interaction with the patient that introduced me to the knitting problem, and the completion of my residency training in medical oncology, I went on to study how identity is impacted following a cancer diagnosis (Thiessen et al., 2018) as part of work leading to completion of a master's degree. Part of this work included a study to understand how a patient's pre-diagnosis identity changes following cancer diagnosis. The study involved semi-structured interviews with patients and their care partners (i.e., friends and family). For me, a key finding from this study was the identification and characterization of the concept of routine (Thiessen et al., 2018). As an individual's identity is made up of multiple social roles, multiple different kinds and types of activities, conducted in the unique context of the individual's world, are required. The concept of routine describes how these activities are organized temporally within the unique social and geographic context of the individual. For instance, some activities may occur regularly and frequently (e.g., dropping off the kids at school) and other occurring infrequently and at irregular intervals (e.g., calling a long-standing friend to exchange emotional support), with the unique order and geographic location of the activities being dependent on the individual's life context (Thiessen et al., 2018).

Data analysis identified that the participants' routines were disrupted due to three main factors: 1) alteration in communication with individuals in pre-diagnosis relationships, 2) changes in support needed from the individuals in previously established relationships, and 3) challenges coordinating being a healthcare recipient with existing social roles (Thiessen et al., 2018). Of these, the third is particularly relevant to the patient who introduced me to the knitting problem. For instance, one participant described being "left in the dark" (Thiessen et al., 2018, p. 2416), needing to use the internet to supplement the information received from cancer specialists, and receiving inadequate information to plan their life around receiving healthcare. Similarly, the patient who first introduced me to the knitting problem identified that the information they needed to make decisions regarding managing the long-lasting side-effect of receiving healthcare only came after the chemotherapy had begun.

In the context of identity (Burke & Stets, 2009), role performance (Asencio & Burke, 2011), and emotion (Stets, 2005), the impact of being inadequately informed regarding what to expect is not trivial. For instance, one participant in the study (Thiessen et al., 2018) described being unable to make plans with friends or family during the preceding months due to a need to travel to another city to attend physician' appointments and tests at short notice. The participant became tearful, banging their fists on the table, and described their ability to plan as "day to day" (Thiessen et al., 2018, p. 2416). This was not an isolated experience as other participants in the study also expressed negative emotions as they reflected on their experiences of attempting to participate in previously established identity roles while engaging with the healthcare system (Thiessen et al., 2018).

Another insight that this study provided was that the cancer care system is experienced by patients and their informal caregivers as a closed system. Like the study described earlier that

tracked the various identities of students in their first semester as freshman who had little opportunity to negotiate how they participate in the coursework (Serpe, 1987), the participants I interviewed (Thiessen et al., 2018) experienced few opportunities to negotiate their roles as patients around their other identity roles. Many described waiting by the phone to find out when they would see their oncologist for the first time, then having to chaotically rearrange their lives to attend the visit after receiving their appointment information only a few days before it was set to occur (Thiessen et al., 2018). To complicate this further, unlike the students in the previously discussed study that were presumably engaging in coursework voluntarily (Serpe, 1987), many participants expressed that participating in the patient role was not voluntary, as one participant stated "... if you want to get better, you have to [do what the doctors say]" (Thiessen et al., 2018, p 2416). Others described pressure from friends and family who endorsed the belief that medical treatment was necessary for cure.

This study added important depth to my understanding of the knitting problem for three reasons. First, it helped me understand that the knitting problem has less to do with peripheral neuropathy and more to do with interruption to how individuals maintain their routine. For the patient I met years ago, their routine was held together primarily through knitting, and without the ability to knit, their routine, and subsequently their identity, became unravelled. While knitting did not present itself as central to the identities of any of the participants in my master's work, it was clear that each maintained their own tapestry of social roles through a series of activities woven together in a style that was just as unique as that of the knitter I met in clinic (Thiessen et al., 2018).

Second, it provided a real-life glimpse outside of the ambulatory clinic of what happens to the lives of those living with cancer when they find themselves in situations where they must adjust their pre-existing identities around the demands of a restrictive social structure (Burke & Stets,

2009; Serpe, 1987). Because of the unique way that each participant maintained their identity, the manifestations of the impact of engaging with the healthcare system was not the same for any two of the study participants. But the common thread between the participants was that the cancer diagnosis had interrupted their routine (Thiessen et al., 2018), and many expressed negative emotions when reflecting on the interruptions that had occurred - supporting that their performance in their social roles had been negatively impacted (Burke & Stets, 2009; Stets, 2005).

Lastly this study helped me understand that the development and implementation of informational interventions focused on supporting individuals as they navigate the cancer journey is an important key to addressing the knitting problem. The participants expressed that they actively attempted to plan their routines around receiving healthcare but simply did not know what to expect and therefore could not plan (Thiessen et al., 2018). As a result, they experienced dehumanization both as a result of being unable to reflect and take action to transform their reality (Freire & Ramos, 1970/2014), as well as due to diminished role performance (Beauchamp & Childress, 2009/1985). It was clear to me at the conclusion of the study that if the participants had been able to access information to guide them in planning their lives around the receipt of care, both in the short and long term, their experiences would have been very different.

The Information Seeking Behaviour Of Those Living With Cancer

An important discovery for me was identifying that one of the ways that the routine of individuals living with cancer is interrupted is due to a lack of the information they need to help them plan their lives around the consequences of receiving care (Thiessen et al., 2018). As a next step, I began to explore how information could be provided to help address this informational need. As part of this exploration, I began to learn about human information seeking behaviour (Wilson, 2000).

The study of human information seeking behavior (HISB), which includes information needs, spans many disciplines, including library sciences, health sciences, education, and computer sciences (Wilson, 2000). Since its origins in the early 20th century with survey research exploring the socio-demographic makeup of library users in the US, the study of human information seeking behaviour has diverged into exploration of how information sources are used and how individuals use information sources to meet their needs (Wilson, 2000). Dr. Tom Wilson is an important scholar and scientist who has studied information behaviour over the course of his career (White, 2021). In a well cited narrative literature review exploring the state of human information behaviour research, Wilson (2000) defined several important concepts related to information seeking behaviour and information needs. According to Wilson (2000), information seeking behaviour involves the purposive seeking of information in response to an information need (Wilson, 2000) and describes individuals' interactions with information sources such as libraries, the internet, or healthcare professionals. Second, Wilson defines information needs as "a subjective experience that occurs only in the mind of the person in need and, consequently, is not directly accessible to an observer" (Wilson, 1997, p. 552). According to Wilson, information needs can only be identified through deduction based on observations of the individual or based on reports from the individual (Wilson, 1997). Wilson describes that information needs are linked to a person's goals and efforts to decrease the uncertainty about an outcome (Wilson, 2000, p. 50).

Wilson identifies that both information seeking behaviour and information needs are affected by a number of factors, including those unique to the individual, their social roles, as well as cultural, and environmental factors (Wilson, 1997). This is reflected in the cancer literature regarding both the information seeking behaviour and the information needs of patients. For instance, a survey of 731 cancer patients made up of both males and females explored information

seeking behaviour before and after cancer treatment (Eheman et al., 2009). Participants were asked to select the response option that best matched their information seeking behaviour. Response options of “I do not seek information” and “I get information that happens to pass my way” were categorized as passive behaviour; “I seek information mostly out of curiosity” and “I seek information to fill in the gaps in my understanding” were categorized as moderately active; and “I see information as a ‘second opinion’ to my healthcare team’s suggestion” were categorized as active behaviour. The survey identified that pre-treatment, 17.0% of patients reported an active information seeking style, 69.2% identified as moderately active, and 13.8% identified as being passive. Younger age, education level greater than high school, professional or managerial occupations, females, and men with genitourinary cancer, and married persons were more likely to be active information seekers. Post-treatment, the rate of passive information seeking increased and active seeking decreased in most groups, including those above 45 years of age, and in the most common cancers (e.g., breast, prostate, gastrointestinal, gynecological, and lung). These findings are consistent with other studies which have explored information seeking behaviour in the cancer population and have demonstrated that age (Czaja et al., 2003), gender (Fletcher et al., 2017), education level (Carlsson, 2000), culture (Kakai et al., 2003), and place (Matsuyama et al., 2013) in the cancer journey all impact information seeking behaviour.

In terms of information needs, one scoping review summarized what information needs of cancer patients have been studied from diagnosis to surveillance and end of life (Fletcher et al., 2017). The review included 104 studies and found a total of 1,709 unique information needs identified in the literature. These information needs could be divided into 17 categories including but not limited to diagnosis, treatment, end of life, and coping (Fletcher et al., 2017). This review is important because it identified both the extent of how information needs of cancer patients have

been described in the literature and highlighted the many information needs that an individual facing cancer may experience over the course of their journey.

Furthermore, information needs have been described as one of the most commonly unmet supportive care needs of individuals living with cancer (Wang et al., 2018). This has been observed in patients and informal caregivers, in both the curative and palliative contexts. As an example, a systematic review including 23 studies exploring the prevalence of unmet supportive care needs of advanced cancer patients identified that unmet informational needs had the highest prevalence (30–55%), followed by psychological (18-42%), and physical (17-48%) needs. Another systematic review identified that the prevalence of unmet information needs of informal caregivers in the advanced cancer setting has been reported to be 100% in some studies (Wang et al., 2018). In the curative intent setting the findings are similar. For instance, one study of supportive care needs in breast cancer patients being treated with curative intent (i.e., without evidence of metastatic disease) identified information needs as the most commonly unmet need (Park & Hwang, 2012) while another study reported that the prevalence of unmet information needs exceeded 50% (Halbach et al., 2016).

The scientific literature supports that unmet information needs have important consequences. Quantitative relationships have been identified between unmet information needs and increased levels of anxiety (Barr et al., 2020; Husson et al., 2011), depression (Husson et al., 2011), and decreased health related quality of life (Husson et al., 2011). Notably, one study explored the relationship between quality of life, symptoms and supportive care needs, including the need for information (Snyder et al., 2008). This cross-sectional study included 117 lung, breast, and prostate cancer patients. The participants completed validated questionnaires for quality of life, and supportive care needs. Responses were then analyzed to develop two different

multivariate regression models to predict function and supportive care needs, respectively. Importantly, the authors identified that unmet supportive care needs were better predictors of function than vice-versa, suggesting that addressed supportive care needs improve function as opposed to decreasing function increasing supportive care needs. They also identified that greater information needs were associated with decreased emotional function, increased fatigue, worse sleep, and poorer social function.

While this study was not explicitly framed within the context of identity theory (Burke & Stets, 2009) or in terms of exploring how unmet information needs disrupt the routine that individuals use to maintain their social roles (Thiessen et al., 2018), the findings do support the validity of these conceptual relationships. Social function and social role performance are clearly similar concepts, and, as has been already discussed, emotional state can be considered to be a function of an individual's performance in their social roles (Burke & Stets, 2009; Stets, 2005). Therefore, the fact that unmet information needs result in both decreased social function and negative emotional states (Snyder et al., 2008), supports the notion that information is key to helping individuals maintain their identity roles in the cancer context.

Overall, these studies demonstrate that information needs are a major issue for individuals living with cancer, and that these unmet needs have important consequences on wellbeing (Fletcher et al., 2017; Snyder et al., 2008). Additionally, they provide empirical support that the knitting problem is not limited to the patient I met in clinic many years ago as many people living with cancer experience unmet information needs with a resulting impact on their quality of life and social functioning. But while these findings highlight the importance and magnitude of addressing the information needs of those living with cancer, they do not offer solutions.

Towards Addressing The Information Needs Of Those Living With Cancer

Given both the high prevalence and important consequences of unmet information needs in the lives of those living with cancer, there is clearly a need for interventions that ensure high quality information is available to those that need it during the cancer journey. A previously conducted systematic review of information interventions in the cancer context is helpful for understanding the state of research regarding information interventions. In the review, a total of ten randomized controlled trials were included (McPherson et al., 2001) that tested informational interventions involving cancer patients, and/or their informal caregivers. Studies reporting on psycho-educational interventions were excluded. The interventions themselves generally included written content presented either through a physical paper package or digitally through a computer.

The interventions included in the review were categorized into those tailored for either shortly after diagnosis or for later in the cancer journey (McPherson et al., 2001). The majority (n = 7) of the interventions were designed for the early stages following diagnosis and focused on preparing individuals for their first clinic appointments, or to address early concerns regarding cancer and what to expect. These interventions were generally found to be helpful, increasing patients' knowledge, and decreasing confusion. A preference for receiving information early by mail was identified, and when information packages were received prior to their appointment, patients described being better prepared (McPherson et al., 2001).

The information interventions designed to help individuals later in the cancer journey were also identified as being effective (McPherson et al., 2001). In these interventions, psychological distress was found to be improved through the studied interventions. Informational interventions were also identified to be helpful for managing pain and for assisting care partners. Importantly though, this review reported on one study where audio-recordings of their physician visits were

provided to patients (McHugh et al., 1995). Compared to those with good prognosis who experienced improvement, those with poor prognosis experienced worsened psychological distress (McHugh et al., 1995). This study highlights the challenges of developing and implementing information interventions as an intervention that is helpful to one patient may be distressing to another (McHugh et al., 1995). In terms of methodological quality, the authors of the review identified issues with reporting, including whether or not the researchers were blinded to the study arm allocation of the participants, and a lack of reporting of the characteristics of the sample (McPherson et al., 2001). While the methodological issues identified by McPherson et al. (2001) are important, the lack of guiding theory grounded in the cancer experience is an additional issue that is important to address.

Interventions in the cancer context are complex healthcare interventions (Craig et al., 2008). Complex interventions are defined as those that a) have a number of interacting components, b) involve required behaviours on the part of those delivering or receiving the intervention that are numerous or difficult, c) involve a number of organizational levels, and d) involve a number of outcomes (Craig et al., 2008). Cancer related informational interventions easily fit this definition because a) they involve multiple components, including the information package itself, the method of delivery, and the individuals involved in either the delivery or use of the intervention; b) involve specific behaviours for effective delivery and use of the intervention on the part of healthcare providers and recipients; c) will involve the co-ordination of front-line caregivers as well as healthcare administrators; and d) have been shown to impact mental, physical, and social outcomes.

The Medical Research Council (Craig et al., 2008) provides best practice recommendations for developing and evaluating complex interventions. In the initial development stage identifying

and/or developing theory is considered to be an essential activity for developing complex interventions. Theory is a foundational part of the scientific process and is important for guiding the rationale for research, selecting appropriate research objectives, identifying what outcomes to measure and how to interpret findings, and identifying which methodological approach is most appropriate (Stewart & Klein, 2016).

Theory grounded in the cancer experience does not appear to be a guiding force for existing information interventions in the oncology context. In the systematic review of information interventions discussed earlier (McPherson et al., 2001), there is no mention of the underlying theory or frameworks that guided the development of the interventions or their evaluation. Upon closer review of the individual studies themselves, theory was mentioned in only two of the studies. These theories were stress and coping theory developed by Lazarus and Folkman (Derdiarian, 1989; Lazarus & Folkman, 1984) and cognitive dissonance theory (Festinger, 1962; Hack et al., 1999). Notably, neither of these theories were developed with the concerns of oncology patients in mind. Stress and coping theory appears to have been developed based on research and clinical traditions not specifically related to the cancer context (Lazarus, 1993; Lazarus & Folkman, 1984). Similarly, cognitive dissonance theory evolved from the psychologist Dr. Leon Festinger's work with members of a unidentified flying object (UFO) doomsday cult (Festinger, 1962; Tanabe & Hofmann, 2017). While fact that the theories that have been utilized to develop and study informational interventions for those living with cancer were not developed through engaging with those with lived cancer experience, or in the cancer context all, is troubling. It does not mean they are necessarily invalid in the oncology context. The challenge is that the theoretical concepts may not be describing what is really important for the individuals in the context, or may be inappropriately applied (Glaser & Strauss, 1967).

The information intervention study which employed cognitive dissonance theory (Hack et al., 1999) identified in the previously described systematic literature review (McPherson et al., 2001) is illustrative of this. Cognitive dissonance theory identifies that psychological tension is created when there is inconsistency between an individual's actions or beliefs and this tension results in change in the individual's actions or beliefs (Tanabe & Hofmann, 2017). The study involved 18 women with newly diagnosed breast cancer and 18 men with newly diagnosed prostate cancer being randomized to one of three groups, those: 1) not receiving an audiotaped copy of their oncology consultation, 2) receiving a copy without needing to request it, and 3) receiving a copy only if they requested it. Cognitive dissonance theory was used to guide the prediction that study participants who specifically requested an audiotope of their oncology consultation would, among other things, listen to it more than those that received it without requesting it. The application of the theory was that those that requested the audiotope would derive more benefit from it because they would develop the cognition that "I chose this audiotope because it has positive value for me" (Hack et al., 1999, p. 5).

The study (Hack et al., 1999) demonstrated a non-statistically significant increase in the number of times the participants listened to the tape in the group that requested the tape (2.5 times versus 1 time on average in the group that did not request the tape). Additionally, participants who requested the audiotope reported that they received a more thorough consultation than the participants that either did not receive the audiotope or received it without having to request it ($\eta^2 = 7.70$, $p < .05$). In light of the small sample size, these findings provide support for the authors' prediction based on cognitive dissonance theory – those that asked for the tape and received it used it more and felt that they had a more thorough consultation. But there are certainly other explanations for these findings other than the author's prediction that was informed by cognitive

dissonance theory. For example, as has been discussed earlier, information preferences and needs have been identified to exist across age, gender, and place in the cancer journey (Eheman et al., 2009). Very little information was reported about the makeup of the participants in study groups, only that that no more than four participants from one of the three centers in Canada recruiting for the study were randomized to any one group (Hack et al., 1999). It is very possible that more factors than simply having the opportunity to request the tape resulted in the findings that were reported. In other words, it is not that the application of the concepts described by cognitive dissonance theory is inappropriate, it is that there may be a lot more to the story than what these concepts can explain.

Importantly, while identity theory was not developed specifically in the cancer context (Burke & Stets, 2009) it does appear to provide a good fit for both explaining and predicting solutions to the knitting problem. First, as has been illustrated in previous sections, the findings of quantitative studies exploring associations between emotion (Stets, 2005), social functioning (Asencio & Burke, 2011), and information needs (Snyder et al., 2008) support that information is an essential part of supporting identity. Second, the findings from the previous study in my master's work (Thiessen et al., 2018) support the fit of identity theory on a conceptual level through exploration of the cancer experience with patients using classic grounded theory. However, while identity theory provides a conceptual backdrop, important theoretical questions specific to designing interventions to deliver information that supports the identity of those living with cancer remain, some of which will be addressed in the manuscripts presented in the following chapters.

Thesis Objectives and Chapter Outline

Addressing the information needs of those living with cancer is likely a key to solving the knitting problem. While the informational needs of those living with cancer and the impact of

unmet information needs have been characterized in the literature (Rutten et al., 2005; Snyder et al., 2008), given the high prevalence of unmet needs, there is clearly more work to be done. In particular, the five concepts previously discussed raise important questions that have been useful for guiding the research that is presented in the following chapters of this thesis.

The understanding that contemporary healthcare delivery reflects the Cnidian ethos (Toombs, 2001), with resulting dehumanizing (Freire & Ramos, 1970/2014) practices and processes, raises an important question about how information needs are conceptualized in such a system. Specifically, it is important to explore whether the informational topics that are considered worth prioritizing in cancer care delivery are those identified as important by, and in some way in service of, healthcare professionals versus those with lived cancer experience. This is important because while there may be overlap between what these two groups believe to be important information needs to address, there is arguably a potential for bias in terms of prioritizing the study of informational topics that focus on biomedical interventions. In Chapters 2 and 3, this question will be explored through a scoping review characterizing existing information needs assessment tools that have been developed for use in the cancer context, including how their development has been informed by those with lived cancer experience. The results of this study are important for guiding appropriate selection of information needs assessment tools and informing whether additional tools need to be developed for guiding clinical practice and research aimed at better addressing information needs.

After examining existing information needs assessment tools, the thesis shifts to developing theory to guide informational interventions. Chapter 4 introduces theory as being important for guiding work to address the information needs of those living with cancer. It outlines important gaps in the theoretical literature regarding information needs and why grounded theory

methodology is useful for filling these gaps. Additionally, it addresses why classic grounded theory, a method for generating theory grounded in empiric data, was chosen to guide the studies presented in Chapter 5 and 6.

Chapter 5 presents a grounded theory study conducted to understand what makes information useful for those living with cancer in terms of supporting identity. This study was conducted, in part, as follow-up to the work performed during my masters to better understand what elements make information most helpful to those living with cancer. Importantly, during this study (Chapter 5), the internet was repeatedly identified as a key resource by the participants. However, exploring what make internet content useful beyond that the internet was accessible around the clock to the participants was outside of the objectives of the study. Therefore, the study presented in Chapter 6 represents a separate and subsequent phase of the study presented in Chapter 5, pragmatically conducted to more closely understand why and how individuals use online information to navigate the cancer journey.

Chapter 7 concludes the thesis by providing a summary of the findings presented in Chapter 3, 5, and 6. It is divided into two sections, first the findings of the manuscripts included in this thesis are discussed in terms of how they inform future work to address the information needs of those living with cancer. Then, the chapter concludes with a reflection on how the work presented in this thesis evolved my understanding of what may have been helpful to the patient I met many years ago that first introduced me to the knitting problem and what thread to pull on next in the ongoing search for a solution.

Chapter 2: What Tools Do We Have For Assessing Information Needs?

Manuscript Title: Examining the development of information needs assessment questionnaires in oncology: A scoping review protocol

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Abstract

Background: Information needs are one of the most prevalent unmet supportive care needs of those living with cancer, including patients and their informal caregivers. Understanding how existing questionnaires for evaluating information needs have been developed is important for guiding appropriate use and informing future research. A literature review examining how information needs assessment questionnaires for use in the cancer context have been developed, with a specific focus on how questionnaire items have been identified, does not exist.

Objectives: This scoping review will examine how questionnaires for assessing the information needs of those living with cancer have been developed with special focus on how patients, informal caregivers, and healthcare professionals have been involved in the selection and identification of questionnaire items.

Methods: This review will include published studies describing the development and validation of information needs assessment questionnaires for use in the oncology context. Medline (Ovid), Embase (OVID), CINAHL, SCOPUS, Web of Science, the Cochrane Database of Systematic Reviews, and PsycInfo will be searched. Articles published at any point, up to the date of the search, will be eligible for inclusion. One person will screen titles and abstracts, two people will screen and extract data from full-text articles.

Results: Results are expected to be available early 2023. Summary tables and a narrative summary will be used to describe results.

Conclusions: This scoping review will assist in identifying appropriate information needs assessment tools to incorporate into clinical and research contexts in oncology. It will also identify if additional information needs assessment tools are needed.

Keywords: information needs; cancer; measure; patient-oriented research; psychometric

Introduction

Information needs are one of the most commonly unmet supportive care needs of patients and informal caregivers (i.e., friends and family who provide unpaid support to patients) (Cuthbert et al., 2020). Information plays an important role in both emotional and problem-based coping (Timmins, 2006). When faced with a health problem, such as a new diagnosis of cancer, individuals seek information to help them adjust and understand what actions they can take to improve their situation - both in the short and long term. When information needs are addressed, patients are more likely to be active participants in decision making (Gaston & Mitchell, 2005), have better health related quality of life, and lower rates of anxiety and depression (Fong, 2021; Husson et al., 2011).

Information needs of cancer patients and their informal caregivers have been assessed in multiple studies using validated questionnaires (Fletcher et al., 2017; Rutten et al., 2005). Validated questionnaires provide researchers with tools that have been rigorously developed (Boynton & Greenhalgh, 2004) and that produce data that can be compared between populations and across time. However, when assessing information needs using a validated questionnaire, it is important to understand how the questionnaire was developed and its intended use. Inappropriate selection of questionnaires can lead to erroneous conclusions and recommendations (Boynton & Greenhalgh, 2004).

One important consideration when selecting a questionnaire is how the questionnaire items were identified. Regarding information needs, at least on a theoretical level, an important distinction is between normative and expressed information needs (Freire & Ramos, 1970/2014). The word “normative” (Timmins, 2006, p. 378) has been used to describe the information needs

identified by healthcare professionals as important for healthcare recipients to know. In contrast, the term “expressed” (Timmins, 2006, p. 378) needs refers to the information needs that are identified as important by healthcare recipients, such as cancer patients and informal caregivers. While there is likely overlap between normative and expressed needs, it is hypothesized here that key differences are also likely to exist both in the content of these different types of information needs and the consequences of whether each type of information need is, or is not, met.

Normative information needs may, at least to some degree, be influenced by the pressures that healthcare professionals face in their respective clinical, research, and administrative roles. On the other hand, expressed information needs may be more likely to reflect the day-to-day challenges that those living with cancer face, as they continue to pursue their pre-diagnosis value-based goals (Freire & Ramos, 1970/2014; Thiessen et al., 2018; Thiessen et al., 2020) while, at the same time, navigating a cancer diagnosis, survivorship, and a healthcare system with its own goals and values. The crux of the distinction is that, at least theoretically (Freire & Ramos, 1970/2014), an educational intervention designed to address normative information needs may facilitate a patient fitting well within the healthcare system, while targeting expressed needs may facilitate healthcare fitting better with the patient’s life and values. If this is true, when selecting or interpreting the results from a questionnaire designed to assess information needs, it is important to have a clear understanding of whether the questionnaire is assessing normative or expressed information needs. This likely requires an understanding of the intended use of the questionnaire, the steps involved in its development, how it was validated, and the processes involved in identifying the questionnaire items – including how healthcare recipients, informal caregivers, and healthcare professionals were involved in questionnaire item generation and selection.

A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews, *JBI Evidence Synthesis*, and *PROSPERO* was conducted to identify previous systematically conducted literature reviews exploring how information needs assessment tools in oncology were developed. This search identified systematic reviews of information needs in the cancer population that included studies utilizing validated information needs assessment tools to describe the information needs of cancer patients (Fletcher et al., 2017; Rutten et al., 2005). Additionally, one review by Christalle and colleagues (Christalle et al., 2019) was identified that systematically reviewed information needs assessment tools across the healthcare spectrum, including in the cancer context. However, similar to other reviews of health needs assessment tools (Pian et al., 2020; Tian et al., 2019), this review focused on the methodological quality and psychometric properties of the tools. A review specifically exploring how questionnaire items have been identified, selected, and who was involved in this process, could not be identified. Therefore, a review specific to the cancer context characterizing how information needs assessment questionnaires have been developed, their intended use, and whether the types of information needs being assessed are likely normative, expressed or both, is needed. The preliminary review performed as part of the development of this protocol supports that there are adequate numbers of information needs assessment questionnaires used in contemporary cancer research to provide data for this review as evidenced by the 11 questionnaires identified in the review by Christalle and colleagues (Christalle et al., 2019).

This review will utilize a scoping review approach. A scoping review is the most appropriate method for examining how information needs assessment tools in the oncology context have been developed. Scoping reviews are a rigorous approach to knowledge synthesis that are also flexible and can be used to address a number of different types of objectives, including to map the literature and describe how research has been conducted (Munn et al., 2018; Peters et al., 2020).

This contrasts with systematic reviews which are best suited for research questions related to clinical practice where a comprehensive and unbiased summary of the literature is required (Aromataris & Pearson, 2014; Munn et al., 2018; Tricco et al., 2016), such as when results from randomized controlled trials are being compared to determine best practices.

The objective of this scoping review is to examine how existing tools for assessing information needs of cancer patients and their friends and family have been developed, including how they have incorporated expressed information needs. This will be achieved by systematically reviewing the literature to comprehensively identify information needs assessment tools developed for the cancer context and then examining how they have been developed and validated. The rationale for development of each questionnaire, as well as the processes for identifying, finalizing, and validating the questionnaire will be described. Regarding expressed information needs, the role patients and informal caregivers played in identifying potential questions, needs domains, and determining the final version of the assessment tool will be summarized.

Review questions

The objectives of this review will be achieved by systematically reviewing the literature to answer the following questions:

1. What questionnaires have been created and validated for evaluating the information needs of people living with cancer?
 - a. What is the stated purpose of each questionnaire?
 - b. What cancer contexts (i.e., cancer type, treatment intent, population) have these tools been developed for?

2. How were the questionnaires developed?
 - a. How were potential questionnaire items identified and finalized?
 - b. How were the questionnaires validated?
 - c. How were patients, healthcare professionals, and informal caregivers involved in the process of developing the questionnaires, including in the identification and selection of questionnaire items?
 - d. How were test and measurement guidelines (e.g., COSMIN Checklist (Mokkink et al., 2010)) used in the development and reporting of the measure?

Methods

The proposed scoping review will be conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews (Arksey & O'Malley, 2005; Peters et al., 2020). The one exception to this is that the screening of titles and abstracts will be conducted by a single author, as supported by Cochrane (*Cochrane Handbook for Systematic Reviews of Interventions*, 2008).

Eligibility criteria

Population

This scoping review is focused on characterizing the development of validated assessment tools, not characterizing differences in measured outcomes in certain populations. As such, the “Participants” aspect of the scoping review eligibility criteria is not applicable.

Concept

The scoping review will examine how information needs assessment tools have been developed, including the motivation for the development, the steps in the development, and the steps taken to include the expressed information needs of healthcare recipients.

Context

This scoping review will include the literature relevant to the cancer context, both in clinical and research settings. It will include published reports describing the development of tools designed for patients, and/or informal caregivers (i.e., friends and family). Literature specific to the paediatric population will be excluded. Non-English language studies will be excluded.

Types of sources

This scoping review will consider any report related to the development of information needs questionnaires for cancer patients published in peer-reviewed journals. Reports will include those that directly describe and report on their development including methods of identifying questionnaire items as well as testing of psychometric properties. Additionally, reports cited as rational for selection of certain items will be included. As a result, this review will include a wide range of reports including, but not limited to: protocols of both experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, before and after studies and interrupted time-series studies; analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies will be considered for inclusion; descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion;

experimental studies; reports on preliminary results and works in progress; qualitative studies; systematic reviews; and peer-reviewed essays and opinion papers.

Search strategy

The search strategy will aim to locate both published and unpublished studies, including protocols, related to the development of information needs assessment tools for the oncology context. An initial limited search of Medline (OVID) and CINAHL Plus with Full Text was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used, in collaboration with a health sciences librarian, to develop a full search strategy for Medline (Ovid), and CINAHL (Appendix A). The search strategy, including all identified keywords and index terms, will be adapted for each included database/information source. The databases to be searched include Medline (Ovid), Embase (OVID), CINAHL, SCOPUS, Web of Science, the Cochrane database of Systematic Reviews, and PsycInfo.

Studies published in English will be included. Non-English studies will not be included as the researchers are primarily interested in learning what tools are available for use in their respective English based clinical and research practices. Studies published since the beginning of the database will be included as there is no reason to exclude older studies.

As appropriate, authors of reports will be contacted to determine if missing or additional data is available in peer-reviewed publications. Grey literature, and non-peer reviewed reports, including unpublished studies or protocols, will be excluded from this review.

Inclusion and exclusion criteria are summarized in Table 1.

Table 1.*Inclusion and Exclusion Criteria for Search Strategy*

Inclusion criteria
<p>Reports indexed up to date when article searching begins (i.e., post completion of blind protocol peer review).</p> <p>Reports describing the development OR use of information needs assessment questionnaires specifically for adults living with cancer, including patients and/or informal caregivers.</p> <p>Reports related to any type of malignancy, including a single or multiple types.</p> <p>Reports related to any point in the cancer journey, from diagnosis to surveillance or palliation.</p> <p>Any geographic location.</p>
Exclusion criteria
<p>Non-peer reviewed literature.</p> <p>Non-English literature.</p> <p>Reports related to the development of multi-dimensional needs assessment tools (i.e., not focused on information needs).</p> <p>Reports related to tools designed specifically for the pediatric population, including for adult informal caregivers of pediatric cancer patients.</p> <p>Reports related to assessing information needs regarding cancer screening.</p>

Study/source of evidence selection

Following the initial database search, all identified citations will be collated and uploaded into Covidence (Covidence, VIC, Australia) and duplicates removed. Titles and abstracts will then be screened by one independent reviewer for assessment against the inclusion criteria for the review (*Cochrane Handbook for Systematic Reviews of Interventions*, 2008). The full text from the screened articles will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, or with an additional reviewer(s). The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic

Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Tricco et al., 2018).

Data will be extracted from papers identified through the search strategy by two independent reviewers using a data extraction tool developed by the reviewers. The data extracted will include specific details about the participants, concept, context, study methods, and key findings relevant to the review questions.

A draft extraction form is provided in Appendix B. It was initially developed from the template provided by JBI for data extraction tools used in scoping reviews (Peters et al., 2020) and informed by the research questions. In particular, specific data extraction questions focused on identifying the level of involvement of patients/informal caregivers, compared to healthcare professionals, will assist in evaluating whether the questionnaire is focused on assessing expressed or normative information, a balance of both, or if it is simply not clear from available literature. Additionally, the COSMIN checklist sections related to general recommendations and content validity were used to inform the development of the data extraction tool (Mokkink et al., 2010) as they closely relate to the objectives of this study.

The draft data extraction tool will not be piloted prior to data extraction. However, the extraction tool is expected to be modified and revised during the process of extracting data in order to capture relevant data, including that which emerges as important during the course of data extraction. Modifications to the extraction tool will be detailed in the scoping review. Any disagreements that arise between the reviewers will be resolved through discussion, or via additional independent reviewers.

Of note, to ensure that the number of information needs assessment tools reviewed in this study is as comprehensive as possible, the titles and abstracts identified through the initial database search will also be reviewed to identify studies reporting on quantitative assessments of information needs using validated questionnaires. Screening for these articles will be accomplished by a single reviewer who will also review the full text of these studies, including their references lists, to identify additional reports potentially meeting the inclusion criteria of this scoping review. These articles will be combined with the other articles selected for full text review of meeting inclusion criteria and, from that point, will be treated equally with articles identified directly through the database search. The number of articles identified through this process will be clearly demarcated in the PRISMA-ScR flow diagram.

Results

Activities related to this scoping review began in December 2021 with the drafting and submission of this protocol for peer-review and publication. Results are expected to be available early 2023 and will be reported in accordance with the PRISMA-ScR reporting guidelines (Tricco et al., 2018). Extracted data will be presented in both narrative and table form. A summary table of the year of publication, country of the lead author, and cancer contexts (i.e., treatment intent, type of cancer, during active treatment or surveillance) for which the questionnaires were developed will be created. Additionally, two separate tables will be created summarizing the data collected related to the first and second research questions.

Discussion

Based on the preliminary search conducted as part of the development of this protocol, the resulting scoping review will be the first to systematically evaluate the development of information needs

assessment questionnaires developed for use in the oncology context. Importantly, it will characterize how the expressed needs of those living with cancer have been incorporated into existing information needs assessment tools. As such, this review has the potential to impact both clinical and research practices in the oncology field, including but not limited to, the development of more rigorous patient reported measures in oncology settings.

In the clinical setting, this review will be helpful for guiding tool selection for capturing information needs in routine practice. Screening for psycho-social distress as part of routine oncology clinical practice is considered standard of care by many professional organizations, including the American Society of Clinical Oncology (Smith et al., 2018). Routinely, patient reported outcome measures (PROMs) are central to distress screening strategies. In some institutions, PROMs specifically assessing information needs are included (Cuthbert et al., 2019). By being the first systematically conducted review to characterize whether existing information needs assessment tools developed for the cancer context assess normative versus expressed information needs, this review will inform clinicians in identifying which information needs questionnaires to include as part of routine assessments. Additionally, it will assist clinicians in the correct interpretation of results, which may lead to better identification of information gaps and guiding the development of improved information provision practices.

From a research perspective, this review is expected to support researchers in identifying appropriate tools for capturing information needs related data and facilitating awareness of the limitations of selected tools (Boynton & Greenhalgh, 2004). It will also identify where there is a need for the development of additional measures and provide insight into best practices for the development of information needs measures in the future. Lastly, by identifying how the expressed information needs (Timmins, 2006) of those experiencing cancer have been included in existing

measures, this review will provide an important lens for interpreting the existing published literature characterizing the information needs of those living with cancer.

Limitations

Despite identifying what appears to be an adequate body of literature to support this review, it is not clear whether sufficient details will be able to be identified in the existing peer-reviewed literature to adequately address the research questions. While the rate of publication of protocols is increasing (van Rosmalen et al., 2017), research results, including descriptions of the research methods employed, commonly go unpublished (Scherer et al., 2015). It is simply not known whether a sufficient level of detail about the procedures used to develop the instruments to answer the research questions will be able to be identified in the peer-reviewed literature. While identifying the relative presence or absence of the details relevant to the research questions in the literature in this review is not an explicit objective of this review, the discovery of insufficient data to address specific research questions will certainly be important for guiding future work such as in-depth qualitative explorations of how existing questionnaires have been developed incorporating semi-structured interviews with the lead developers.

Conclusions

Information needs are one of the most commonly unmet supportive care needs of those living with cancer (Cuthbert et al., 2020). Unmet information needs negatively impact the cancer experience (Fong, 2021; Gaston & Mitchell, 2005; Husson et al., 2011). Understanding how the questionnaires have been developed that are used to assess the information needs of those living with cancer is key to appropriate questionnaire selection and interpretation of reported results (Boynton & Greenhalgh, 2004). Systematic literature reviews exist exploring various aspects of information needs questionnaires (Pian et al., 2020; Tian et al., 2019) and have included tools

specific to oncology (Christalle et al., 2019). However, a review is needed to specifically explore how information needs assessment questionnaires in the oncology context have been developed. This review will address this gap in the literature and, in doing so, assist future work to better support those living with cancer.

Acknowledgements

The authors would like to acknowledge Dr. Alix Hayden, Nursing Librarian, University of Calgary, for assisting with the development of the methods and search strategy for this protocol.

This review will contribute towards the completion of a doctoral degree from the Faculty of Nursing, University of Calgary for the first author (MT).

Funding

This project was supported in part by scholarship funding provided by the Faculty of Nursing and the Department of Graduate Studies at the University of Calgary as well as an unrestricted research grant from Knight Therapeutics awarded to the lead author.

Conflicts of interest

None declared.

Chapter 3: A Critical Scoping Review

Manuscript Title: Examining The Development of Information Needs Assessment Tools for Use in The Cancer Context: A Scoping and Critical Review

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Abstract

Background: Information needs are one of the most common unmet supportive care needs of those living with cancer. Little is known about how existing information needs questionnaires have been developed and the role those living with cancer played in their development. This review aimed to characterize the intended use and development of existing information needs assessment tools in the cancer context.

Methods: A systematic scoping review was conducted using a peer-reviewed protocol informed by recommendations from the Joanna Briggs Institute and the PRISMA-ScR reporting guidelines.

Results: Twenty-one information needs assessment tools were included. Most tools were either breast cancer specific ($n = 8$) or primary tumor nonspecific ($n = 8$). Patients and informal carers participated in initial identification of questionnaire items in the minority of cases ($n = 6$) and were more commonly involved in reviewing the final questionnaire prior to use or formal psychometric testing ($n = 9$). Most questionnaires were not assessed for validity or reliability using rigorous quantitative psychometric testing.

Conclusion: Information needs assessment tools suitable for guiding intervention development, such as those tailored to specific aspects of the cancer journey, are needed. The development of these tools should involve those who have experienced cancer at all development stages, including when initially identifying items.

Keywords: neoplasms; information; information needs; instrument validation; patient education; psychometrics; structured questionnaires; supportive care

Introduction

Information can be defined as the awareness an individual has of the patterns of reality, including the structures placed upon reality by humans (Dervin, 1976; Freimuth et al., 1989; Rogers & Kincaid, 1981). People seek information to reduce the uncertainty they have about the nature of their reality, including how to meet their goals both in the short and long term (Wilson, 1997). Importantly, uncertainty is an important source of stress, as stress occurs when individuals perceive that the challenges they are facing may exceed the resources they have (Lazarus, 1993; Lazarus & Folkman, 1984). In situations of uncertainty, stress may occur for a few reasons, including because an individual perceives that they do not have the resources to manage the challenge they are facing, or they find themselves in a situation where they have not planned effectively and have under assessed the resources needed to manage the challenge. The cancer journey is one where individuals face many new and unfamiliar challenges, often simultaneously (Thiessen, Harris, et al., 2022), making information a key supportive care need for those living with cancer (Rutten et al., 2005; Thiessen et al., 2020).

Healthcare providers play an important role in the provision of information for both patients and their care partners. Healthcare providers are consistently identified in survey research as one of, if not the most, important informational resources for cancer patients and their informal caregivers (Chua et al., 2020; Chua et al., 2018). The information that comes from healthcare providers is generally described as high-quality (Thiessen et al., 2020), in that it is generally considered to be both credible and applicable for the healthcare recipients receiving it. However, credibility and applicability alone do not necessarily guarantee the information that healthcare providers share will be useful, as accessibility and how the information is framed, in terms of

providing hope and empowerment, are also important features of high-quality information (Thiessen et al., 2020).

Critical education theory explores how power and politics in educational settings impacts the wellbeing of individuals and societies (Mellor, 2013) and provides a valuable perspective for understanding the impact of unmet information needs on the lives of those living with cancer. In his work, Paulo Freire, who is considered a foundational figure in the early evolution of critical education theory, explored how the education system in Brazil reinforced classism and propagated poverty for Brazil's poorest citizens (Elias, 1975). Freire described that the traditional Brazilian education system viewed students as empty vessels, and it was the educators' job to deposit the knowledge into the pupils that would ultimately lead to their value in society and as human beings (Freire & Ramos, 1970/2014). This is the banking concept of education – where educators, and the system they operate in, determine what is important for the learners to know, disregarding the challenges the learners are trying to overcome in their own lives and communities. As part of his work to teach literacy, Freire developed the problem-based education approach. This approach involved first engaging with communities to understand the issues that were important to them, and then developing a literacy curriculum that encouraged dialogue around these issues (Freire & Ramos, 1970/2014). Notably, the results that Freire achieved were impressive, with some reports identifying that in one community his methods resulted in 300 adults learning to read and write in 45 days (Elias, 1975).

Freire's work raises important questions about what is known about the information needs of those living with cancer and whether what is considered to be important by healthcare professionals reflects the actual information needs of those living with cancer (Elias, 1975). This is not a small issue given the reported prevalence of unmet information needs, cited between 50%

- 100% for patients and informal caregivers, in both the curative and non-curative contexts (Christophe et al., 2022; Fletcher et al., 2017; Halbach et al., 2016; Matsuyama et al., 2013; Moghaddam et al., 2016; Park & Hwang, 2012; Puts et al., 2012; Rutten et al., 2005; Wang et al., 2018). These high rates of unmet needs highlight an urgency for tools that can accurately identify information needs and guide the development and implementation of effective and sustainable evidence-based interventions for delivering information (Craig et al., 2013). However, little is known about the tools that exist for assessing information needs in the cancer context. While one systematic review explored information needs assessment tools, this review was not specific to the cancer context, and did not explore the role of patients and informal caregivers in the tool development process (Christalle et al., 2019).

To characterize the tools that are available for assessing the information needs of those living with cancer, this literature review was undertaken. The scoping review methodology (Arksey & O'Malley, 2005; Peters et al., 2020) was utilized for this review, as it provides a rigorous approach to systematically reviewing the literature, as well as flexibility in terms of the types of research objectives that can be achieved (Munn et al., 2018). This is in contrast to systematic reviews (Aromataris & Pearson, 2014) which may be better suited for exploring the literature related to a specific clinical question, requiring systematic and unbiased review of clinical experimental reports. The review was guided by the objectives of a) identifying existing information needs assessment tools developed for the cancer context and b) summarizing how they were developed, including how patients and informal caregivers influenced the information needs being assessed. The specific research questions that informed data collection and analysis were:

1. What questionnaires have been created for evaluating the information needs of people living with cancer?

- a. What is the stated purpose of each questionnaire?
 - b. What cancer contexts (i.e., cancer type, treatment intent, and population) have these tools been developed for?
2. How were the questionnaires developed?
 - a. How were the questionnaire items initially identified and finalized?
 - b. How were patients, informal caregivers, and healthcare professionals involved in item identification, and finalizing the questionnaires?
 - c. How were the questionnaires validated?
 - d. What guided assessments of validity and reliability of the questionnaires?

Methods

Protocol and Registration

Prior to conducting this review, a protocol, including search strategy, was developed based on guidance for scoping reviews from the Joanna Briggs Institute (Peters et al., 2020), published in a peer-reviewed journal (Thiessen, Harris, et al., 2022), and the review was registered (PRR1-10.2196/35639). The Prisma-ScR reporting checklist is found in Appendix C.

Eligibility Criteria

To be included in this review, papers needed to report on the development or initial testing of questionnaires for assessing the information needs of adult cancer patients and/or their care partners – at any point after initial diagnosis. Only peer-reviewed articles published in English that were available in full-text were included. Articles reporting on the development or use of questionnaires in the pediatric population and in the cancer screening context were excluded. Articles reporting on multidimensional tools that assessed multiple supportive care need domains, in addition to information needs, were also excluded.

Information Sources

To identify as many relevant articles as possible, articles published at any date up to the date of search initiation (i.e., January 1, 2022) were included. Databases searched included MEDLINE (OVID), EMBASE (OVID), CINAHL, Scopus, Web of Science, the Cochrane Database of Systematic Reviews, and PsycInfo. The search strategy was developed by MT, with guidance from a health science librarian, based on a preliminary limited search of MEDLINE (OVID) and CINAHL Plus. The search strategy is published with the study protocol (Thiessen, Harris, et al., 2022).

Selection of Sources of Evidence

The database search results were exported to COVIDENCE (www.covidence.org) to facilitate article screening and data extraction. After duplicates were removed, initial title and abstract screening was performed by MT. Next, full-text versions of the articles were uploaded into COVIDENCE and screened independently by MT and DH. Data extraction was subsequently performed, again independently by MT and DH. All disagreements in terms of screening decisions and data extraction were resolved through discussion. Data extraction utilized the template previously generated as part of protocol development. As expected, the template evolved from the protocol version (Thiessen, Harris, et al., 2022) in the initial phases of data extraction to ensure the extracted data were suitable for answering the study questions. The data extraction sheet, in its final form is reported in Appendix D.

Synthesis of Results

Following completion of data extraction, the extracted data was exported into an Excel (Microsoft) spreadsheet to facilitate synthesis of results. Tables were then generated summarizing the data relevant for answering each of the guiding research questions.

Results

Forty-eight articles describing the development and use of 21 questionnaires were identified in the literature. The PRISMA flowchart summarizing the article selection process is presented in Figure 1. Articles were published between 1990 and 2020. Based on country of first author, Canadian teams ($n = 7$) were responsible for developing most of the instruments identified. Most tools were designed to assess the information needs of patients, not informal caregivers, and were developed to be applicable either in the breast cancer context or were non-specific to a certain cancer type. Table 2 summarizes the countries of article first authors reporting on the development of the questionnaires as well as the cancer contexts the questionnaires were developed for.

Figure 2.

PRISMA Flowchart of Study Selection Process

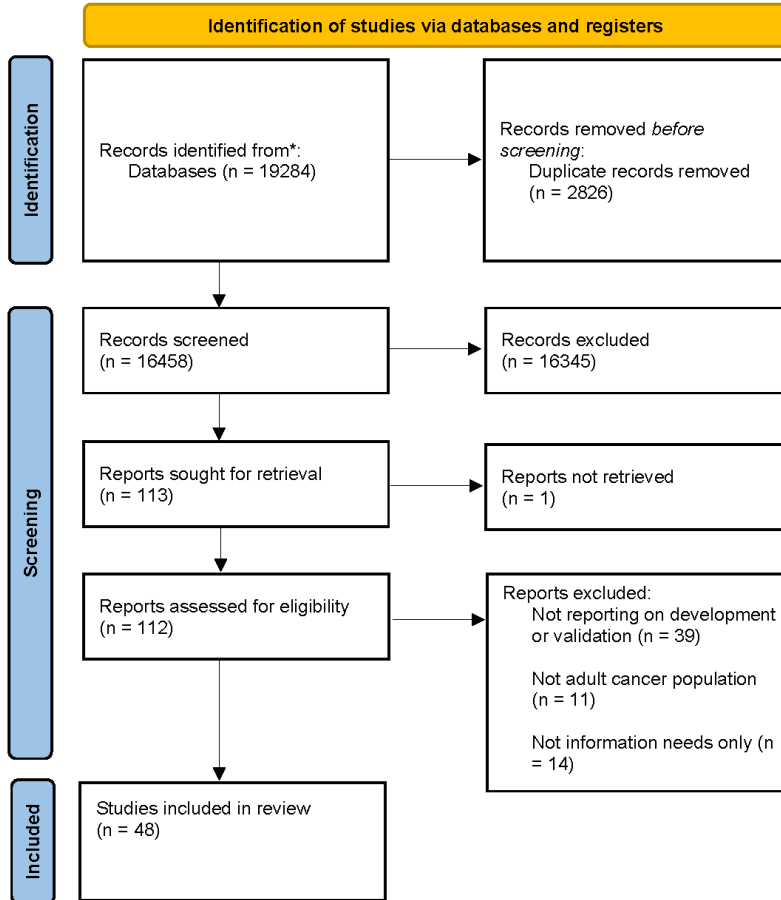


Table 2.*Summary of Identified Information Needs Questionnaires*

Unique Questionnaires Identified	n = 21
Countries of First Author	
Canada	7
Australia	3
United Kingdom	3
The Netherlands	2
Other	6
Questionnaire Designed For	
Patients	17
Informal Caregivers	2
Both	2
Cancer Types	
Breast	8
All	8
Prostate	2
Other	3
Treatment Intent	
Curative	9
Both	6
Non-Curative	1
Not Specified	5

What questionnaires have been created for evaluating the information needs of those living with cancer?

Each questionnaire, including the purpose and cancer context it was developed for, is listed in Table 3. Information needs questionnaires that were either not specific to a type of cancer (n = 8) or were focused on the breast cancer experience (n = 8) were the most common. In terms of non-type specific questionnaires, four were global assessments of information needs as opposed to focusing on any specific aspect of the cancer journey. Of these global assessments, one of these was designed specifically to identify the information priorities of patients to guide information sharing. The remaining tools were designed to assess information regarding specific challenges that patients face including related to brain metastases (Papadakos et al., 2019), chemotherapy (van Weert et al., 2009), radiotherapy (Halkett & Kristjanson, 2007; Zeguers et al., 2012), and online information needs (Maddock et al., 2011).

Table 3.*Summary of Information Needs Measures*

Name	Development Described In	Rationale	Stated Used			Cancer Type	Curative vs. Non-Curative	Patients' vs Informal Caregivers	Context of Development	Also Validated In	Adapted For
			Clinical	Research	Q.I.						
EORTC-INFO25	(Arraras et al., 2010; Arraras et al., 2007; Arraras et al., 2011; Arraras et al., 2004)	Assess level of information received by cancer patients. (Arraras et al., 2004)	-	x	x	NS	Both	Patients	Austria, Croatia, Germany, The Netherlands, Norway, Spain, Sweden, and UK (Arraras et al., 2007; Arraras et al., 2004).	Iran (Asadi-Lari et al., 2015), Poland (Puskulluoglu et al., 2014), Lebanon (Tabchi et al., 2016)	-
Bilodeau (NOS)	(Bilodeau & Degner, 1996; Degner et al., 1997)	Assess patients' information priorities. (Bilodeau & Degner, 1996)	x	x	-	NS	Both	Patients	Britain, Canada	-	-

Toronto Information Needs Questionnaire (TINQ-BC)	(Galloway et al., 1997; Harrison-Woermke & Graydon, 1993)	Measure informational needs during the first course of breast cancer treatment. (Galloway et al., 1997)	x	x	-	Breast	Both	Patients	Canada (Ontario)	South Korea (Yi et al., 2007), Rectal cancer (O'Connor et al., 2010)	General (non-breast cancer specific) population (Matsuyama et al., 2011), Rectal cancer (O'Connor et al., 2010)
D'Alimonte (NOS)	(D'Alimonte et al., 2011)	Assess information needs regarding salvage radiotherapy. (D'Alimonte et al., 2011)	x	-	-	Prostate	Curative	Patients	Canada (Ontario)	-	-
Head and Neck Information Needs Questionnaire (HaNiQ)	(Dall'Armi et al., 2013)	Assess the information needs of head and neck patients and carers. (Dall'Armi et al., 2013)	x	-	-	Head and Neck	Both	Both	Australia	-	-
Dorri, NOS	(Dorri et al., 2020)	Identify and investigate informational needs, delivery methods, and timing for receiving information about lymphedema. (Dorri et al., 2020)	-	-	-	Breast	Both	Patients	Iran	-	-

Feldman-Stewart (NOS)	(Feldman-Stewart et al., 2000)	Identify a core set of information needs regarding decision making for early, potentially curable, prostate cancer. (Feldman-Stewart et al., 2000)	-	x	-	Prostate	Curative	Patients	Canada (Ontario)	-	-
Radiotherapy Information Needs Scale (RINS)	(Halkett & Kristjanson, 2007)	Assess radiotherapy related information needs to guide patient education. (Halkett & Kristjanson, 2007)	-	-	-	Breast	Curative	Patients	Australia	-	-
Family Inventory of Needs - Husbands (FIN-H)	(Kilpatrick et al., 1998)	Extend FIN to assess information needs of husband of patients undergoing breast cancer treatment. (Kilpatrick et al., 1998)	-	-	-	Breast	Both	Informal Caregivers (Husbands)	Canada (Manitoba)	-	-
Sri Lankans' Informational Needs Assessment Questionnaire of Breast Cancer (SINAQ-BC)	(Kuruppu et al., 2017)	To guide the provision of relevant and accurate information in a socially-culturally appropriate manner. (Kuruppu et al., 2017)	-	-	-	Breast	NS	Patients	Sri Lanka	-	-
Maddock (NOS)	(Maddock et al., 2011)	To assess online information needs.	-	x	-	NS	NS	Both	Europe	-	-

		(Maddock et al., 2011)									
Cancer Patients Information Needs Scale (CaPIN)	(Neumann et al., 2011)	To explore and guide the provision of information for cancer patients. (Neumann et al., 2011)	-	x	-	NS	NS	Patients	Germany	-	-
Papadakos (NOS)	(Papadakos et al., 2019)	To guide the development of comprehensive informational pathways to meet the informational and supportive care needs of patients with brain metastases. (Papadakos et al., 2019)	-	x	-	Brain Metastases (any primary)	Non-Curative	Patients	Canada	-	-
Papadakos (NOS)	(Papadakos et al., 2012)	As part of needs assessment for launching gynecological survivorship program. (Papadakos et al., 2012)	-	-	x	Gynecological	Both	Patients	Canada	-	-
Rees (NOS)	(Rees & Bath, 2000)	To assess the information needs of daughters of female breast cancer	-	-	x	Breast	Curative	Informal Caregivers (Daughters)	United Kingdom (England)	-	-

		patients. (Rees & Bath, 2000)									
Hematology Information Needs Questionnaire (HINQ-62)	(Rood et al., 2018)	To aid in the comparison of patients' information needs across studies and in the assessment of particular patients' information needs. (Rood et al., 2018)	x	x	-	Hematological Malignancies	Both	Patients	The Netherlands	-	-
Information Satisfaction Questionnaire (ISQ)	(Thomas et al., 2004a)	To inform the optimization and standardization of information within a region. (Thomas et al., 2004a)	-	-	x	NS	Both	Patients	United Kingdom (England)	-	-
Quote-Chemo	(van Weert et al., 2009)	To assess patients communication needs and experiences regarding chemotherapy. (van Weert et al., 2009)	x	x	-	NS	Both	Patients	The Netherlands	-	-
Breast Cancer Information Test-Revised (BCIT-R)	(Ward & Griffin, 1990)	Test women's knowledge regarding surgical treatments options for early stage breast cancer. (Ward & Griffin, 1990)	x	-	-	Breast	Curative	Patients	United States	-	-

Zaid (NOS)	(Zaid et al., 2016)	To understand the information needs of women who were diagnosed with breast cancer and the sources of information they utilize to find information about the illness and possible treatment. (Zaid et al., 2016)	-	x	-	Breast	NS	Patients	Nigeria	-	-
Information Preference for Radiotherapy Scale (IPRP)	(Zeguers et al., 2012)	Assess patient information needs regarding radiotherapy. (Zeguers et al., 2012)	-	-	-	NS	NS	Patients	The Netherlands	-	-

NS - not stated.; Q.I. – quality improvement.

In terms of breast cancer related information questionnaires (n=8), four of these were designed to be used in the curative context, two in both the curative and non-curative context, and for the remaining two, it was not specified which context it should be used in. Two of the measures were designed to assess global information needs of patients while the remaining were designed to assess information needs regarding specific aspects of the breast cancer journey including those related to those arising during the first course of treatment (Galloway et al., 1997; Graydon et al., 1997), lymphedema (Dorri et al., 2020), radiotherapy (Halkett & Kristjanson, 2007), and surgical options for managing early breast cancer (Ward & Griffin, 1990). Notably, the only two questionnaires intended to assess the information needs of informal caregivers identified in this review were developed in the breast cancer context, with one being designed to assess the information needs of husbands whose wives were undergoing breast cancer surgery (Kilpatrick et al., 1998), and the other being to assess the information needs of daughters of breast cancer patients (Rees & Bath, 2000).

Two questionnaires were identified in this review that had been developed to assess the information needs of those living with prostate cancer. These were developed to assess information needs related to treatment decision making in the curative intent context, including regarding salvage radiotherapy post-prostatectomy. Questionnaires were also designed for gynecological (Papadakos et al., 2012), hematological (Graydon et al., 1997), and head and neck patients (Dall'Armi et al., 2013), with each providing a global assessments of patients' information needs. Most questionnaires were designed for use outside of the front-line care setting as either research tools (n=14) or as part of quality of improvement work (n=2). Notably, four instruments were developed with the intention of being able to be incorporated into clinical practice to guide tailoring information to meet the needs of the patient who completed the questionnaire.

How have information needs assessment questionnaires been developed and validated?

A summary of the steps taken for instrument development, as identified in the literature, from item identification to psychometric evaluation is found in Table 4. The development of the information needs assessment questionnaires, prior to psychometric testing, typically involved two steps. First, initial item selection occurred. This process was accomplished using some combination of six approaches including: 1) adapting items from previously developed questionnaires, 2) creating items based on a review of the literature, 3) obtaining direct input from healthcare professionals, and/or 4) patients and/or informal caregivers, and 5) conducting formal qualitative research with patients/informal caregivers, and/or 6) healthcare professionals. Adapting previously developed questionnaires was the most common method incorporated (n=9), followed by utilizing a literature review (n=7), with one questionnaire being developed using both approaches.

Table 4.*Item Identification and Evaluation of Questionnaires*

Questionnaire	Initial Item Identification						Final Item Selection		Psychometric Evaluation
	Established Literature	Previous Instruments	Input From HPs	Input From Pt/Cr	Qual. With Pt/Cr	Qual. With HPs	Feedback From HPs	Feedback From Pt/Cr	
EORTC-INFO25	x	-	x	x	-	-	x	x	+
Bilodeau (NOS)	x	-	-	-	-	-	x	x	+
TINQ-BC	x	-	x	-	-	-	-	-	+
D'Alimonte (NOS)	x	-	-	-	-	-	-	-	-
HaNiQ	-	x	-	-	-	-	-	-	+
Dorri (NOS)	-	x	-	-	-	-	x	-	C
Feldman-Stewart (NOS)	x	-	-	-	-	-	x	-	C
RINS	-	-	-	-	x	x	-	-	+
FIN-H	-	x	-	-	-	-	-	x	+
SINAQ-BC	x	-	-	-	-	-	x	x	+
Maddock (NOS)	-	-	-	-	-	-	-	x	C
CaPIN	-	x	-	-	x	-	-	-	+
Papadakos - Brain Mets (NOS)	-	x	-	-	-	-	x	x	C
Papadakos - Gyne (NOS)	-	x	-	-	-	-	x	x	C
Rees (NOS)	-	-	-	-	x	-	-	-	-
HINQ-62	-	x	-	-	-	-	x	x	+
ISQ	-	-	-	-	x	-	x	x	C
Quote-Chemo	x	x	-	-	x	-	-	-	+
BCIT-R	-	-	x	-	-	-	x	-	+
Zaid (NOS)	-	-	-	-	-	-	-	-	C
IPRP	-	x	-	-	-	-	-	-	+

Qual. = qualitative research; Pt/Cr = patients and/or carers; HPs = healthcare professionals; + = quantitative evaluation of psychometric properties; C = content validity assessment, including through review by HPs or Pt/Cr as part of item finalization.

In terms of generating questionnaire items using input from healthcare professionals, patients, and informal caregivers, two approaches were used. These included either obtaining direct feedback, including through panel discussions, on items that should be included or conducting formal qualitative research to identify information needs. None of the questionnaires were developed using both direct input and formal qualitative research. One questionnaire was developed based on direct input from both patients and healthcare professionals (Arraras et al., 2004) and two incorporated direct input from healthcare professionals. No questionnaires were identified to have initial item selection based on only input from patients or informal caregivers. Initial item selection using qualitative research methods, including interviews and focus groups, were described in the development of five questionnaires. This research involved both patients and healthcare providers for one questionnaire (Halkett et al., 2012). The development of three questionnaires involved only patients, and one included only informal caregivers (Rees & Bath, 2000). Notably, the development of one questionnaire involved patients completing an open ended writing assignment to identify information needs instead of participating in formal interviews or focus groups (Thomas et al., 2004b). Importantly, the initial item selection of questionnaire items was based on either direct input from patients/informal caregivers or qualitative research involving people with lived cancer experience in six of the 21 identified questionnaires.

After initial item selection, the second step generally involved developing a draft of the questionnaire and forwarding it to health professionals and/or patients/caregivers for additional feedback regarding clarity of items and the identification of any missing items. Patient and healthcare provider feedback was obtained at this stage in seven cases, healthcare professional feedback only was obtained in three cases, patient feedback only in one case, and informal carer feedback only in one case.

Most instruments had undergone some aspect of psychometric testing. It was identified that quantitative testing of psychometric properties such as content validity, internal consistency, and reliability, in addition to an assessment of content validity, had been performed on 12 of the questionnaires. Assessment of content validity, which, at a minimum, included evidence of review of the questionnaire by healthcare providers or those with lived cancer experience, was found for seven of the questionnaires. For two questionnaires, no evidence of validity testing was identified in the articles reviewed. Of the questionnaires identified, only the EORTC-INFO25 (Arraras et al., 2010; Arraras et al., 2004) was identified to have had psychometric property testing guided by established guidelines, as the testing was done in accordance with procedures previously established by the EORTC (Sprangers et al., 1993).

Discussion

This review identified and described the development of 21 information needs assessments questionnaires developed for cancer patients and informal caregivers. The majority of questionnaires were designed to be used in the research setting or quality improvement setting and intended to be applicable to all cancers or specific to the breast cancer patient population. Very few questionnaires were designed to assess needs at a specific point in the cancer journey (D'Alimonte et al., 2011; Feldman-Stewart et al., 2000; Galloway et al., 1997; Ward & Griffin, 1990) and only two were designed to specifically assess the information needs of informal carers (Kilpatrick et al., 1998; Rees & Bath, 2000). Importantly, input from patients and/or healthcare professionals was obtained in the minority of cases for initial questionnaire item identification, and in only 12 of the 21 questionnaires as part of finalizing questionnaire items. These findings suggest that existing information needs assessment questionnaires may be limited in their ability

to accurately assess what is most relevant to those living with cancer, as item selection has, in many cases, excluded patients and informal caregivers with lived experience.

This review identifies two important issues. First, very few questionnaires were identified that are suitable for assessing information needs regarding specific cancer challenges (Thiessen, Bouchal, et al., 2022). Of the 21 questionnaires, only seven focused on specific challenges arising during the cancer journey such as curative intent treatment decision making in prostate cancer (D'Alimonte et al., 2011; Feldman-Stewart et al., 2001) or lymphedema in the breast cancer context (Dorri et al., 2020). Of these, only five were identified to have undergone some form of rigorous psychometric evaluation. The remainder of the questionnaires were global assessments of information needs, designed to assess information needs for multiple informational topics at once, well suited for use in health services research and quality improvement work. The development and implementation of evidence based informational interventions focusing on specific cancer challenges are likely needed to decrease the prevalence of unmet information needs. However, this review identifies that targeted information needs assessment tools suitable for evaluating such interventions need to be developed given the number of unique challenges that those living with cancer face (Thiessen, Bouchal, et al., 2022).

Second, this review suggests that the expressed information needs of those living with cancer may not necessarily be reflected in existing questionnaires. Initial item selection commonly evolved from pre-existing literature, previously developed instruments, and, presumably, the expertise of the research teams. Patients and carers were only involved in this process in six cases (Arraras et al., 2004; Halkett & Kristjanson, 2007; Neumann et al., 2011; Rees & Bath, 2000; Thomas et al., 2004b; van Weert et al., 2009). More commonly, patients and carers, along with healthcare care professionals, were involved at the stage of reviewing a version of the

questionnaire, developed by the team of researchers developing the questionnaire, to help finalize it. In eight instances, patients or carers were not identified as having been involved in any aspect of questionnaire development. Certainly, the expertise of healthcare providers and the value of the peer-reviewed literature should not be discounted. But discrepancies between what those receiving healthcare want to know, and what those providing it feel is important to share, are known to exist (Thiessen, Bouchal, et al., 2022). The risk of not including patients and informal caregivers in developing questionnaires that are intended to assess their informational needs is not small, as the findings from these questionnaires inform future research and clinical practice. If what is important to patients and their informal caregivers is not reflected in these tools, the ability of cancer care to evolve to better support those living with cancer is limited. Moving forward, teams developing information needs assessment questionnaires are encouraged to carefully consider how to systematically ensure that the items included in their tools authentically reflect the information needs of those living with cancer (Sinclair et al., 2020).

Limitations

This review did not include non-cancer specific tools or those that included domains not exclusively related to information needs. As a result, it is possible that tools useful for assessing information needs of those living with cancer, but not specifically developed for the cancer context, may have been inadvertently missed. When working to identify measures for work where information needs require assessment, previously published reviews (Christalle et al., 2019) may be helpful for identifying appropriate tools in addition to the work presented here. Similarly, this review was limited to articles published in English. As was described by a number of the articles reviewed here (Zeguers et al., 2012), adaptation of measures initially developed in English to other languages occurs, and it is possible that a number of questionnaires exist that have been reported

on only in the non-English literature. Lastly, the psychometric testing and properties of each questionnaire was not explored in detail as this was outside of the scope of this review (Arksey & O'Malley, 2005). Therefore, this review does not attempt to provide a critical evaluation of the quality of existing measures in terms of validity or reliability and should not be interpreted as such.

Conclusion

The information needs of those living with cancer often go unmet, resulting in negative consequences (Husson et al., 2011; Mesters et al., 2001; Mollaoglu & Erdogan, 2014; Thiessen et al., 2018; Thiessen et al., 2020; Wang et al., 2018). While interventions are needed to improve information provision, tools available for quantitatively assessing whether information needs in the cancer context are being met are limited. While several tools exist for globally assessing information needs, few tools are designed to assess information needs at specific parts of the cancer journey (Dorri et al., 2020; Galloway et al., 1997; Graydon et al., 1997; Halkett & Kristjanson, 2007; Ward & Griffin, 1990) where targeted informational educational interventions could be developed. Additionally, only a few tools exist for assessing the unique informational needs of informal carers, who are important, often unacknowledged partners in patients' cancer journey (Kilpatrick et al., 1998; Rees & Bath, 2000). More research is needed to develop tools that can be confidently used to assess the information needs of those living with cancer, including to assist with the development of informational interventions (Craig et al., 2013). In order to ensure that this work is in line with the priorities and needs of those living with cancer, effective engagement with patients and informal caregivers should be a priority at all stages of measure development (Merker et al., 2022).

Author Contributions

Conceptualization, M.T. and S.S.; methodology, M.T. and S.S.; data extraction, M.T. and D.H.; data analysis, M.T.; writing-original draft preparation, M.T.; writing-review, S.S., P.T., S.R.B.; supervision, S.R.B., P.T., S.S..

Funding

The research received no external funding.

Chapter 4: Choosing Grounded Theory

Chapter Overview

This chapter presents the grounded theory methodology which is used in the studies presented in the two subsequent chapters. The chapter begins with a discussion of the role of theory in developing scientific knowledge, including the unique characteristics of a grounded theory. Next, grounded theory, including its history, central tenets, methods, and the three main variants (i.e., classic, Struassian, and Charmazian) are discussed. Lastly, why classic grounded theory is an ideal method for addressing important gaps in the literature regarding the interplay between identity, information, and the cancer experience is explored.

Why Theory? Why Grounded Theory?

Scientific theories provide a comprehensive explanation of some aspect of nature supported by evidence obtained through rigorous methods (Pusic et al., 2018). Over time, scientific theories are forwarded, refuted, revised, and eventually discarded when new theories are developed that provide more comprehensive explanations for natural phenomena (Fleck et al., 1981). Theory is central to the scientific method. First, theory provides common ground for scientists to build on, as it provides language, defines concepts, and facilitates making assumptions explicit (Alderson, 1998). Second, theory is important in guiding research activities, as it can play an important role in informing research questions, methods, and interpretation of results (Stewart & Klein, 2016).

Individual theories exist as a part of a larger system describing a body of knowledge and can be grouped and described in terms of the level of conceptualization they provide (Higgins & Shirley, 2000). Higgins and Shirley (2000) describe four levels of theory, including micro-range theory, middle-range theory, grand-theory, and meta-theory. Micro-range theory is the most limited in scope, and describes specific situations, a limited number of concepts, and informs

working hypotheses. For instance, in the larger body of healthcare education, a micro-range theory might define best practices for instructing medical students how to take a history from a geriatric patient on a hospital ward. The micro-range theory might describe specific questions that should be asked of this population and strategies for ensuring a thorough, efficient, patient-centered approach. Middle-range theories are broader in scope than micro-range theories, being applicable to a broader range of contexts in the knowledge system, but not relevant across all contexts. For instance, a middle-range theory might provide guidance for how to best obtain a history from a geriatric patient, or a patient in general, but provides less guidance on the specific situation that the patient is in (i.e., not specific to an inpatient admission).

Grand theories represent global paradigms of the knowledge system being described. Grand theories are highly abstract, define the boundaries of the knowledge system, and legitimize it from other systems (Higgins & Shirley, 2000). Unlike micro-level and middle-level theory, grand theories are relevant across the spectrum of context relevant to the practice but are not specific enough to generate hypothesis that can be tested (Higgins & Shirley, 2000). A grand theory might outline why it is important to take a history from a patient in general but specifics about what should be included in the history or how specifically a clinician should act on the information. Lastly, meta-theory addresses the epistemological concerns about what can be known, how to know it, as well as philosophical questions about what should be known (Higgins & Shirley, 2000). For instance, using the example of healthcare education, theory about whether knowledge regarding the impact of power differentials in teacher/student relationship should be included in the knowledge system would exist at the meta-theory level.

While theories can evolve over time, the initial form of a theory, and how accurately it reflects the phenomena it seeks to explain is important. As theories represent the basis for scientific

exploration, a theory that doesn't adequately identify and define the important concepts making up the phenomena it claims to explain may lead scientists to explore questions that aren't relevant, make inappropriate assumptions, and interpret results in an erroneous way (Glaser & Strauss, 1967; Thyer, 2008). Clearly, building on a theoretical understanding of a phenomenon that is flawed at a fundamental level will be less successful than building on one that is not, both in the short and long term resulting in negative consequences for the careers of the scientists, the scientific fields they work in, and the value that funders of research receive for the dollars they contribute towards misguided scientific research (Glaser & Strauss, 1967; Thyer, 2008). In the health sciences in particular, the consequences of poorly developed theories impact the education of trainees if erroneous theoretical principles are presented as this can result in both misdirection of trainees, their subsequent practices, and consume learning time that could be otherwise used for other topics (Thyer, 2008). Similarly, for practicing healthcare providers, recipients, and informal caregivers, healthcare delivery informed by poorly developed theory can have significant consequences for the wellbeing of everyone involved, including injury and loss of life (Thyer, 2008).

Broadly, in the social sciences, as well as aspects of health sciences which apply concepts from the social sciences, how theories are generated can be divided along a spectrum. At one end, there are theories that are logically deduced by scientific theorists, and not necessarily grounded in empirical data. On the other hand, there are theories that are heavily informed by, or grounded in, empirical data. According to Glaser and Strauss (1967), theories that are grounded in empiric data (i.e., grounded theories) have a number of strengths, compared to those that are not. These include being more difficult to refute, lasting longer, being a better fit with empiric observations, and working better to describe the phenomena under study (Glaser & Strauss, 1967).

A Need For Middle-Range Grounded Theory

The findings of the scoping review presented in the previous chapter highlight that there are outstanding questions regarding the information needs of those living with cancer. In particular, the finding that current tools are limited to mostly global assessments non-specific to the many unique challenges individuals face on their journey raises the uncomfortable possibility that little is actually known about what those experiencing cancer would themselves consider helpful (i.e., expressed needs) to navigate the cancer journey. Additionally, because the specific information needs assessed by existing tools have been primarily identified by healthcare clinicians and researchers, it raises considerable concerns that the information needs prioritized in existing research reflect the biases of healthcare professionals and the implicit values of their institutions.

Theory at all levels has an important role to play in advancing what is known about the information needs of those experiencing cancer. For instance, at the high level of meta-theory and grand theory, whether information needs are truly the concern of medical practitioners is not clear as the ethos of the Coan and Cnidian schools can be seen as representing competing meta-theories as they define the boundaries of medical practice differently, and the place of information needs within these boundaries (Toombs, 2001). Similarly, questions regarding who gets to choose how the information needs of patients and informal caregivers are identified, and which ones are prioritized in research and practice, represent topics belonging to the domains of high-level theory, existing alongside other issues related to power such as the place of race, gender, and class in the medical knowledge system.

While discourse around the topics belonging to high-level theory such as the place of patient and informal caregiver information needs and the role of those with lived cancer experience in guiding how these needs are addressed is important, reaching a conclusion about their place in

medical practice is beyond the scope of this thesis. However, within the confines of this thesis work, as has been outlined in the introduction, the stance that is being taken is that addressing the information needs of those living with cancer is a key component to providing good medical care, in keeping with the Coan ethos of medicine (Toombs, 2001). Additionally, in keeping with the critical pedagogy of Paulo Freire (Freire & Ramos, 1970/2014), it is assumed that the information needs of those living with cancer are best addressed only by actively engaging with those with lived experience in order to understand and identify how to address the informational concerns that they personally face.

Moving from the realm of high-level theory to middle-level theory, an important gap in the literature is identified. Based on the assumptions guiding this work, it appears that theory grounded in the experience of those living with cancer is needed to inform both research and practice regarding the information needs in the cancer context. That is not to say that helpful theory does not exist. As outlined in Chapter 1, works from Wilson (1997) and Lazarus and Folkman (1984) provide important conceptualizations necessary for understanding the importance of information and its relationship with stress and coping at a high level (Case & Given, 2016). Additionally, two theories of information behaviour have been developed that are specific to the cancer journey. The health information acquisition model by Freimuth et al. (1989) was developed using data collected from the Cancer Information Service, a telephone-based information service developed by the National Cancer Institute in the United States. Additionally, Longo (2005) developed a conceptual model of health of information behavior of women with cancer, in part, through interviews with breast cancer patients. These theories provide important insight into understanding how information impacts the cancer journey. For instance, the health acquisition model (Freimuth et al., 1989) identifies the presence of a risk/benefit analysis taking place by the information searcher

to determine whether the costs of information searching will outweigh the benefits of any information discovered. Additionally, the work by Longo (2005) links useful information to patient empowerment and satisfaction.

While these works underscore the importance of providing those living with cancer useful information, they provide little in terms of operationalizing the impact of information on the lived experience of those living with cancer, including what characteristics make information useful, how to deliver it, or what informational topics should be addressed and when (Craig et al., 2013). These more granular problems exist at a lower theoretical level than currently available information seeking behaviour theory addresses. Importantly, the assumptions that guide this thesis and the need for theory addressing these lower-level concepts make grounded theory a good fit for generating knowledge to address the existing gap in the theoretical literature. This is because grounded theory methodology provides researchers with an approach for generating theory that is both rigorous and systematic, and at the same time responsive to the real-world concerns of the research participants with lived experience of the phenomena being studied (Glaser & Strauss, 1967).

Introducing Grounded Theory

Grounded theory originated in the 1960's as a methodology for developing social science theory from empiric data. Methods for revising theory had been previously developed (Merton, 1949/1968), but an approach for discovering novel theory through rigorous analysis of empiric data was novel (Glaser & Strauss, 1967). Since its origins, grounded theory has been used in a diverse number of fields including business management, education, the performing arts, food services, and the health sciences (Birks et al., 2019; Higginbottom & Lauridsen, 2014; Kunkwenzu & Reddy, 2008) becoming one of the most widely used research methodologies (Birks et al., 2019).

Importantly, grounded theories are generally considered to be middle-range theories, as they describe a small number of concepts (i.e., those related to a core concept) regarding a defined phenomenon, that can be applied across a number of contexts and offer both explanatory and predictive properties (Glaser & Strauss, 1967; Higgins & Shirley, 2000; Holton & Walsh, 2016).

A number of variants of grounded theory have been developed, all of which can be linked back to the original work of Glaser and Strauss in the 1960's (Bryant, 2019) and the seminal text outlining grounded theory methodology, *The Discovery of Grounded Theory* (or simply *Discovery*) (Glaser & Strauss, 1967). Today the most widely recognized variants of grounded theory are the three distinct approaches developed by 1) Strauss and Corbin, 2) Glaser, and 3) Charmaz (Bryant, 2019).

While all three variants can be linked back to the original *Discovery* text (Glaser & Strauss, 1967), and the work of Glaser and Strauss in the 1960's (Bryant, 2019), each provides a unique philosophical and methodological approach. Notably, Glaser and Strauss parted ways after the publication of the original text, each going on to further develop the grounded theory methodology in keeping with their own views of what the method should become. Glaser went on to extend and refine the original approach he developed with Strauss, referred to as classic grounded theory, that focused on providing the researcher with maximum flexibility to interpret data and creatively develop theory. While Glaser himself did not position the methods he developed with in a specific epistemological perspective (Glaser & Holton, 2004), operationally the researcher is positioned as an objective observer of the data and discoverer of the resulting theory (Bryant, 2019; Sebastian, 2019), reflecting a positivist approach. Glaser's approach involves initial open coding of collected data, followed by selective coding of concepts once a core category (or concept) has been identified, followed by theoretical coding to identify interactions between the concepts that

emerged, including their relationship with the core category (Glaser & Strauss, 1967). Importantly, the coding approach that Glaser presents is not restrictive, and while Glaser does identify a number of coding frameworks that may be helpful, the specific details of the coding process are left to the researcher (Glaser, 1978).

In contrast, the method developed by Strauss and Corbin (Corbin & Strauss, 1990) provides the researcher with both a specific philosophical framework as well as clearer guidance for the development of codes. Unlike the work of Glaser, who presents a methodology not situated in a pre-determined philosophical framework (Glaser & Holton, 2004), the work of Strauss and Corbin is specifically situated within the traditional symbolic interactionist paradigm (Chamberlain-Salaun et al., 2013; Stryker, 1980). In Straussian grounded theory, the researcher is considered to actively participate in the research and interpreting the data in the process of developing the theory (Sebastian, 2019). Additionally, Straussian grounded theory provides a much more rigid coding structure. While open coding remains a feature of Straussian grounded theory, axial coding is introduced as the subsequent phase of coding, and it provides the researcher with a predetermined framework for systematically developing each category of codes (Corbin & Strauss, 1990). This is followed by selective coding, where the researcher unifies the categories which have emerged around a core category (Corbin & Strauss, 1990).

Finally, Charmazian grounded theory, or constructivist grounded theory, is rooted in the constructivist paradigm (Bryant, 2019; Charmaz, 2014; Sebastian, 2019). Charmazian grounded theory considers the researcher to play an active role in constructing the theory and does not attempt to separate the research, or the interpretation of the data, from the researcher's prior experiences, knowledge, or world view (Sebastian, 2019). In terms of coding, Charmazian grounded theory provides perhaps the most flexible approach, allowing for multiple core

categories, and a two step coding process involving open coding, followed by grouping the most relevant resulting codes around the identified core categories (Sebastian, 2019).

Importantly, all of the three variants share a number of common tenets including the importance of emergence, the role of constant comparison, the role of theoretical sampling, and the importance of achieving theoretical saturation (Holton & Walsh, 2016). Emergence is a concept that is critical to the successful development of a theory that is truly grounded in the data. It reflects the idea that the concepts and the resulting theory are informed primarily by analysis of the data, as opposed to a priori concepts known to the researcher or those that are established in the literature. This makes the role of literature reviews prior to conducting a grounded theory study a particularly contentious issue, as a risk exists that the resulting research may simply end up validating or refuting established concepts which may or may not be grounded in the reality of the phenomena being explored.

Ultimately, while each grounded theory variant handles a priori knowledge differently (Sebastian, 2019), there are a number of shared methods and principles. First, in addition to the rigorous collection of study data, the generation of memos in grounded theory is key to ensuring emergence. The researcher can use memos to keep a transparent and auditable trail outlining the rationale behind each open and theoretical code, as well as how a priori ideas have influenced the emergence of each theoretical concept (Glaser, 1978; Glaser & Strauss, 1967; Holton & Walsh, 2016). Second, constant comparison is another key aspect of grounded theory methodology. Constant comparison evolved from a procedure called index formation, which Glaser learned from his mentor, Paul Lazarsfeld (Glaser, 2020). It involves comparing instances of similar codes to determine the properties of the theoretical code they represent. Constant comparison is a keystone

of grounded theory, being used at all stages of data analysis from the initial data collection until the theory is finalized (Holton & Walsh, 2016).

Lastly, theoretical sampling and saturation are two closely related concepts that are key to ensuring a theory is complete (Glaser & Strauss, 1967). Theoretical sampling can be understood as a complimentary concept to constant comparison. Whereas constant comparison involves comparing the properties of data similar codes to allow concepts to emerge by identifying similarities and differences, theoretical sampling involves capturing data from different data sources, and comparing the properties of the coded data between sources. This is an important part of the work of doing grounded theory because it provides the researcher with an opportunity to explore emerging concepts in different contexts to identify commonalities, differences, and facilitate further emergence of new concepts not evident in previously explored settings. Additionally, theoretical sampling can be seen as an important aspect of reaching theoretical saturation. Theoretical saturation is said to occur when new concepts and properties cease to emerge from the collected data (Glaser, 1978; Holton & Walsh, 2016). Essentially, reaching theoretical saturation is a sign that data collection and analysis is complete. Importantly, theoretical saturation only occurs when each of the concepts that have been identified as key to the emerging theory have been saturated (Glaser & Strauss, 1967). Theoretical sampling is therefore an important tool for reaching saturation, as it facilitates analysis of data from sources likely to present codes with contrasting properties, ensuring that all emerging concepts have been rigorously explored.

Selecting a Grounded Theory Methodology

Each of the three variants of grounded theory provide researchers with a unique set of tools and perspectives for generating theory. As discussed previously, each approach is associated with

unique methods and underlying epistemology which need to be carefully considered prior to selecting the most appropriate variant for the research being undertaken (Bryant, 2019; Evans, 2013). In order to address the gaps in the literature regarding the information needs of those living with cancer, classic grounded theory was selected to guide the research presented in Chapter 5 and 6. This section discusses the reasons for selecting classic grounded theory.

In contrast to Glaser's resistance to anchoring classic grounded theory with a specific philosophical paradigm, Charmazian grounded theory is clearly positioned within the constructivist paradigm, raising the questions of whether or not the research problems identified herein should not be addressed using a constructivist lens. One of the key features of Charmazian grounded theory that make it constructivist is that it does not separate the researcher from the research. Data collection, analysis, and the resulting theory are all understood to be implicitly influenced by the researcher. Consequently, the resulting theory is considered to be a co-construction of the research participants' and researcher's perspectives. Theoretically, this makes interpreting and applying the resulting theory challenging as it is not simply an account of the phenomena being researched, but also reflects the reality and perspective of the researcher. It could be argued however that to better understand the information needs of those living with cancer, a constructivist lens may be helpful – especially if a healthcare professional with clinical experience is the one conducting the research. As a medical oncologist, I feel that I have important expertise and insights that are valuable in interpreting the experiences of those living with cancer. Certainly, at least in the clinic setting, I can appreciate that challenges individuals experience with getting their information needs met. Often patients and informal caregivers are overwhelmed when they come to see me and clinic visits need to be truncated before all of the information needs that the individuals have are unpacked and addressed. I can therefore appreciate that there may be value in

choosing a methodology that acknowledges my professional insights and facilitates cocreation of theory with research participants in a way that leverages my perspective.

The challenge, however, with a constructivist approach is that, in this instance, it may limit what can be discovered. As identified in the scoping review presented in Chapters 2 and 3, to date the information needs of those living with cancer have been defined primarily by healthcare professionals, including clinicians and researchers. Along the same lines, from a critical theory perspective, it is important to question how my personal biases as a clinician may influence how I collect and influence the data analysis and resulting theory. Arguably, as a medical oncologist, my professional appreciation for concepts like cure and survival have the potential to bias me in terms of how I prioritize what data is coded, and the concepts that are forwarded. As a result, a methodology that incorporates a constructivist viewpoint, while having some benefits, is ultimately incongruent with these research aims, especially if I am the one to lead data collection and analysis.

Similar to classic grounded theory, Straussian grounded theory is not clearly centered within an epistemological paradigm (Corbin & Strauss, 1990; Martin & Gynnild, 2011). Some suggest that Straussian grounded theory underwent an evolution, initially being aligned with the positivistic paradigm and then evolving to fit better in the constructivist paradigm as Strauss and Corbin further developed the method (Martin & Gynnild, 2011; Sebastian, 2019). Regardless, the Straussian approach has other characteristics beyond its epistemological grounding that are important for determining its fit for this work. In particular, in contrast to classic grounded theory, Straussian grounded theory provides a more rigid coding strategy, as well as predetermined theoretical codes. Through the use of a conditional matrix, axial coding prompts the researcher to sort out the why, where, when, by whom, how, and the consequences for each code, guiding the

researcher through a specific, systematic, and relatively rigid sequence of steps to code the data in preparation for the final stage of selective coding. In contrast, in classic grounded theory, aside from being guided by philosophical questions such as “what is this data a study of?” (Glaser, 1978, p. 57), and general directions on how to develop selective and theoretical codes, a coding structure is not pre-prescribed. As a result, the researcher determines the best coding strategy based on the emerging concepts. Having a pre-prescribed approach, such as that outlined in Straussian grounded theory, for data analysis has advantages. For instance, the researcher is not limited as much by their ability to appropriately develop a coding strategy - as this has already been provided.

However, the challenge with the Straussian approach is that the predetermined analysis structure limits what can be found. For instance, the axial coding question “by who?” suggests that all consequences or actions are the result of a human actor, anchoring the properties of the concepts being discovered to interactions between people. But is it safe to assume that the only relevant concepts that exist for understanding information needs are reflected in human interactions? By forcing such a coding strategy on the data, as opposed to choosing a strategy that best reflects the emerging concepts, there is a risk that the most impactful theory will not be discovered in the collected data. Given that it appears that relatively little is actually known about information needs of those living with cancer, it is important to be as open as possible to what can be discovered in the data. For these reasons, classic grounded theory was selected as the methodology to guide the studies presented in the next two chapters.

Chapter 5: Information Access and Use

Manuscript Title: Information Access and Use by Patients With Cancer and Their Friends and Family: Development of a Grounded Theory

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Abstract

Background: Information has been identified as a commonly unmet supportive care need for those living with cancer (i.e., patients and their friends and family). The information needed to help individuals plan their lives around the consequences of cancer, such as the receipt of healthcare, is an example of an important informational need. A suitable theory to guide the development of interventions designed to meet this informational need has not been identified by the authors.

Objective: The aim of this study is to generate a grounded theory capable of guiding the development of interventions designed to assist those living with cancer in meeting their informational needs.

Methods: Classic grounded theory was used to analyze data collected through digitally recorded one-on-one audio interviews with 31 patients with cancer and 29 friends and family members. These interviews focused on how the participants had accessed and used information to plan their lives and what barriers they faced in obtaining and using this information.

Results: The theory that emerged consisted of 4 variables: personal projects, cancer as a source of disruption to personal projects, information as the process of accessing and interpreting cancer-related data (CRD) to inform action, and CRD quality as defined by accessibility, credibility, applicability, and framing. CRD quality as a moderator of personal project disruption by cancer is the core concept of this theory.

Conclusions: Informational resources providing accessible, credible, applicable, and positively framed CRD are likely key to meeting the information needs of those affected by cancer. Web-based informational resources delivering high-quality CRD focused on assisting individuals living with cancer in maintaining and planning their personal projects are predicted to improve quality

of life. Research is needed to develop and integrate resources informed by this theoretical framework into clinical practice.

Keywords: persons; adaptation; cancer; empowerment; grounded theory; health education; health information-seeking behaviour; mobile phone; patient-centered care; personal autonomy; psychological; qualitative research

Introduction

Background

One of the most commonly reported unmet supportive care needs of those facing cancer, including patients (Fletcher et al., 2017; Mistry et al., 2010; Rutten et al., 2005; Tariman et al., 2014) and their friends and family (Bonacchi et al., 2018; Lambert et al., 2012; Moghaddam et al., 2016; Wang et al., 2018), is for information. Common informational needs include those related to prognosis, how to care for someone with cancer, and the benefits and toxicities of treatment (Bonacchi et al., 2018; Fletcher et al., 2017; Halkett et al., 2010; Hubbeling et al., 2018; McCarthy et al., 2018; Meredith et al., 1996; Preisler et al., 2019; Vivar & McQueen, 2005). Unmet information needs are associated with decreased treatment adherence (Arthurs et al., 2015; Boons et al., 2018), increased healthcare costs (Ferrari et al., 2019; Stacey et al., 2017; Veroff et al., 2013; Walsh et al., 2014), anxiety (Ferrari et al., 2019; Ugalde et al., 2012), and depression (Ferrari et al., 2019).

In a previous study conducted by the lead author (MT) (Thiessen et al., 2018) it was identified that the diagnosis of malignancy resulted in widespread interruption to the lives of those affected by cancer. This study used grounded theory (Glaser & Strauss, 1967; Holton & Walsh, 2016) to analyze data from 43 semi structured interviews conducted with 18 patients who had been recently diagnosed with cancer and 15 friends and family in Manitoba, Canada. One conclusion from this study was that to support individuals affected by cancer, information is needed that supports them in planning the activities necessary for maintaining participation in the relationships and projects they established before diagnosis—such as those with family, friends, and their work—both in the short and long term. Addressing this finding was a major motivator for the work presented in this study.

Health information-seeking behavior (HISB) is a field of research encompassing how those affected by illness utilize health information. Important areas of study within HISB include how individuals seek, use, and share information (Lalazaryan & Zare-Farashbandi, 2014; Lambert & Loiselle, 2007; Savolainen, 2019). The HISB literature can be broadly divided into 3 main categories: (1) coping with health situations, (2) involvement in shared medical decisions, and (3) behavior change and preventative behavior (Lalazaryan & Zare-Farashbandi, 2014; Lambert & Loiselle, 2007; Savolainen, 2019). In their concept analysis of HISB, Lambert and Loiselle (2007) identified that one goal of the individual engaging in HISB is to better understand what to expect. They identified that HISB serves to “increase predictability” (Lambert & Loiselle, 2007, p. 1009) and may assist with “anticipating the sequence of events” (Lambert & Loiselle, 2007, p. 1010) that will likely take place. These goals of HISB are consistent with the informational need identified in the study leading up to this work: that information is essential to helping individuals know what to expect in the future so that they can effectively plan how to live their lives (Thiessen et al., 2018).

The factors that affect HISB are complex, as illustrated by the examination of the Miller Behavioral Style Scale (MBSS) (Lalazaryan & Zare-Farashbandi, 2014; Lambert & Loiselle, 2007; Miller, 1987) and the model of health information acquisition (HIA) (Freimuth et al., 1989; Lalazaryan & Zare-Farashbandi, 2014; Lambert & Loiselle, 2007), both of which are utilized in the HISB literature (Lalazaryan & Zare-Farashbandi, 2014; Lambert & Loiselle, 2007). The MBSS is a validated scale (Miller, 1987; Rees & Bath, 2000) useful for characterizing individual information-seeking styles in response to both physical and psychological stress (Miller, 1987). The MBSS categorizes individuals as either information seekers (high monitors) or information avoiders (low monitors) (Miller, 1987; Rees & Bath, 2000). High monitors are more likely to seek

out information to cope with stressors, whereas the response of low monitors is to avoid information (Kola et al., 2013; Miller, 1987, 2015; Rees & Bath, 2000). The HIA, developed by Freimuth et al. (1989) from their work with the National Cancer Institute's telephone-based Cancer Information Service (Lalazaryan & Zare-Farashbandi, 2014), predicts that the decision to seek information involves a cost-benefit analysis.

The expected benefit of information is weighed against the effort to seek additional information (Freimuth et al., 1989; Lalazaryan & Zare-Farashbandi, 2014; Lambert & Loiselle, 2007) in terms of cost considerations such as “financial and time expenditures, frustration, confusion, [and] emotional distress” (Freimuth et al., 1989, p. 10). Together, the MBSS and the HIA suggest that both intrinsic and external variables impact an individual's ability to access and use health information to plan around the receipt of healthcare. This conclusion is supported by the wealth of empirical evidence, including multiple systematic reviews (Biernatzki et al., 2018; Carey et al., 2012; Clarke et al., 2016; Faury et al., 2017; Howell et al., 2017; Hyun et al., 2016; Kotronoulas et al., 2017; Moghaddam et al., 2016; Qan'ir & Song, 2019; Tariman et al., 2014; Wang et al., 2018), consistently correlating specific demographic factors (e.g., age, gender, education) (Biernatzki et al., 2018; Jacobs et al., 2017; Saab et al., 2018) with various types of information-seeking behavior (Lambert & Loiselle, 2007; Rutherford et al., 2017) and health information needs (Clarke et al., 2016; Wang et al., 2018).

In the context of cancer, it is not clear how to optimally design interventions to support individuals in obtaining the health information that is most useful for them. In general, using theory to guide intervention design results in better outcomes (Craig et al., 2008; Heath et al., 2015). The application of theory in intervention design facilitates the identification of key constructs to be included in the intervention, potentially resulting in a stronger effect (Michie & Prestwich, 2010).

In addition, the results of testing theory-based interventions provide valuable feedback about the accuracy of the theory (Glaser & Strauss, 1967; Michie & Prestwich, 2010), furthering the understanding of the contextual area under study and facilitating modification of the theory to enhance its accuracy (Glaser & Strauss, 1967).

Multiple theories have been used to guide both the understanding of HISB (Lalazaryan & Zare-Farashbandi, 2014; Lambert & Loiselle, 2007) and the development of interventions (Howell et al., 2017). Importantly, besides the model of HISB by Longo (2005) and the HIA by Freimuth et al. (1989), few theoretical frameworks regarding HISB have been developed within the context of cancer. In addition, although existing theories in the HISB literature facilitate understanding and explanations of HISB patterns, the utility of these theories for developing interventions is not clear. For instance, although existing theoretical frameworks employed in the HISB cancer context (Longo, 2005; Longo et al., 2009; Longo et al., 2001; Rees & Bath, 2000) described a cost-benefit relationship in terms of whether an individual will search for additional information, they did not provide guidance in terms of how to structure interventions for those affected by cancer to minimize the cost and maximize the benefit of information seeking. A theoretical framework that addresses this gap in the literature is thought to be valuable for developing interventions that address the informational needs of those living with cancer (Boons et al., 2018; Clarke et al., 2016; Hyun et al., 2016; Longo et al., 2001; McCarthy et al., 2018; Meredith et al., 1996; Rutten et al., 2005; Tariman et al., 2014; Vivar & McQueen, 2005). Such a framework would be capable of informing the development of interventions that support individuals in planning their lives around the short- and long-term consequences of cancer, including the receipt of treatment and altered life expectancy (Galloway et al., 1997; Thiessen et al., 2018).

Objectives

The objective of this study was to develop a grounded theory capable of guiding the creation of informational resources designed to assist individuals living with cancer in meeting their informational needs by minimizing the cost and maximizing the benefit of information seeking.

Methods

Study Approach

This study used classic grounded theory (CGT), a method for discovering theory through iterative data collection and analysis (Glaser & Strauss, 1967; Mediani, 2017; Rieger, 2019). CGT has been identified as a method for uncovering latent behavioral patterns and generating theory capable of guiding practical action for problem solving (Simmons, 2011). This was one reason that CGT was considered the ideal method for this study as the objective required a theory that operationalized (1) why information related to cancer is important for supporting individuals affected by it and (2) how information about cancer can be optimally provided to improve the lives of those affected by it. Both questions assume that shared patterns of behavior exist among those affected by cancer

Study Procedures

The study procedures, including the study design, data collection, analysis, and drafting of the report, were conducted primarily by the lead author, who was completing a medical oncology fellowship during the first year of the study and enrolled in a PhD graduate program as well as in active independent clinical practice as a medical oncologist for the subsequent portion of this study. The second and fourth authors provided methodological support in conducting and

presenting the grounded theory analysis. The third author provided general research expertise and contextual expertise regarding clinical oncology practice.

Ethical Considerations

Approval for this study was obtained through the Health Research Ethics Board of Alberta (Study ID: HREBA.CC-17-0365) before the initiation of recruitment, data collection, and data analysis.

Recruitment

Patients were recruited using posters and invitation letters from a large outpatient cancer facility in Western Canada. Interested patient participants contacted the lead author or primary investigator who provided further details of this study, including its methods, objectives, risks, benefits, and obtained written consent. The patient participants were invited to approach any friends and family to participate in this study as secondary participants. This study was open to all patients aged 18 years or older who had received oncology care. Friends and family participants aged 18 years or older were welcome to participate. Exclusion criteria were limited to not being able to communicate in English and being aged below 18 years. Incentives for participation included being eligible to win one of four Can \$25 (US \$18.79) gift certificates.

The rationale for inclusion of both friends and family participants as well as patient participants in this study was three-fold. First, it was assumed that, besides instances where patients were receiving medications affecting their cognition or had severe neurological sequelae of their cancer, such as a debilitating brain metastasis, there would be no psychological or sociological phenomena differentiating the processes of information seeking and use for those diagnosed with cancer from their family and friends. Therefore, the concepts and resulting theory that would emerge would likely be valid for both friends and family as well as patients. Second, it is

recognized that informal caregivers are often left behind when it comes to supportive care research, including research related to information needs. Although the theory that was expected to emerge would likely be applicable to both groups, without including both patients and friends and family in the study, the validity of the theory for the group not included would likely be questioned. Finally, the contrasting perspectives of friends and family and patients were expected to provide extremely useful data for the purposes of constant comparison, ensuring that theoretical saturation occurred (Glaser & Strauss, 1967; Holton & Walsh, 2016).

Data Collection

After obtaining written consent, all participants completed a demographic questionnaire (Appendix E). A review of the electronic medical charts of patient participants was performed to facilitate the identification of details that were not readily available outside of a thorough interview in the style of detailed medical and treatment history. The data from the chart review and questionnaires were compiled into a database to assist with theoretical sampling, an iterative sampling technique to ensure theoretical coverage and heterogeneity (Glaser & Strauss, 1967; Holton & Walsh, 2016). For instance, patients were initially interviewed as they were recruited, resulting in a predominance of patients >50 years of age with breast and colorectal cancer being interviewed. Therefore, the database was used to identify and select participants for interviews who were primarily younger patients with less common malignancies. This was important to ensure that the emerging concepts were adequately informed by data from individuals likely to have had contrasting experiences.

All interviews were semi-structured (Appendix F), face to face, and audio recorded. The interviews were carried out in participants' homes, apart from three interviews conducted over the phone. Interviewees were encouraged to stop the interview at any point if they were no longer

comfortable proceeding or needed a break; in addition, they were provided with contact information for psychosocial support available through the cancer center. The interviews with participants took place separately, except for seven interviews where the patients and their friends and family wanted to be interviewed together. Participants were interviewed once; no repeat interviews were conducted. The audio recordings from the interviews were transcribed by a professional transcriptionist as soon as possible after each interview to facilitate ongoing and iterative data analysis. The average interview length was 53 minutes overall, 1 hour and 4 minutes for interviews involving patients, and 36 minutes for interviews with only friends and family participants. Participants who participated in interviews were offered a 24-hour parking pass to the cancer center.

Data Analysis

Data analysis using constant comparison was carried out in keeping with the CGT (Glaser & Strauss, 1967). Data analysis and data collection occurred in an iterative manner, beginning once the first interview was transcribed. Coding, memoing, and theory generation were guided by comparing coded incidents and intentionally selecting participants and interview questions likely to result in data being collected that would contrast with previously collected data, providing new insight to guide the emerging theory (Glaser & Strauss, 1967). Data collection ceased when data saturation occurred, whereby no new data emerged from the ensuing interviews. The initial stage of coding the collected data (i.e., open coding) resulted in a coding schema emerging and the identification of a core category. This facilitated the next stage of the CGT analysis (i.e., selective coding), where the theory began to emerge around the coding categories (i.e., variables) associated with the consequences of access to the information that participants identified as being helpful or unhelpful. The final stage of the CGT analysis (i.e., theoretical coding) involved coding to finalize

theoretical links between the categories connecting the challenges faced by the participants, their experience with cancer, and information.

Results

Participant Characteristics

A total of 37 patients and 36 friends and family consented to be contacted for interviews, with 31 patients and 29 friends and family (Table 5) completing interviews. The sample of patients who completed the interviews was relatively balanced in terms of gender and included patients with ages ranging from their late 20s to early 80s. Importantly, there was a mix of patients who were being treated with curative intent, as well as those being treated non-curatively for de novo or recurrent metastatic disease, suggesting a wide range of cancer experiences. In terms of friends and family interviewed, ages were similar to patients, likely reflecting the high number of spouses who were included in the interviews.

Table 5.*Interviewed Participant Demographics*

Interviewed Primary Participants (PPs)		n = 31
Age	Average (min – max)	60 (29 – 81)
Gender		
	Male	14
	Female	17
Initially Curative at Time of Diagnosis		
	Yes	26
	No	5
Currently Curative (at Time of Interview)		
	Yes	19
	No	12
Malignancy Type		
	Colorectal	8
	Non-Colorectal	5
	Gastrointestinal Malignancy	9
	Breast	5
	Melanoma	3
	Hematologic Malignancies	1
	Osteosarcoma	
Interviewed Secondary Participants (FFPs)		n = 29
Age	Average (min - max)	56 (27-83)
Relationship to Primary Participant		
	Spouse	17
	Child	3
	Sibling	2
	Parent	2
	Friend	5

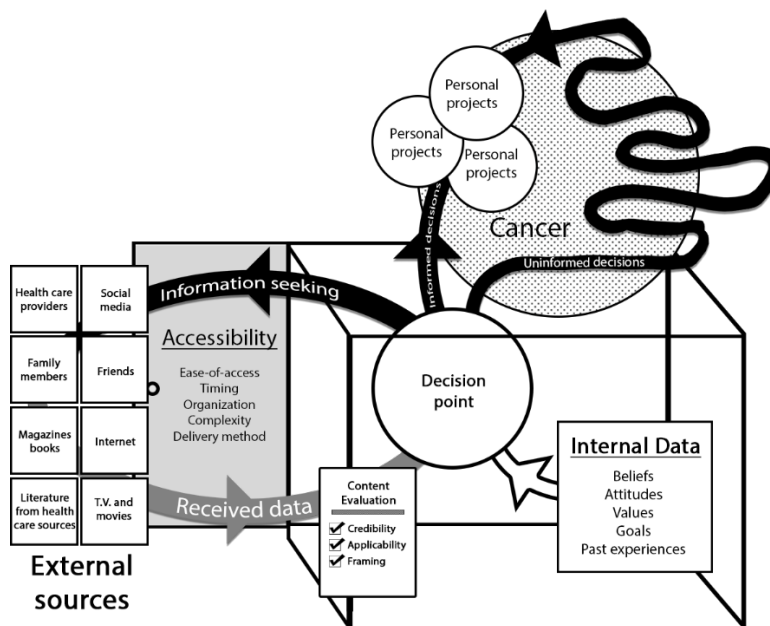
The Grounded Theory of Information Access and Use

The primary finding, or core variable (Glaser & Strauss, 1967), was that the quality of cancer-related data (CRD) that patients and their friends and family received impacted their ability to plan their lives around the consequences of the malignancy diagnosis. The theory consists of four interrelated concepts: (1) personal projects, (2) the cancer project, (3) information as the process of receiving and interpreting data to inform action, and (4) the quality of CRD received.

At the conclusion of this study, information was understood as the process of informing action based on the CRD that patients and their friends and family received about cancer. For those affected by cancer, CRD came from multiple sources, including healthcare providers, family, friends, and the internet. CRD from healthcare providers were the most credible and applicable; however, access to healthcare providers was often limited to clinical visits where the uptake of the CRD was limited. CRD found on the internet were readily accessible and provided an opportunity for repeated access. Received CRD are interpreted in the context of internal data, including the individual's personal values, how the individual understands their life story, goals for the future, and previously obtained CRD. This process informs the individual's actions related to managing cancer or their personal projects (e.g., career, raising children, being physically fit). The concepts that comprise the theory are described in the following subsections. A graphical model of the theory is presented in Figure 3.

Figure 3.

A Graphical Model of the Theory of Information Access and Use



Note. The theory suggests that a cancer diagnosis is disruptive, in part, because it decreases the ability of an individual to effectively make decisions about how to invest their time and energy into their personal projects. This is due to a resulting lack of certainty about what to expect, both in terms of the cancer itself and how the consequences of cancer, such as treatment and altered life expectancy, will affect their personal projects. Information is understood as a process involving receiving data about cancer and interpreting it to increase the certainty of the outcome of different actions. High quality data, defined as data that is accessible, credible, applicable, and positively framed, enhances decision-making support and results in improved engagement with personal projects. The dark black arrowed lines represent aspects of the information/action continuum in which energy and time is diverted between personal projects and seeking information. The indirect winding line titled “uninformed decisions” illustrates the inefficient use of an individual’s finite energy and time when decisions are not informed by high-quality cancer data.

Personal Projects: The Context of Cancer

Personal projects refer to the collection of activities that an individual invests a significant amount of energy and time in over a prolonged period of their life. The following quote demonstrates how time and energy shift from one personal project (e.g., child rearing) to another (e.g., the project of being healthy) over the course of a lifetime:

I worked and I [raised] the kids and I was very involved, and I volunteered a ton and then once they graduated it was my turn. And I started to do things for me and get myself healthy and eat healthy and all that. (Patient 1)

The personal projects of the participants created a unique context for each individual to face the challenges of the cancer experience. Each participant had a unique group of ongoing personal projects, allotting different amounts of time and energy to each, and each was ascribed with unique meaning. Importantly, before diagnosis, these personal projects—and the activities and roles that comprised them—were what the participants invested their time and energy in.

Cancer: A New Disruptive Project

The personal projects of the participants were disrupted following the malignancy diagnosis. Energy and time were diverted from preexisting personal projects to managing the consequences of the cancer diagnosis. Some participants described being able to continue with most aspects of their personal projects but were unable to plan how these would fit into the future. This was because the necessary details that would facilitate planning, such as prognosis or the time and energy commitment needed for treatment, were not made clear for weeks, or even months, after the initial diagnosis. Others described that following the diagnosis, their personal projects essentially halted:

I was given the diagnosis, sent to the [hospital ward] and then I was in there for over I think it was two weeks or something or longer. (Patient 15)

For friends and family, disruption to personal projects was related to the amount of support they provided to the individual who received the malignancy diagnosis. A partner of a patient described the disruptive effect of cancer as follows:

Well obviously, it's been life altering. I guess it's – it's certainly changed what the priorities are in our short term, midterm and long-term activities. ...because like the first priority is always caring for [spouse] making sure [they] get the right [treatment]. (Friends and Family 15)

In this example, priorities were understood to relate to the relative energy and time that the participant planned to invest in various projects. In contrast, a participant identified as a friend to a primary participant but not as a central member of the patient's support network indicated that the malignancy diagnosis was not disruptive to their personal projects stating:

I avoid the issue of [their] illness. ...I don't make [them] sick. (Friends and Family 26)

Information: Definition and Function

At the conclusion of this study, information came to be understood as a multistage process, with steps occurring both externally and internally to the individual. The process participants described included searching for, receiving, and interpreting data related to cancer (i.e., CRD) to inform action related to their personal projects and managing cancer. CRD came in many forms, including through conversations with healthcare providers, friends and family, web searches, and personal experiences. Participants also described actively searching for CRD, using time and energy that would otherwise be used for their personal projects, to understand the diagnosis and

its consequences. For instance, one participant described searching for CRD and using them to answer questions related to the project of raising a family following the malignancy diagnosis:

But at the start, 'cause I was so scared, I thought "oh my God, I have these little kids that I have to raise" you know? I have a long haul ahead of me, like I got to get through this. What can I do that's going to help benefit me in the long run? ... what things are going to benefit me health wise? That's going to... help me get through this? (Patient 2)

This participant went on to describe finding books and other resources that contained CRD that were helpful in navigating the challenges of being a parent while dealing with the consequences of the malignancy.

In contrast to the CRD that were actively sought out, CRD were also obtained passively through sources such as TV shows, news, and casual conversations with friends and family and from clinical encounters with physicians and nurses. In addition, participants indicated that although much of the CRD that they used were obtained from external sources, they also identified internal sources of CRD. For instance, personal knowledge gained from previous cancer experiences with family and friends was identified as an important source of CRD.

After CRD were accessed, participants described using it to guide both small-scale decisions, such as the day-to-day logistical coordination of the activities related to a single personal project (e.g., taking time off work to provide transportation to a patient), and large-scale decisions, such as those that would affect all of an individual's personal projects:

... if I had had a better idea about what the progression, the path [forward] is going to be - that would be helpful for me. ... And I want to plan, right now I want to plan six months, I want to plan a year from now. ... Because of this situation I'm going to be leaving my job

and [moving] and to the extent possible I'd like to know, this sounds terribly selfish, but there's a little bit of: how does this affect me? (Friends and Family 27)

Quality CRD: Accessibility, Credibility, Applicability, and Framing

To understand how information could be optimally provided to those affected by cancer, many of the study interviews included a focus on how CRD had been provided through the cancer center or by clinicians, whether these CRD were helpful, and discussions about how CRD could be better provided. Through this exploration, and the many contrasting examples provided by the participants, four themes defining the quality of CRD were identified: accessibility, credibility, applicability, and framing.

Accessibility. Accessibility refers to how CRD are made available to individuals and is characterized by *ease of access, timing, organization, complexity, and delivery method*.

Ease of access. Some external CRD sources can have limited accessibility, whereas others can be repeatedly and conveniently accessed. Healthcare providers and cancer centers are sources of CRD that have limited access. Participants described CRD available through clinic visits, support groups, and education sessions as being accessible only in certain locations and at certain times. As a result, the CRD provided were not always able to be effectively received. One participant described the experience of comparing the details that they recalled from clinician visits with a friend who had been present for the visits and had been taking notes:

I still haven't been to a single appointment without bringing someone with me. ... every single car ride home [when we discuss the appointment] it was like we were in two different [doctor's visits]. (Patient 30)

Resources that could be accessed repeatedly, such as printed materials or the internet, allowed participants to access and interpret CRD at their own pace. The internet was a highly accessible source of CRD for many participants. One patient participant described being confused about the prognosis of their breast cancer despite receiving prognostic CRD from a physician. The participant used Google to gather additional CRD as the physician was not readily available to provide further clarification. The participant eventually decided to accept the treatment that had been recommended after learning through the internet that their breast cancer is a “more aggressive type so that’s kind of scary, but then there’s the treatment for a year that’s supposed to balance it out” (Patient 29).

Timing. For CRD sources with limited access, participants needed to be able to receive them when they were available. Timing refers to issues where individuals are simply not able to receive CRD even if they are physically presented with CRD. One friend and family participant described an instance of poor timing when CRD was shared with a loved one who was in the hospital and recovering from cancer surgery:

Well, he was on hard drugs. So I couldn’t – like he is stoned, when he was in the hospital. And they are throwing a ton of information at him that I am having a hard time grasping and retaining and so he doesn’t have a hope in hell of getting it. (Friends and Family 3)

Organization. Organization affects how efficiently individuals are able to identify what content of the provided CRD is relevant to them. One participant described the experience of receiving a printed package of CRD from the cancer center, and the subsequent investment of energy and time to identify what was important:

... it was a lot of brochures and then for me it was about weeding out what was important and relevant, so I just focused on like overall what's going to happen with chemo and then just hone in on like [the patient's type of cancer]. Not that anything – like it's not like the other things aren't relevant but [I had to focus on] what I could like absorb [and] what I needed to know. (Friends and Family 22)

Complexity. The complexity of the CRD being shared also affected participants' ability to interpret it. One participant described receiving CRD with technical medical content as “good, but you can only give so much to a laymen and they're not going to understand the rest of it like, it can only be so difficult” (Friends and Family 15). Another participant described the amount of time and energy required to navigate through complicated treatment decisions that had been offered by the medical oncologists. The participant described having multiple “family group meetings” (Friends and Family 9) in which the members of the family would sit in the patient's living room and repeatedly play the recording of the doctor's visit, trying to understand the CRD that were shared in the consultation to make decisions both regarding medical management and how to plan their lives around the data received.

Delivery Method. The method of delivery was also important in terms of participants' ability to access CRD. Different formats of delivery, such as face-to-face discussions with clinicians, education sessions at the cancer center, and internet content, resulted in differences in terms of ease of access. Participants also expressed relative differences in their comfort in each format. Text-based CRD were universally described as helpful. However, some individuals expressed issues with retrieving internet content (e.g., "I don't do the computer" (Patient 3)) or a preference for reading things on paper as opposed to on a computer or smartphone screen.

Credibility. Participants described receiving CRD from their healthcare providers, friends, family, the internet, TV, and other cancer survivors. The usefulness of these CRD was related to the credibility (i.e., reliability) of the source.

CRD received from healthcare providers, including handouts and brochures, were generally considered credible. Oncology specialists, including physicians and nurses, were identified as being the most credible sources of CRD. They were described as being able to anticipate questions and provide answers without even being asked, capable of providing reassurance, and answering the patient's questions based on "where [the patient was] coming from" (Patient 7). General practitioners or family physicians were also considered credible sources; however, several participants indicated that they received little CRD about their cancer from their general practitioner. One participant indicated that they did not trust anything from the general practitioner stating that the general practitioner had "missed the diagnosis [of malignancy] for many years" (Patient 1). Although participants described various degrees of trust in internet sources of CRD, websites such as the Canadian Cancer Society's website were identified as highly credible.

Cancer survivors, defined here as those with a personal diagnosis or the close friend or family member of someone with a diagnosis, were also credible sources of CRD. Survivors provided practical, real-world knowledge about how to manage the consequences of cancer. Participants described “comparing notes” (Patient 12) about where to source complementary products such as hand creams and how to plan for certain treatments. In addition, survivors who had been diagnosed with cancer decades earlier and were still alive existed as CRD that a malignancy diagnosis was not necessarily a death sentence:

Since I have seen people stay over ten years with [specific type of cancer], I’m hoping I will stay about ten years ... I met a woman who told me “oh, this is my tenth year.” So, I believe that if some people can survive it then I will. (Patient 10)

Participants also described CRD from sources that were not credible. They described interactions with well-meaning friends and family who provided CRD about conspiracy theories and unproven controversial treatments. These examples of CRD were described as “uncomfortable noise” (Patient 30) requiring time and energy to evaluate both its credibility and how best to manage the relationship with its source.

Applicability. Although participants described the CRD obtained from healthcare providers as highly credible, the data were not always applicable. Participants described receiving general information packages about nutrition and managing side effects but finding these of limited use or even a source of potential distress. One participant who was receiving immunotherapy described receiving a list of potential side effects of treatment from the medical team providing treatment. The participant described reading through the list and feeling anxious about the potential side effects only to become frustrated when at the bottom of the list it said that immunotherapy patients should “ignore [the list of side effects] and just call the triage number” (Patient 17).

Many participants described receiving CRD from the TV and the internet. CRD from these sources presented challenges for the participants as they were a potential source of fear. One participant described being: “worried about how bad [chemotherapy] was going to be” based on “pictur[ing] it from TV and stuff. Like people just puking all the time” only to find that “nausea was hardly a problem” (Patient 31).

Personal experience provided a source of internal CRD considered to be extremely applicable. Participants, including patients and those supporting them, described that as they gained personal experience with receiving medical care, they were able to find a “rhythm” (Patient 31) as they knew what to expect. This allowed them to become increasingly able to plan activities related to their personal projects, such as their work or other relationships. However, each new challenge, such as an unfamiliar treatment, procedure, or symptom, had the potential to interrupt this rhythm, causing disruption until a new rhythm could be established.

Framing. Whether CRD were framed in a positive way also affected participants' ability to use the data. Positive framing involved communicating information in an honest manner that (1) also highlights the best possible outcome including exceptional outliers and (2) provides options for moving forward. Even when the odds were seemingly against them, participants stressed the importance of focusing on positive outcomes and what they, or clinicians, could do to optimize the situation:

Maybe they're not right with me. Maybe I'm one of the 5%, because I exercise or whatever. ... I can pretend that maybe I'm one of the [few] that will beat this, to some degree, not beat it forever, but go a little longer than they told me. (Patient 1)

You don't want someone telling you, you're for sure going to have, you know, a really bad rash on your hands and feet. You want someone saying, you might have a bad rash on your feet and this is what you do about it. (Patient 2)

They've been amazing, everybody. And helpful and encouraging. ... They haven't been negative about [it], they've just said that there is no cure for this, yet. (Patient 8)

I guess the negative part to me is – cause I've heard and seen people that [say] “well I have cancer so I'm going to die, I know that whether it's five years down the road, I'm going to die.” ... The negative part is “I'm going to die” you know? (Patient 21)

Discussion

Interpretation of Findings

A classic definition of information is “a difference in matter-energy which affects uncertainty in a situation where a choice exists among a set of alternatives” (Freimuth et al., 1989; Rogers & Kincaid, 1981). Benner (2001) suggests that illness and losses such as death “can disrupt

(if not shatter) one's taken-for-granted world" (Benner, 2001, p. 354) and that recovery comes both from "curing the body" (Benner, 2001, p. 354) and through (re)integration of the self into "his or her particular world" (Benner, 2001, p. 354). The theory that emerged in this study links an individual's ability to remain integrated in a world changed by cancer, through maintenance of connection with personal projects to their ability to access helpful information in a way that does not result in further disruption to their life.

The risk benefit consideration identified in existing theories, such as the HIA (Freimuth et al., 1989) and the theoretical framework of HISB by Longo et al. (2009), identify that an important step in the information process is deciding whether additional information should be sought (i.e., cost-benefit analyses). Similarly, this study identified that the cost of seeking CRD is two-fold. First, seeking CRD was an activity that diverted time and energy from personal projects. Second, the cost of basing expectations and making decisions on CRD that are inaccurate is not negligible, as exemplified by the quotes provided in the Applicability subsection in the Results section. Interventions structured on the four components of high-quality CRD outlined in this study, including accessibility, credibility, applicability, and framing, are likely to minimize the cost and maximize the benefit of health information seeking for those living with cancer.

Extending the Theory—A Deeper Grounding of Accessibility and Time

An important component of the information process, in addition to seeking, receiving, and ultimately acting on CRD, occurs between when CRD are received and action occurs. Although the process of interpreting CRD to inform action was not explored explicitly in this study, insights can be gained by examining the findings of this study in conjunction with the existing literature. First, participants in this study indicated that some of their decisions regarding treatment and their personal lives were based on limited or inaccurate CRD. Second, as participants shared and

reflected on their cancer journey, they both reflected feeling and displayed anger, sadness, joy, and a wide range of other emotions. Both observations are congruent with the existing literature regarding the challenges individuals living with cancer face in obtaining useful information (Boons et al., 2018; Fletcher et al., 2017; Halkett et al., 2010; Hyun et al., 2016; Kotronoulas et al., 2017; Longo et al., 2001; McCarthy et al., 2018; Meredith et al., 1996; Mistry et al., 2010; Rutten et al., 2005; Saab et al., 2018; Tariman et al., 2014; Vivar & McQueen, 2005) and the significant role emotions play during the cancer experience (Jagannathan & Juvva, 2016; Thornton et al., 2014). The role of emotions in decision making has been well documented, with both theory and empirical data supporting that emotions affect decision making in different ways (Lerner et al., 2015; Mazzocco et al., 2019). For instance, fear is associated with the interpretation of greater risk, whereas anger is associated with less perceived risk (Lerner et al., 2015; Mazzocco et al., 2019). In addition, research supports that individuals revert to less emotional states as time passes from the inciting stressor, resulting in decision making that is less reactive, and instead guided by reasoning that is more rational, better reflecting the individual's personal values (Lerner et al., 2015; McAlpine et al., 2018).

The insights gained from the data regarding emotions and decision making is important because they add depth to the concept of accessibility and the sub-concept of timing that emerged from this theory. On the basis of the theoretical and empirical data regarding emotion and decision making (Lerner et al., 2015; Mazzocco et al., 2019), for CRD to be useful, they must be provided well in advance of decision making to increase the probability that decision making will be interpreted in a nonemotionally heightened state. Although there is limited empirical evidence to support this conclusion in the cancer context, the literature regarding patient decision aids (PDAs) is informative. PDAs consist of questionnaires or informational packages provided to patients to

assist them in better understanding and engaging with medical decision making ("An introduction to patient decision aids," 2013; Stacey et al., 2017). In a recent Cochrane Systematic Review, although not directly compared in any of the studies reviewed, PDAs provided before consultation compared with usual care appeared to have a positive impact on patient's accurate perception of risk compared with PDAs provided during consultation (risk ratio 2.25, 95% CI 1.65-3.07 vs risk ratio 1.79, 95% CI 1.28-2.52, respectively) (Stacey et al., 2017). If fear is indeed associated with inaccurate risk perception (Freimuth et al., 1989), then this trend suggests that endeavors to understand the role of early provision of high-quality CRD to patients with cancer and those supporting them, guided by the intention of reducing fear and improving decisional quality, may be fruitful.

From Theory to Innovation

The theory that emerged in this study is useful because it identifies guiding concepts for developing high-quality CRD. Providing CRD that are accessible, credible, applicable, and positively framed is predicted to minimize the cost and maximize the benefit of information seeking. On the basis of what was shared by the participants in the interviews and the resulting theory, it is expected that the internet will be the primary delivery method of any novel informational intervention informed by this study. Although universal access to the internet is not a reality, with barriers to access existing for some groups such as those of low socioeconomic status (McCloud et al., 2016), it is estimated that approximately 90% of North Americans have internet access (Statistics Canada, 2020), with rates of internet usage in seniors (aged 65 years and older) being over 70% in some areas (Statistics Canada, 2020). As identified in this study and in the HISB literature in general (Ashkanani et al., 2019; van der Maas et al., 2019), the internet circumnavigates common issues with accessibility, such as the need to travel or being available

only during business hours and the requirement of appointment times to receive information (van der Maas et al., 2019). In other words, it facilitates access to CRD in a way that minimizes the cost to the individual and their personal projects.

Perhaps the biggest challenge with providing highly accessible internet-based CRD is ensuring that it is adequately applicable to “assist with anticipating the sequence of events that will likely take place” (Lambert & Loiselle, 2007). It is plausible that an inversely proportional relationship exists between applicability and accessibility. For instance, in this study healthcare providers were identified as providing the most applicable information, yet they could only be accessed through an appointment taking place at the cancer center. The internet, on the other hand, was very accessible, but many participants identified not being sure of what information was relevant to them. Similar findings have been reported elsewhere (Rolfe et al., 2014; Sbaifi & Rowley, 2017). Taken together with the theory that emerged, this relationship suggests that any novel online informational intervention should be integrated with and informed by local clinical practice patterns.

Given the current state of oncology practice, developing informational interventions that deliver high-quality CRD is likely possible. Contemporary clinical oncology practice relies on evidence-based, guideline-informed practice. A recent retrospective analysis of the Surveillance, Epidemiology, and End Results Program-Medicare database identified deviations from guideline recommendations in the metastatic breast cancer setting occurring only 18% of the time (Williams, Azuero, et al., 2019). Similar findings in the early breast cancer population have been observed (Williams, Kenzik, et al., 2019), supporting that, at least within the breast cancer context, care is relatively standardized in many centers. Standardization of care means that informational content can be developed that is capable of being both applicable to those in any given cancer context,

providing information that helps them predict what to expect. This is because standardization likely facilitates the production of informational content that can be specific about what is going to happen regarding any given process. In contrast, when there is little standardization, specific management details, such as which clinicians will be involved, the treatments that will likely be offered, or the timing of these treatments, may quickly become inaccurate or unreliable, resulting in confusion and distress for individuals using those details to plan their lives. In addition to standardization, internet-based patient portals, which connect patients with cancer to their healthcare data such as consultation reports, imaging, laboratory values, and informational support, are being established at an increasing number of cancer centers (Alpert et al., 2018; Ashkanani et al., 2019; Han et al., 2019; Pho et al., 2018). This also supports that clinical integration of online informational resources delivering high-quality CRD is possible. Given that the hurdles of applicability and accessibility can be overcome, understanding how best to meet specific content needs is an important next step on the path to improving the cancer experience.

Clinical Implications

The theory that emerged in this study informs current clinical practice in several ways. First, it highlights that clinicians are an important source of CRD. The CRD they provide is considered to be both highly credible (Sbaffi & Rowley, 2017) and applicable by those affected by cancer. However, the observed limitations associated with healthcare providers as an information source include accessibility and framing. Clinicians are encouraged to be mindful of overloading patients and their informal caregivers. The theory that emerged here supports that providing CRD to patients when they are emotionally overwhelmed, physically exhausted, or impaired by medication is not effective. The concept of accessibility highlights one benefit of patients having access to recordings of their visits with healthcare providers (Hack et al., 2011), as

this intervention allows the CRD shared by healthcare providers to be carefully reviewed at a time that best suits the patient and their informal caregivers. With regard to framing, it has been reported elsewhere that identifying what the clinician can do for the patient, including treatment options, is an important aspect of sharing bad news (Baile et al., 2000; Girgis & Sanson-Fisher, 1995; Rat et al., 2018). On the basis of the findings of this study, clinicians are also encouraged, when appropriate, to empower patients and informal caregivers following bad news discussions by helping them identify ways to help themselves. This may include assisting with realistic goal setting and identifying activities that the patient and informal caregivers can engage in that will improve their situation in a meaningful way, whether directly related to the disease outcome or not.

Research Implications

It is anticipated that this theory will be useful in guiding the development of novel interventions by providing a framework of key considerations for maximizing the benefit of information seeking in the cancer context. However, it does not provide explicit guidance on content to be included in a novel resource or the format of that content. Although the information needs of those affected by cancer are well characterized, it is not clear from the literature what specific content and resources would be most helpful for meeting those needs. Researchers are encouraged to build on this study and engage with those affected by cancer as partners (Mallidou et al., 2018) to systematically identify the content and method of delivery that is most helpful to those navigating the cancer journey, both in general and in specific contexts not limited to geography, culture, age, gender, sexuality, education, and income.

Limitations

This theory was generated by engaging with adult patients and their friends and family, without exclusion on the basis of cancer type, stage, or treatment intent. The sampling approach focused on obtaining diverse, contrasting perspectives and experiences (Birks & Mills, 2010; Glaser & Strauss, 1967). It is expected that, through the constant comparative method used in this grounded theory study, the emerging theoretical framework will be applicable across the general cancer context. However, specific demographic and cultural groups were not focused on, as this was not within the scope of this study. It is certainly plausible that the concepts, such as the components of high-quality CRD that emerged from this study, will be of varying relevance in different populations. For instance, it is plausible that accessibility may be more important for persons with hectic schedules—such as young adults balancing establishing a career, growing a young family, maintaining a social schedule, and facing the challenges of a new cancer diagnosis—compared with individuals with fewer competing commitments. In addition, although the interpretation of CRD is presented here as a personal process, it has been demonstrated that some individuals may prefer to involve various members of their community, including elders, extended family, and/or spiritual leaders in decision making (Dolan et al., 2019; Hawley & Morris, 2017). These two observations serve as a reminder that theory is not a substitute for engaging with the expected end users when developing interventions intended to help improve their cancer experience (Carman et al., 2013). Finally, as this research study was conducted in the context of the cancer experience in Western Canada, it is certainly possible that how this framework applies to other areas in Canada, and the world for that matter, may differ. Researchers and clinicians are encouraged to explore how the framework presented here can be modified to best reflect the context of living with cancer in their area (Glaser & Strauss, 1967).

Conclusions

The objective of this study was to develop a theoretical framework grounded in the cancer experience capable of guiding the development of informational resources. The framework that emerged links the quality of CRD received to the impact that the cancer diagnosis has on an individual's life. The theory comprises four variables: personal projects, cancer as a project that interferes with existing personal projects, information as the process of receiving and processing CRD to inform action, and CRD quality. Key features of high-quality CRD include accessibility, credibility, applicability, and framing. On the basis of this theory, the internet is foundational for delivering highly accessible information interventions. Clinicians are encouraged to consider accessibility and framing in how they provide information to those they care for. Future directions for research are expected to include engaging with those affected by cancer as partners to develop and integrate informational interventions based on this theory into clinical care. Interventions informed by this theoretical framework are expected to help individuals remain effectively engaged with the personal projects in their lives following a cancer diagnosis and minimize the disruptive impact of the cancer diagnosis on patients and their informal caregivers by decreasing the cost of obtaining useful information.

Conflicts of Interest

None declared.

Chapter 6: Orientation Theory and Optimizing Online Content

Manuscript Title: Navigating The Cancer Journey Using Online Information: A Grounded Theory Emerging From The Lived Experience of Cancer Patients and Informal Caregivers With Implications for Online Content Design

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Abstract

Background: The internet is an important source of information for many patients and informal caregivers living with cancer. A better understanding of how individuals use the internet to meet their informational needs is important for guiding intervention development. The objectives of this study were to: 1) develop a theory describing why individuals living with cancer use the internet to find information, 2) characterize the challenges faced with existing online content, and 3) inform recommendations for online content design.

Methods: Adults (18+) with a history of being a cancer patient or informal caregiver were recruited from Alberta, Canada. After informed consent, participants were engaged through digitally recorded one-on-one semi-structured interviews, focus groups, an online discussion board, and emails. Classic grounded theory guided study procedures.

Results: Twenty-one participants participated in 23 one-on-one interviews, and five focus groups. Mean age was 53. Breast cancer was the most common cancer type. Fourteen cancer patients, six informal caregivers, and one individual reporting both roles participated. Participants experienced many new challenges on their cancer journey and used the internet to become better oriented to them. For each challenge, internet searching attempted to address one or more of the three key orientation questions of: 1) why the challenge was happening, 2) what to expect, and 3) options for managing it. Better orientation resulted in improved physical and psychosocial well-being. Content that was well laid out, concise, free of distractions, and that addressed the key orientation questions was identified as the most helpful in assisting with orientation. Online content creators are encouraged to: 1) clearly identify the cancer challenge and population the content is addressing as well as the presence of any potentially distressing information; 2) provide versions of the content in different formats including (e.g., printer-friendly, audio, video, and alternative languages); 3)

state who created the content, including the individuals, organizations, and processes involved; 4) place hyperlinks after the key orientation questions have been addressed; and 5) ensure content is optimized for discovery by search engines (i.e., Google).

Conclusions: Online content plays an essential role for many on the cancer journey. Clinicians are encouraged to take active steps to help patients and informal caregivers find online content that meets their informational needs. Content creators also have a responsibility to ensure that the content they create assists, and does not hinder, those navigating the cancer journey. Research is needed to better understand the many challenges individuals face on their cancer journey, including how they are temporally related. Additionally, how to optimize online content for specific cancer challenges and populations should be considered an important area for future research.

Keywords: adults; health information behaviour; information needs; internet; neoplasm, theory

Introduction

An information need is an individual's recognition that their knowledge is inadequate to satisfy their goals (Case & Given, 2016). Most of those living with cancer experience unmet information needs at some point (Christophe et al., 2022; Fletcher et al., 2017; Matsuyama et al., 2013; Puts et al., 2012; Rutten et al., 2005). In the curative intent setting, information needs have been identified as the most commonly unmet supportive care need (Park & Hwang, 2012), with a prevalence exceeding 50% (Halbach et al., 2016). In the non-curative intent setting, similar findings have been identified, with information needs consistently being one of the most common and important unmet supportive care needs (Moghaddam et al., 2016). For informal caregivers, including friends and family supporting a patient, information needs are just as important and likely to go unmet with one study reporting a prevalence of unmet information needs approaching 100% (Wang et al., 2018). These findings are not limited to a few studies, as the importance of information and the high prevalence of unmet information needs in the populations affected by cancer has been well characterized in many studies including across different cancer types (Okuhara et al., 2018), and points in the cancer journey (Beernaert et al., 2018; Gianinazzi et al., 2014; Matsuyama et al., 2013). Importantly, the range of information needs experienced during the cancer journey is vast. A recent review identified that the number of distinct information needs characterized in the literature totaled 1,709 (Fletcher et al., 2017). These needs were able to be organized by the authors into 17 distinct categories and 119 sub-categories ranging from treatment-related information to financial and legal information (Fletcher et al., 2017).

Addressing the information needs of those living with cancer, including patients and informal caregivers, should be prioritized by both clinicians and healthcare systems. From a healthcare systems perspective, one systemic review explored the impact of decisional support for

healthcare interventions on the costs of care (Walsh et al., 2014). A total of seven studies were included with decisional support being provided primarily through information sharing interventions delivered via DVDs, booklets, online content, videotapes, and coaching. The review identified that the information interventions were associated with decreased costs of healthcare delivery including through reduced treatment utilization rates (Walsh et al., 2014). Despite not including studies from the cancer context, these findings can be extrapolated. For instance, one systematic review of shared decision making in the lung cancer context demonstrated that shared decision making resulted in decreased emergency room visits and a reduction in the amount of chemotherapy received (Geerse et al., 2018), presumably resulting in decreased healthcare resource utilization and costs.

In terms of clinical consequences, unmet information needs have been shown to be associated with negative outcomes in the short and long term. One systematic review explored the link between information and physical and psychosocial outcomes in cancer patients (Husson et al., 2011). This study found that information provision, quality of information, and satisfaction with information provided were positively associated with health-related quality of life and physical-wellbeing and negatively associated with anxiety and depression (Husson et al., 2011). Similar findings were identified in another systematic review focusing on unmet care needs of both patients and informal caregivers in the advanced cancer setting (Wang et al., 2018). For patients, unmet needs related to information provision, including communication with healthcare providers, and specific information needs, were identified to be associated with increased symptom burden and distress (Baskin et al., 2021). For informal caregivers, the review did not specifically explore how information needs and provision were associated with physical or psychosocial

wellbeing. However, one study included in the review identified that increased caregiver information needs were associated with increased fatigue ($p = .005$) (Chen et al., 2016).

The relationship between information and the physical and emotional well-being of patients and carers is, at least to some extent, causal. Support for this comes both from the theoretical and empiric literature. From a theoretical perspective, information plays a key role in coping with stress (Lambert & Loiselle, 2007; Lazarus & Folkman, 1984). According to stress and coping theory (Lazarus & Folkman, 1984) individuals engage in two types of coping when confronted with a new challenge, these include problem based and emotional based coping. Information can assist with both, as it can help individuals decrease uncertainty about what is to come, resulting in decreased anxiety, and also help individuals plan what action to take to promote an outcome that is in line with their personal goals. Through this theoretical lens (Lambert & Loiselle, 2007; Lazarus & Folkman, 1984; Wilson, 1997), the published literature demonstrating a statistically correlated relationship between unmet information needs and higher levels of depression, anxiety, and increased psychosocial complaints (Husson et al., 2011; Mesters et al., 2001; Wang et al., 2018), supports the important role information plays in assisting with emotional coping.

The literature also provides support for information as a key part of problem-based coping. For instance, one quasi-experimental study (Mollaoglu & Erdogan, 2014) evaluated the impact of an educational intervention on the side-effects of chemotherapy. Compared to usual care, participants in the experimental group received three personalized educational sessions focusing on self-management of chemotherapy side-effects. Participants in the experimental group experienced significantly less (i.e., $p < .05$) nausea, constipation, pain, mouth sores, weight gain/loss, fatigue and difficulty sleeping (Mollaoglu & Erdogan, 2014). Information has also been

shown to help individuals navigate the impact of the cancer journey on the aspects of their lives outside of being patients or informal caregivers by supporting them in coordinating their non-cancer related social roles (e.g., being employees, parents, and friends) around the demands of the cancer journey (Thiessen et al., 2018; Thiessen et al., 2020).

The Internet and the Cancer Journey

Multiple studies have demonstrated that the internet is a key resource for those living with cancer. In one Swedish survey study of cancer patients (n=282), 76.2% of respondents reported using the internet to find cancer related information after their diagnosis (Mattsson et al., 2017). Another survey of advanced breast cancer patients reported that 83% of respondents used the internet to find information related to their diagnosis and navigating the cancer journey on a daily basis (Kemp et al., 2019). Other studies have identified that high rates of internet use are likely related to the fact that, unlike healthcare providers, the internet is accessible around the clock, does not require an appointment/travel to the doctor's office, and affords the individual with a sense of anonymity (Holmes, 2019).

While the internet plays an important role for many on their cancer journey, it by no means is a perfect source of information. An internet connection and appropriate device are required and individuals may not be aware of or feel comfortable accessing online information (Holmes, 2019). For those who can access the internet, the content may be inaccurate, misleading, and a source of confusion and distress (Baskin et al., 2021; Esquivel et al., 2006; Laugesen et al., 2015). A recent review of online content from 48 websites for cancer patients about depression used a validated quality rating tool to evaluate the quality of the content (Li et al., 2021). This review identified issues with accountability in 63% of websites, readability in 54%, and found that only 38% of websites had been updated in the last two years raising concerns about content accuracy. Another

study found that the information patients need and what is available online is not always well aligned (Alba-Ruiz et al., 2013).

A Gap in The Literature

Developing online content to assist individuals living with cancer is a complex challenge where theory, rigorously grounded in empirical data from the cancer context, has an important role to play. Theory facilitates the identification of important factors and variables important for planning how interventions are deployed, predicting expected outcomes, and informing what should be measured to assess efficacy (Craig et al., 2013). Additionally, theory can evolve over time, being revised as newly discovered scientific findings emerge to better reflect the phenomena in question (Glaser & Strauss, 1967; Merton, 1949/1968). Lastly, theory provides common conceptual ground, promoting collaboration amongst researchers, institutions, and across disciplines (Alderson, 1998). In the context of evolving how those living with cancer are cared for, the importance of structuring the development and evaluation of any novel intervention on a robust theory, grounded in the cancer context, cannot be overstated.

Several theoretical conceptualizations addressing how individuals living with cancer get their informational needs met exist. Those by Freimuth et al. (1989) and Longo (2005) are important to mention because they both describe the information seeking behavior of those living with cancer and were developed from data collected in the cancer context. The health information acquisition model by Freimuth et al. (1989) was developed using data collected from the Cancer Information Service, a telephone based information service developed by the National Cancer Institute in the United States (Freimuth et al., 1989). Longo developed a theory of health of information behavior beginning with initial work involving interviews with breast cancer patients (Longo, 2005). Notably, Wilson (1997) incorporated the work of both Longo (2005) and Freimuth

et al. (1989) as well as many other theorists/researchers across a number of disciplines, and synthesized a comprehensive theory of information seeking behavior.

The works of Wilson (1997), Freimuth et al. (1989), and Longo et al. (2001) all provide important insight into how individuals living with cancer seek information. Importantly, the representative models from Freimuth et al. (1989) and Wilson (1997) identify that important cyclical feedback mechanisms exist between stimuli, or perceived information need, and information seeking (Lalazaryan & Zare-Farashbandi, 2014). Both models incorporate cost/benefit (or risk/reward) analysis being performed by the information seeker to determine whether potential benefits to searching for more information outweigh the anticipated costs (Lalazaryan & Zare-Farashbandi, 2014; Wilson, 1997) such as time, energy, and potential emotional distress (Thiessen et al., 2020). An important question that follows from these models relates to how online content can be created to optimize the benefit for the end-user, while minimizing costs.

To work towards addressing this important question, a rigorously developed theory grounded in the cancer experience is needed. This theory needs to conceptualize the challenges that individuals are facing when they turn to the internet, and what makes internet content useful for addressing these challenges. Such a theory would be useful for guiding content creators in creating online content to better meet the needs of those living with cancer.

Study Objectives

This study was conducted to understand how to better support those living with cancer through online information. The objectives of this study were to: a) develop a theoretical conceptualization of what goals individuals living with cancer are trying to achieve (Glaser, 2021) when they use the internet to find information, b) the challenges they face with existing content,

and c) to understand what online design elements would assist them in meeting their informational needs.

Methods

Research participants were recruited from emailing lists maintained by Alberta Health Services (AHS) including individuals living with cancer, as well as a cancer support clinic network. Recruitment posters were placed in clinical areas accessible to ambulatory patients at a major health center in Calgary, Alberta. Participants did not have a previous relationship with the researcher (MT). They were informed of the researcher's professional practice as a medical oncologist in Manitoba, Canada and that the research project was being conducted in conjunction with the researcher's doctoral thesis.

After informed consent was obtained, participants completed a short intake survey (Appendix G) capturing demographics, characterizing their cancer journey (i.e., cancer type, treatment intent, role as patient or informal caregiver), and their interest in participating in one-on-one interviews and focus groups. They then received a study specific username and password to facilitate anonymous participation on the study's online discussion forum as well as email correspondence with the study lead (MT). Study activities included digitally recorded one-on-one semi-structured interviews (via telephone or Zoom), focus groups (via Zoom), email correspondence, and participation in a private password protected online discussion forum.

An initial interview guide (Appendix H) was developed by the authors that was modified as the study progressed, in keeping with classic grounded theory methodology (Glaser & Strauss, 1967). One-on-one interviews and focus groups were conducted with individuals selected to ensure all emerging concepts reached saturation. This involved identifying individuals for these types of study activities based on their responses to the intake questionnaire, availability, and what was

known about them from their responses in earlier study activities (i.e., interviews, focus groups, emails, and online forum response). As concepts emerged, in addition to being explored through interviews and focus groups, questions were posed to all participants on the discussion forum as well as through group emails.

Data collected included field notes (generated by the researcher during interviews and focus groups), transcripts generated from audio recordings of the interviews and focus groups, as well as email correspondence and posts from the online forum. Data analysis involved open, selective, and theoretical coding, as well as the generation and subsequent analysis of memos. Coding was conducted manually using NVIVO 12 Plus (QSR International). Data collection and data analysis continued until theoretical saturation was achieved and a theory had emerged describing a core concept, a number of related concepts, and how these concepts interact (Glaser, 1978). Study procedures were performed by MT and were in keeping with classic grounded theory as outlined by Glaser and Strauss (1967), Glaser (1978), and Holton and Walsh (2016). A summary of methods of rigour employed, as outlined by Chiovitti and Piran (2003), is located in Appendix I. The COREQ checklist (Tong et al., 2007) was utilized to guide the development of this report, and is found completed in Appendix J.

Ethical Considerations

Ethics board approval for this study was obtained through the Alberta Health Research Ethics Board (HREBA.CC-20-0429) prior to the initiation of study recruitment. Informed consent was obtained from all study participants prior to study enrollment. The informed consent process included a discussion with potential participants and the researcher (MT) about the study objectives, methods, risks and benefits, and the option for study withdrawal at any point. These details were also outlined in the consent form. Participants were required to sign the consent form

and return it to the researcher (MT) prior to study enrollment. All data collected was de-identified prior to analysis using a separate master-list. Study data was only accessible to members of the research team. Participants did not receive compensation for study participation.

Results

Between August 2021 and June 2022, 21 participants participated in 23 one-on-one interviews, five focus groups, 26 online forum postings, and sent the lead investigator a total of ten emails responding directly to study questions. Eight participants participated in a single interview or focus group, while 13 participants participated in more than one. The average duration of one-on-one interviews was 52 minutes and 30 seconds. The average duration for focus groups was 57 minutes and 48 seconds. Demographics of the study participants are reported in Table 6.

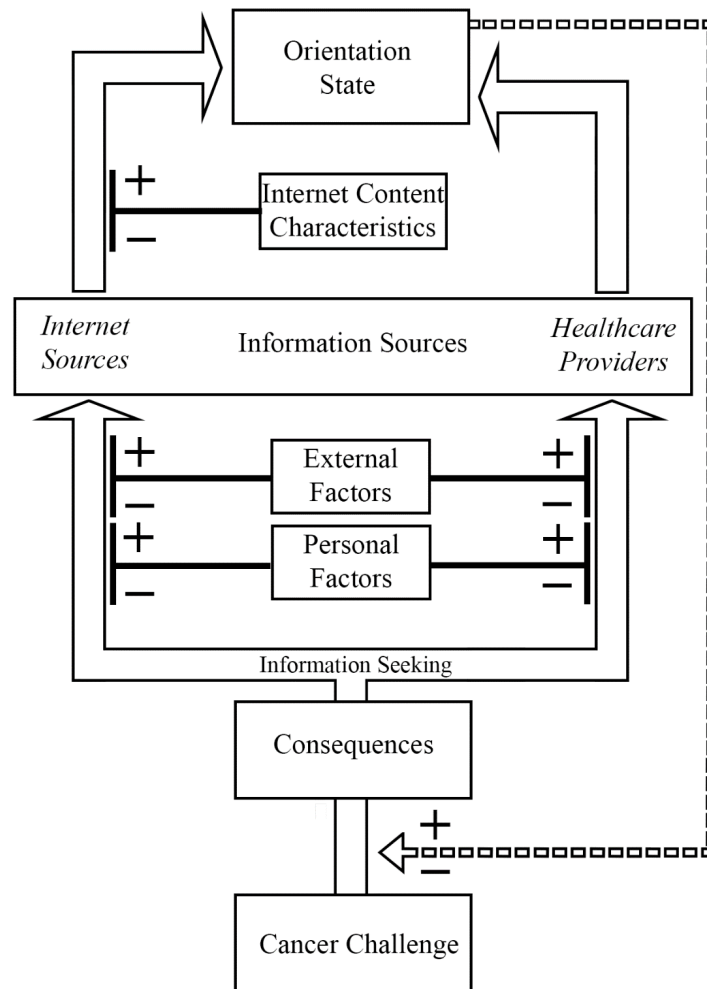
Table 6.*Participant Demographics and Cancer Journey Characteristics*

Characteristic	n	%	Average (min - max)
Female	16	76	
Male	5	24	
Age			53 (19 - 80)
Marital Status			
Single	5	24	
Married	11	52	
Widowed	1	5	
Divorced	4	19	
Cancer Type^{††}			
Breast	4	17	
Gynecologic	4	17	
Hematologic	4	17	
Lung	3	13	
Gastric	2	8	
Colon	2	8	
CNS	2	8	
Prostate	1	4	
Sarcoma	1	4	
Thyroid	1	4	
Reported Treatment Intent^{††}			
Curative	11	50	
Non-Curative	8	36	
Unsure	3	14	
Reported Role			
Patient	14	67	
Informal Caregiver	6	29	
Both	1	5	

† 22 individuals consented to participate in the study, but one was unable to participate in any study activities due to re-occurring scheduling issues.

†† Some participants reported multiple cancer experiences with more than one cancer type and treatment intent.

The theory that emerged consists of six interconnected concepts. These include: 1) cancer challenges, 2) orientation, 3) cancer challenge consequences, 4) information sources, 5) personal and external factors, and 6) internet content design characteristics. Cancer challenges describe the challenges individuals face resulting from a cancer diagnosis. Orientation, the core concept, describes the awareness individuals have of why a challenge is happening, what to expect, and the options that exist for dealing with the challenge. Cancer challenge consequences, or simply consequences, describe the impact that the cancer challenge has on an individual's life. Consequences are potentially ameliorated by how oriented the individual is to the challenge. Information sources are where individuals seek information from to become oriented, not limited to healthcare providers, TV, internet, family, and friends. Factors intrinsic to the individual (i.e., personal factors) and external factors influence individual's preferences for accessing the different information sources. Healthcare providers and the internet were identified as primary sources of information. The characteristics of the accessed internet content impacts how effective it is in helping the individual becoming oriented. The theory that emerged is subsequently referred to as orientation theory. A graphical model of orientation theory is presented in Figure 4. The following sections describe the properties and relationships of these concepts, beginning with the concept of cancer challenges.

Figure 4.*Model of Orientation Theory*

Note. Individuals may seek information as a consequence of facing challenges related to the cancer journey. The internet and healthcare providers are both important information sources. Individuals may use the internet preferentially for a number of reasons including, but not limited, to ease of access, preference for anonymity, or lack of trust in their healthcare providers. Internet content design influences how well individuals are able to use it to become oriented. The state of orientation, in turn, influences the consequences of the cancer challenge being faced, including whether additional information seeking is necessary.

Cancer Challenge

A cancer challenge describes the issues that are introduced into an individual's life because of a malignancy. Participants described a wide range of challenges, ranging from planning travel to the cancer center and managing their day-to-day lives around the cancer diagnosis to dealing with uncertainty and existential issues around end-of-life:

... like how do we manage to get to these appointments and still maintain an income in the family and juggle all of these medical appointments and needs? (Participant #24)

There were important questions about how quickly can you die from lung cancer. ... I think we became more acquainted in the death conversations as the journey became more clear. (Participant #5)

Appendix K contains an illustrative list of the cancer challenges identified through the coding/data analysis process but should not be considered a comprehensive list of cancer challenges individuals experience.

Cancer challenges can be divided into two broad categories: direct and secondary. Direct challenges are related to the physical consequences of malignancy and participating in the receipt of healthcare. Examples include dealing with symptoms related to the malignancy, side-effects of treatments, and navigating the healthcare system to get to appointments and treatments. Secondary challenges are those that arise as a result of direct challenges. They describe the collateral challenges of the malignancy diagnosis on the participant's life in their roles as employees, parents, spouses, and friends. The following two quotes illustrate examples of direct (i.e., managing a

cancer related medical complication) and secondary challenges (i.e., maintaining a household income), respectively:

.. the blood clot that I got in my leg which was actually the sign that we have to do some looking into what's going on – so the blood clot came out of the blue and I [had] absolutely no idea that cancer and blood clots were related. (Participant #12)

And I think that was probably one of the biggest challenges was managing on one income and I'm self-employed, so how do I work around getting to all of these appointments? (Participant #24)

Participants described dealing with many cancer challenges throughout their cancer journey. Data analysis identified that certain cancer challenges more commonly occurred, or become more prominent, at typical times in the cancer journey. For instance, some of the common challenges participants described facing at the time of initial diagnosis included understanding why the cancer occurred, prognosis, figuring out which healthcare providers were going to be helpful, and planning their lives around the receipt of healthcare. Importantly, a common challenge participants experienced was finding information resources to help them navigate the cancer journey. This was especially true in the initial weeks to months between receiving the diagnosis and being connected with the cancer specialists who would be managing their care:

I [had] questions and so I didn't have anyone, not my family doctor, not the specialist, not the surgeon, I didn't have anyone that I could connect with and say: "hey I have questions." "This is what I am concerned about." "This is how I am feeling right now." (Participant #10)

Table 7 provides illustrative examples of cancer challenges identified in this study, including their categorization as either direct or indirect and when they were observed to occur in the participants' lives.

Table 7.

Category, Types, and Timing of Examples of Cancer Challenges

Challenge Category	Challenge Type	Observed Timing*
Direct	Understanding what the diagnosis means	Beginning
	Making treatment decisions	Throughout active treatment
	Starting new treatments	Throughout active treatment
	Identifying which healthcare provider to see for which problem	Beginning, during active treatment
	Sharing diagnosis with friends and family	Beginning
	Managing new treatment side-effects	Re-occurring with each new treatment
	Fear of re-occurrence	After active treatment
	Travelling to cancer center(s) (e.g., driving, parking, lodging)	Beginning and active treatment
	Finding helpful sources of information to help navigate cancer challenges	Throughout the cancer journey
Secondary	Maintaining control of personal schedule	Diagnosis, active treatment
	Maintaining commitments outside of those related to receiving cancer care	Diagnosis, active treatment
	Performing in roles outside of being a cancer patient, or assisting a cancer patient with receiving care	During active treatment and palliation

*Timing reflects general trends when the challenge is common and/or most significant, phases considered include: beginning includes diagnosis and initial treatment decision making; active treatment includes treatments that contain one or more type of treatment and/or multiple treatments in sequence; surveillance occurs following active treatment with the intent of more anti-cancer treatment in the setting of re-occurrence or progression; and palliation includes best-supportive care and symptom management with no additional anti-malignancy directed treatment.

Orientation

Orientation describes the relative state of knowledge a person has regarding each individual challenge they face on their cancer journey. Broadly, the state of orientation an individual is in with respect to a given challenge can be described as oriented or unoriented. Individuals progress from a state of being unoriented to oriented by developing the knowledge needed to address the questions they have regarding the cancer challenge. The questions participants described could be categorized into three groups of representative key orientation questions: 1) “why is this happening?” 2) “what can I expect?” and 3) “what are my options for dealing with this?”

The first category of orientation questions relates to the nature of the challenge, including why something is or has happened. Examples include questions about why certain treatments are being recommended, why symptoms are occurring, and what has caused the cancer diagnosis. For instance, one participant described their experience becoming oriented to why they developed lung cancer:

I [googled] why did I get it? ... Like I am a non-smoker. I have never smoked in my life. ... Was I exposed to any of those chemicals [at work] and you know the answer was “no” I was just an office guy for all those years. ... I’ve got great genes – my mom died at 100 and my dad at 93. ... It’s just luck of the draw and I – I guess I was hoping for something a little more concrete. (Participant #12)

The second category of questions (i.e., “what can I expect?”) reflects the participants concerns about planning for the future and anticipating what kind of challenges they will face. Examples include questions about life expectancy, what the side-effects of treatments will be, and

the timing of appointments. For instance, one participant who was an informal caregiver for elderly parents that had passed away shared:

I remember needing to find out the prognosis ... especially for my dad, [for my] mom it was just three weeks [after the diagnosis] and she was dead. For my dad it was five years and so for him, periodically, I would check in like, has the research changed? (Participant #5)

The third category (i.e., “what are my options?”) reflects the participants search for answers about what can be done to optimize/improve the outcome to the cancer challenge they are facing. Participants described looking for answers regarding treatment options (including conventional biomedical treatments, alternative, and complementary options), exercise, nutrition, and other strategies to manage the many different types of challenge. For instance, one participant described searching for options to minimize chemotherapy toxicities:

I did ask [in the information session], I said “is there anything else I could do or any supplements I can take that would help to boost or build my immune system?” because there is no mention of it whatsoever in any of the [information that was provided]. (Participant #10)

Consequences

The relative state of orientation has important consequences on the wellbeing of the individual facing the challenge. Participants described more negative consequences managing cancer challenges when in an unoriented state, compared to an oriented state. An unoriented state was associated with increased uncertainty about what to expect, what action to take, and a negative impact on the time, emotional and physical energy, and financial resource they had available to

use for the other aspects of their lives. For instance, one participant described the impact of being unoriented about how to manage a common side-effect of chemotherapy, and how information from a healthcare provider helped them become oriented and avoid the problem in the future:

I had a problem after the IV infusion that I would feel like my throat had closed off and I could not breathe - very scary as I thought I was going to pass out. I could not find anything about this side effect. My oncologist was able to tell me some of his understanding of the side effect and how to avoid future problems. (Participant #21)

Another participant, an informal caregiver, shared their experience working with a healthcare provider to manage their partner's seizure medications, and how becoming better oriented to the limitations of the healthcare provider's scope of practice and the resources available improved their cancer experience:

[the specific healthcare provider] only prescribes and knows a couple of very common [seizure medications]. ... because the first medication ... wasn't working, [they] added a benzodiazepine, and then just kept on upping it, and so [the patient] was having pretty detrimental side effects from the benzos entirely, and they also weren't working for seizure control. ... [it] took months [to find a neurologist]. ... the next time that we needed adjustments to medication, ... we just straight up, just went back [to the specific healthcare provider] and said, "We wanna see [the neurologist]." (Participant #9)

Importantly, just as cancer challenges were identified to occur concurrently throughout the cancer journey, the consequences of cancer challenges did not occur in isolation. Participants described being overwhelmed, experiencing intense emotion, and being essentially unable to function at times when they faced many challenges at once – especially if they were unoriented to

several of the challenges they were facing. One participant, an informal caregiver, shared their experience following the diagnosis of their partner:

Yeah, honestly, I think at the time, I don't know if I was feeling much for emotion [I] was just totally overwhelmed. We went from a diagnosis of, "Yes, we believe this is lymphoma," [to] starting chemo because it was stage four [two week later]. So it was very fast and very overwhelming and ... yeah, I mean the dread, the fear, the unknown, it was really so challenging. ... The financial aspect was terrifying, what are we gonna do? My partner had no health insurance and no backup savings or anything like that, and so that was really challenging. And yeah, so feeling very helpless, very alone in trying to navigate things. (Participant #24)

Table 8 provides a summary of the consequences described by participants as they faced cancer challenges from different states of relative orientation.

Table 8.*Consequences of Managing Cancer Challenges From Different Orientation States*

		Orientation Category	
		Unoriented	Oriented
Consequence		Being unsure about how to act, increased chances of making a regrettable choice	Awareness of right choice of action
		Not knowing what to expect	Knowing what to expect
		Not being able to provide others with accurate information	Able to help orient others
		Increased fear, anxiety, stress, pessimism	Reassurance, hope
		Increased requirements of time, energy, and money to deal with challenge	More efficient use of personal resources, including for finding information
		Less effective in participating in management of health issues	More effective role in managing health issues

Information Sources

Obtaining the information needed to become oriented to a cancer challenge occurs in many ways. Participants described receiving information from multiple sources including friends and family, television, and books/audiobooks. Personal experience was also an important source of information, particularly for addressing the key orientation question of “what can I expect?” One participant shared their experience with treatment, and how they had come to learn that their reaction to treatment was unique:

... so you know the treatment has not really affected me I see people come in and they are very [emaciated] and they have no hair and they are very sluggish. ... [I find] that half

way [through treatment] I have a nap, at the first of the treatment and then I'm like ready to tear apart the place I am just so full of energy ... it's been just the opposite for me I guess than it has been for a lot of people. (Participant #13)

Of all the potential sources of information, participants consistently identified healthcare providers as an important source of information. With few exceptions, participants described that they trusted the information that healthcare professionals provided the most compared to other sources. However, the internet was also consistently described by participants as an equally essential source of information.

Personal and External Factors Influencing Information Source

Participants described several factors influencing their choice to use internet content for information, as opposed to healthcare providers. The factors can be divided into the categories of personal and external factors. Preference for exploring content related to cancer challenges anonymously, respect for the healthcare providers' time, or being in an overwhelmed state at the time of the healthcare provider visit were some of the personal factors described. One participant described their experience obtaining information from their healthcare provider:

It wasn't Pollyanna because at that time [of the oncologist visit] you are absolutely on overload already ... I wouldn't have found [more information] useful because you are already up to your shoulders and you just keeping your head above water to help you exist. (Participant #3)

External factors, such as the characteristics of the healthcare system (i.e., clinic location, operational hours) as well as the attitudes and language used by healthcare providers were important in determining the participants choice to use the internet as a potential source. Among

these factors, accessibility of healthcare providers, in terms of geographic location, appointment availability/duration, and general convenience were commonly identified as factors that influenced internet use:

Yah, basically I think as a patient, if I could like email my [healthcare team] I think there would be a lot less random googling, you know? (Participant #15)

Importantly, internet content was not only accessed when participants were unable to utilize information from healthcare providers due to personal or external factors. Even when healthcare providers had provided potentially useful information for helping participants address a cancer challenge, the internet still played an important role for many in becoming oriented. A common practice described by multiple participants was to use the Google search to verify the information they received from healthcare providers, non-healthcare providers, and else-where on the internet. This practice involved looking for additional sources to compare whether the information was consistent. Participants described that when information was consistent between sources, they considered the information accurate and the sources credible. In contrast, inconsistent patterns raised questions of doubt. For instance, one informal caregiver described their experience with a healthcare provider that they ultimately determined as not credible:

... I was looking for other sources of information to see if I could validate or discredit what [the oncologist] was telling [the patient]. And then when I found things online then I went to my [family physician] and asked more questions because that was someone that I trusted, and I didn't trust [the patient's oncologist] and it's a good thing we didn't. (Participant #2)

Situations where internet searching was preferential to obtaining information from healthcare providers was able to be divided into six categories, summarized in Table 9.

Table 9.*Six Situations Where Participants Prefer Online Information*

Category	Supporting Participant Quotes
Accessing routine health services. Looking up things to assist with accessing healthcare services (i.e., directions, phone numbers, hours of operation, parking, lodging).	Sometimes it just basic as getting peoples' phone numbers, so, I might have commented already on that in the blog. But you cannot find palliative care's phone number online anywhere. (Participant #5)
Accessing additional services outside of what the healthcare team routinely provides. Looking up how to access healthcare services not provided through consultation/referral from a healthcare provider in the public healthcare system (e.g., massage therapy, self-referral physiotherapy, naturopath, medical assistance in dying).	Why else did I go to the internet? Sometimes just practical stuff like for a lot of the homecare needs, you know where do you find, you know, a wheelchair and how does that process work? Just the practical details of all of the associated equipment and supplies that were needed because that is not in one place, and it is hard to find. (Participant #5)
Cannot access healthcare providers. Addressing questions that arise in-between, or after appointments.	You know you leave the oncologist's office and it's like "oh shit I should have asked [them] about this" and so I go home and do that kind of searching. (Participant #12)
Questions where a healthcare provider likely will not be helpful, may be hurtful, or there is a preference for anonymity. Questions are out of the provider's scope or not relevant to the specific clinical interaction or responses aren't expected to be helpful.	I had an issue with the eating ... as a big [person], I am programmed not to eat stuff different things. ... I wouldn't talk about it anymore with the doctor for sure. ... they are going to be like "what is wrong with you?" you know it is just going to make me feel bad and life is too short now. (Participant #10)
Validate/fact checking information from healthcare providers or other sources. These questions are related to confirming information received by healthcare providers, other individuals, or other sources - such as the internet.	... so trying to sort out and match what was being told to us by physicians with what the literature was saying out there and seeing if it matched. So a little bit of triangulating, like trying to figure out you know what my parents were saying, what the doctors were saying when I was able to sit in on appointments with either of them and then what I was able to read on the internet. (Participant #5)
Questions not directly related to the care of the individual living with cancer, or the care of a loved one. These questions might include those related to opportunities for publish advocacy or improving cancer care for the future.	I am also part of a support group here in Calgary for Lung Cancer patients, and there are triggers that could come out of that. Somebody will say something about "oh there is this new brigatinib drug" which is like the next level up for me, "oh maybe I should look that up". (Participant #14)

Internet Usage Patterns

Internet Use Timing. In contrast to information accessed through healthcare providers, internet resources are generally accessible around the clock and without travel. Internet information gathering commonly occurs in-between other activities which either cannot be rescheduled or are of higher priority. However, participants also described re-arranging their schedules and setting aside time to facilitate online information gathering to address orientation questions they consider to be high priority. As an example, one informal caregiver described transitioning from searching in between other tasks while “on break” (Participant #5) at work to scheduling time to sit down to find specific information. This occurred when the individual was struggling to address the key orientations questions of “what to expect?” and “what are my options for dealing with this?” after having a disappointing experience with healthcare locally:

So that became a lot more specific in terms of setting aside half an hour to sit down and figure out “who am I going to call at this [out of country] clinic? What information do they need before I call? What do I need to have next to me?” (Participant #9)

Sources and Strategies for Finding Online Information. In general, participants identified that internet information gathering included using search engines, browsing familiar sites, scrolling through social media feeds and discussion boards, as well as accessing online patient portals. Participants described different sources as being useful for identifying different types of information. Social media sources were helpful for connecting with people who had experienced similar cancer journeys, especially in the setting of rare malignancy types. Social media sources were found to be a common source of peer-support, first-person accounts of what to expect, and direction to resources that had been identified as particularly helpful by those in similar situations.

So Facebook I find to be helpful, Twitter, Instagram, TikTok. TikTok is the one when I go on and talk about what I live with and stuff and I blog as well and I do YouTube. (Participant #19)

However, some participants felt that social media and discussion forum content was untrustworthy and avoided it. As one participant stated "... not TikTok or whatever. I refuse to believe anything that's on there." (Participant #14)

A few participants identified that recommendations for internet sites were provided directly by healthcare providers, or indirectly through pamphlets and handouts provided through healthcare system facilities. However, Google searching was identified consistently by participants as the primary approach for finding online information. Participants described using the Google search engine to conduct searches using several keywords related to the cancer challenges they were facing and then browsing search results selecting ones that were assumed to be helpful based on previous experiences with the site, familiarity with the website domain name, or prior recommendations from healthcare providers.

Online Cancer Content Design: Challenges Experienced With Webpage Content

Rabbit Holing. Participants described that when they would begin searching for information about a cancer challenge, they would come across unfamiliar terms and concepts. They would then redirect their internet searches to further explore these new concepts. This process involved clicking on links discovered on websites, or conducting new searches related to the unfamiliar terms. Inevitably, they would end up not addressing the information need related to the initial search. The process, described by the participants as rabbit holing, was eventually terminated when the individual was interrupted by another task or became emotionally exhausted. Going down the

rabbit hole was identified as being a distracting and undesirable event. One participant described their experience:

... you get in that rabbit hole, you click. ... And then you click, and you click, and you click, and you click, and I've done that before myself. And all of a sudden I'm like, "Oh, I actually came here to look up whatever, and an hour and a half later, I'm on some other random site that I've just gone down this rabbit hole." (Participant #24)

Lack of End-User Oriented Design. On multiple occasions participants described accessing online content intended to provide a comprehensive overview of a topic but found the content presented in a way that was problematic. Common issues were too much content, non-intuitive organization/lay-out, or lack of details specific enough to help the individuals address the key orientation questions. One participant described the experience with a website from a prominent Canadian health center:

... you go looking for a certain type of information it does not bring you to what the next logical step is. It is like you have to go really deep into the [website] to find the one piece of the information you are looking for and it shouldn't be like that. (Participant #9)

Participants also described that, without warning, they came across information that was distressing or that they were actively trying to avoid such as information on prognosis. Additionally, content irrelevant to the cancer journey of the individual was often presented on websites from well-regarded cancer centers, including targeted advertisements on webpages designed for people living with cancer. This was identified as a source of distraction that was upsetting to some participants.

Discussion

The cancer journey presents patients and informal caregivers with many new and unfamiliar challenges. The challenges are numerous and varied and include those directly related to engaging with the healthcare system as patients and informal caregivers, and those related to navigating roles as parents, spouses, friends, and employees outside of the cancer context (Thiessen et al., 2020). How well an individual is oriented to these challenges as they navigate them has important consequences for their well-being and their overall cancer experience (Baskin et al., 2021; Chen et al., 2016; Husson et al., 2011; Wang et al., 2018). While healthcare providers are an important source of information, the internet may be a preferred source depending on the challenge the individual is working to becoming oriented to, the personal characteristics of the individual, and those of the healthcare provider and healthcare system.

The characteristics of online content impact how useful it is for helping individuals to become oriented to the cancer challenges they face. The presence of distracting links, unfamiliar terms, distressing content, lack of intuitive design, and absence of information addressing all/any of the key orientation questions are characteristics expected to make online content less useful. Based on the findings of this study, five recommendations for creating online content that supports orientation are as follows:

1. Clearly identify the cancer challenge and population the content is addressing as well as the presence of any potentially distressing information.
2. Provide versions of the content in different formats (e.g., printer-friendly, audio, video, and alternative languages).
3. State who created the content, including the individuals, organizations, and processes involved.

4. Place hyperlinks after the three key orientation questions have been systematically addressed.
5. Ensure content is optimized for discovery by search engines, especially Google.

An infographic outlining these recommendations is found in Appendix L. A detailed discussion of how these recommendations were informed by orientation theory is included in Appendix M. Appendix N includes sample online content developed through the course of the study with the participants, along with an explanation of how it reflects the principles of orientation theory and the five recommendations for online content design.

Building on Existing Theories

Orientation theory is a substantive middle-range theory addressing information seeking behaviour in the cancer context with implications for guiding online content design (Case & Given, 2016) that complements the work of Wilson (1997), Longo (2005), and Freimuth et al. (1989). Both Wilson (1997) and Longo (2005) connect information seeking behavior and information needs with important consequences. Wilson (1997) describes that information seeking, and information behavior in general, is an important part of effectively dealing with stresses. Longo (2005) links addressed information needs with themes of empowerment, satisfaction, increased participation in activities of daily living, and improved health outcomes. Similarly, the consequences of orientation (Table 8) include empowerment through the ability to participate actively in care (including self-management), enhanced emotional wellbeing, and improved participation in the roles and relationships existing outside of healthcare receipt, such as those with friends, family, and the workplace.

Both Wilson (1997) and Longo (2005) identified that individuals obtain information from a number of different sources, but neither of these theories detail specifically why individuals

living with cancer utilize the internet. Orientation theory adds to these works by both identifying the importance of information from healthcare providers and characterizing the internet as a uniquely important source of information in the cancer context that is preferred in some instances (Table 9). Additionally, this theory highlights the important process that individuals engage in to validate information by cross-checking the information they receive from sources, including healthcare providers, with content on the internet. These findings underscore that internet sourced content is not just complementary, but an essential source of information for many living with cancer.

Clinical Implications

Orientation theory describes healthcare providers as both a source of information and an influencing factor on information source preferences. This places clinicians in a position to both provide information and influence which sources are accessed by individuals. Therefore, clinicians should consider providing direction to useful, credible websites, and to support staff such as nurse educators as part of routine practice. Additionally, the provision of educational content that assists patients and informal caregivers in becoming better skilled at evaluating the quality of online content may be a welcome addition by many experiencing cancer, as this will likely go a long way in helping them navigate the many challenges not brought to the attention of their care providers. In particular, online resources that individuals living with cancer may find helpful include: *Health On The Net* ("Health On The Net,"), which provides a search engine restricted to certified high quality online health information; and *Discern* ("Welcome to Discern,"), which provides a tool and instructions developed to help healthcare consumers evaluate the quality of written health information.

Lastly, orientation theory outlines that individuals may have varying levels of comfort with healthcare providers and prefer to explore some topics anonymously or out of clinic. As a result, clinicians should not assume that just because a patient or informal caregiver doesn't ask about a topic, they do not have unanswered questions about it. Orientation theory supports that clinicians should consider voluntarily providing information, including written material or direction to web content that can be reviewed outside of the clinical setting. This is especially true for cancer challenge topics of a sensitive nature that may have major impact on both the patient and informal caregiver such as end of life (Fenton et al., 2023) and the impact of cancer and cancer treatment on sexuality (Albers et al., 2021).

Research Implications and Future Directions

The identification that orientation has multiple consequences and involves finding answers to multiple questions raises concerns about appropriate study measures for evaluating the effectiveness of informational interventions. A scoping review examining existing validated information needs assessment tools developed in the cancer context will hopefully provide some insight into which questionnaires best reflect the concepts outlined by orientation theory (Thiessen, Harris, et al., 2022). However, additional work is needed to explore how the identified consequences of orientation are reflected in existing instruments.

On a larger scale, how to address information needs in a way that results in a meaningful improvement in the cancer experience remains an important question. This study provides an important theoretical starting point (Craig et al., 2013) by describing the concept of “cancer challenges” and the process and consequences of orientation. However, it does not attempt to provide an exhaustive list of the cancer challenges that an individual is likely to face on their cancer journey. This study identified that cancer challenges occur concurrently and that they may be able

to be grouped by their stereotypical temporal relationships. Therefore, it is likely that the most impactful interventions will be designed to support orientation to multiple cancer challenges at once. To accomplish this, research is needed to systematically map out the cancer challenges that individuals face on their journey, including when they are likely to arise to inform subsequent intervention development.

Lastly, one important consideration relevant to both coping with cancer and information seeking behaviour is the distinction between high monitors and low monitors (i.e., bluntes) (Miller, 1995). The literature supports that individuals can be dichotomized into one of these two coping styles, with each having important implications on how an individual navigates health concerns. High monitors have been characterized by being more likely to seek out information about their illness while low monitors typically avoid seeking information (Miller, 1995). Some evidence suggests that these coping styles may be, at least in part, situational (Kaushal, 2002) with individuals exhibiting blunting behaviour in response to some stressors and high monitoring behaviour in response to others. Given the considerable number of cancer challenges that the participants in the study identified, it is certainly possible that there are specific challenges an individual may preferentially seek out information for at any given time, while ignoring others. However, this was not explored in any detail in the current study. Exploring the relationship between cancer challenges and coping style in future research is important as the answers have important implications for further refining orientation theory and informing how to best develop and deliver helpful information interventions.

Limitations

Glaser identifies that theory produced using the classic grounded theory approach is robust and valid, because it emerges from data obtained directly from the field of interest (Glaser &

Strauss, 1967). However, there are a number of important considerations in terms of interpreting and applying the findings of this study. First, the data used in this study was collected from participants who had internet access in a geographic region where healthcare is administered through one body (i.e., Alberta Health Services). Additionally, strategies guiding participant selection for data collection were driven primarily by age, role as either patient or informal caregiver, cancer type, and curative versus non-curative intent. The role of factors such as ethnicity, sex, and gender were not explored. Given the similarities between orientation theory and other pre-existing theoretical work (Lalazaryan & Zare-Farashbandi, 2014; Lazarus & Folkman, 1984; Longo, 2005; Wilson, 1997), it is likely that the identified concepts, and their relationships, have relevance across a wide range of populations. However, the concepts described here, such as the consequences of orientation, likely manifest differently in different contexts. Therefore, some caution should be exercised when applying the concepts of orientation theory to develop content or guide other interventions as the concepts may not be universally applicable. For this reason, including individuals from the target audience in content or intervention development is likely key to ensuring the content is both applicable and appropriate (Manafó et al., 2018).

Lastly, internet use in orientation theory was primarily focused on that of webpage content. This was because webpages discovered through Google searches were identified as the primary source of online content for the participants, with other sources playing a lesser and more inconsistent role. As a result, these other sources of internet content were not explored after the conclusion of open coding (Glaser & Strauss, 1967). Therefore, while it is certainly possible that the insights gained in this study are relevant across other mediums such as social media, patient portals, discussion boards, as well as non-online paper-based content, content creators should exercise caution in applying them outside of webpage design.

Conclusion

Through the lens of orientation theory, the cancer journey can be viewed as one that involves navigating many unfamiliar and often unwanted challenges. How informed individuals are about why each challenge is occurring, what to expect, and the options for managing it has important implications for the individual's wellbeing and cancer experience (Chalmers et al., 2001; Chen et al., 2016; Fletcher et al., 2017; Wang et al., 2018). The high prevalence of unmet information needs of both patients and informal caregivers suggests that there is considerable opportunity for transforming the cancer experience by improving information provision (Halbach et al., 2016; Moghaddam et al., 2016; Wang et al., 2018). The internet has the potential of being a source of low cost, highly quality, easily accessible information capable of improving the journey of many living with cancer. However, in order to create robust and effective online informational interventions, further work is needed to fully understand the cancer journey, the many challenges faced, and how to assess the consequences of orientation. In the meantime, cancer clinicians and creators of online cancer content must recognize the power of information to transform the cancer journey, and their responsibility to share information in a way that does no harm.

Acknowledgements

The authors wish to thank the research participants for the time, energy, and commitment they gifted to this project. This project was supported through scholarship funding awarded to Dr. Thiessen from the University of Calgary Department of Graduate Studies, Faculty of Nursing, as well as from the Dobson Family. This project was completed as part of doctoral work at the University of Calgary, Faculty of Nursing, by Dr. Thiessen.

Data Availability

The data sets generated during the current study are not publicly available as they contain sensitive information that may make it possible to identify study participants, despite careful steps being taken to remove identifying details. Data may be made available upon reasonable request to the corresponding author with ethics board consultation.

Chapter 7: Conclusion

Knitting It All Together: Exploring the Research Findings Using The Key Concepts

The manuscripts presented in previous chapters contribute to the health information behaviour literature as it relates to the cancer experience in several important ways. First, the findings of the scoping review (Chapter 2 and 3) exploring the development of information needs assessment tools for use in the cancer context confirm that the current understanding of the information needs of those living with cancer may be limited, in part, by a lack of engagement with those with lived experience about which informational topics are important to assess and address. Existing tools designed to assess the information needs of those living with cancer have been primarily informed by literature searches and the opinions of the research teams of scientists and clinicians who developed them. Given the context of contemporary healthcare, primarily focused on biomedical care (Toombs, 2001), these findings raise concerns that the information needs assessed by existing informational needs tools may not be those that would primarily support the identities of individuals navigating the cancer journey. Most importantly perhaps, the findings of the scoping review (Chapter 3) suggest that, given the number of information needs that individuals have during the cancer journey (Fletcher et al., 2017; Rutten et al., 2005), there is a paucity of high-quality tools for assessing whether these needs are met.

While work is clearly needed to develop tools for assessing the information needs of both patients and informal caregivers throughout the cancer journey, the findings of the scoping review (Chapter 3) and the insights from the five key concepts presented in the introduction (Chapter 1) provide useful guidance on how to develop these tools. First, tools should assess informational needs related to both biomedical interventions and, importantly, how aspects of the individual's life will be impacted by the receipt of biomedically focused care, reflecting the Coan ethos of

medicine (Toombs, 2001) and Freire's concept of what it means to be human (Freire & Ramos, 1970/2014). Additionally, identity theory (Burke & Stets, 2009) informs the hypothesis that considerable damage to identity, and wellbeing, comes not from the actual medical interventions or cancer diagnosis, but how these impact the individual's ability to participate in the roles and relationships they have outside of participating in cancer care. Identity theory also supports that this impact manifests itself not just in changes to social roles, but also in the emotional experience of living with cancer (Stets, 2005). Therefore, to minimize harm, in keeping with the ethical principle of non-maleficence (Beauchamp & Childress, 2009/1985), information needs assessment tools intended to inform the evolution of both healthcare and research should assess more than just whether individuals have unmet needs related to their biomedical care directly. Tools need to additionally evaluate the individual's understanding of both how care may impact their roles and relationships outside of receiving care and their options for minimizing any negative impacts of biomedical care on their identity.

Developing information needs assessment tools that effectively evaluate information needs both related to the direct receipt of biomedical care as well as the potential impact of biomedically focused care on an individual's roles and relationships requires thoughtful engagement with those that have lived experience. In particular, the issue of how questionnaire items are initially identified and ultimately selected for the final questionnaire needs to be carefully navigated with the concept of identity salience in mind. As discussed in Chapter 1, identity salience (Burke & Stets, 2009) reflects the idea that the identity role an individual participates in a given situation can be predicted by both the priority the individual places on that social role as well as the availability of opportunities to participate in that role. If patients and informal caregivers are asked to participate in the development of an information needs assessment questionnaire, with the intention of

ultimately guiding informational interventions that support not just participation in biomedical care, but also support the individuals in the aspects of their lives outside of receiving care, then the steps to identify what informational topics are important to assess likely need to take place in situations where the individuals are engaging in the social roles not just restricted to participating in healthcare. While it was not rigorously explored in the scoping review, the specific settings where the assessment tools were developed and tested may have had an impact on which information needs were included in the finished questionnaires. For instance, for one questionnaire where the initial items were identified by healthcare professionals, a number of items including those regarding financial support, talking to children about illness, sexual activity, and work were eliminated from the final version of the questionnaire because less than 13% of the patient participants in the final item selection procedure identified these items as important (Galloway et al., 1997). Interestingly, the procedures to identify which items were important appeared to have taken place while patients were in the healthcare setting through interviews that occurred either in ambulatory care clinics, or while participants were admitted to the hospital (Galloway et al., 1997). While it is possible that the low ranking of the items that were removed was related to engagement with participants that did not have children, were previously un-employed, financially well-off, or generally not interested in sexual activity, the concept of identity salience (Burke & Stets, 2009) supports that because the participants were engaged while they were in a setting where they were actively receiving cancer care, and not engaged in the other aspects of their lives (e.g., preparing their taxes), they may have been more focused on informational issues directly related to biomedical care. While the relationship between the setting where the informational needs are identified and what informational needs are identified as important to individuals needs to be explored further, at a minimum, teams developing questionnaires are encouraged to consider ways

to identify informational needs that acknowledge the potential implications of identity salience. Incorporating techniques that encourage the identification of informational needs while participants are outside of the healthcare settings, such as journaling, to identify potential questionnaire items or completing procedures to identify which items should ultimately be included in a questionnaire in a variety of settings, not limited to the hospital and outpatient clinic, are likely to assist in ensuring that questionnaires are not primarily biomedically focused.

The findings of the grounded theory studies presented in Chapter 5 and 6 extend the theoretical literature regarding the information needs of those living with cancer, the role of the internet, and the powerful impact information can have on the cancer journey. First, the identification that high-quality information is that which is 1) accessible, 2) credible, 3) applicable, and 4) framed in a positive way (Thiessen et al., 2020), suggests that assessing whether information needs have been addressed for a topic is more complex than can be accomplished through a few Likert items on a global information needs assessment questionnaire. While such approaches may be appropriate as part of supportive care needs screening, more rigorous approaches to assessing whether the information being delivered is of high-quality are needed for assessing the effectiveness of informational interventions (Craig et al., 2013). Additionally, providing information for those living with cancer, whether in the one-on-one clinical setting or through mass media approaches such as web-content or email newsletters, requires care as each of the four characteristics that define high-quality information need to be integrated into informational content to ensure it is both impactful and useful. Conversely, as identified in Chapter 6, while information is key to helping individuals understand and navigate the challenges they are facing, low quality information can be confusing, dis-orienting, and result in harm to the end-user's wellbeing. It is therefore important that interventions and initiatives intended to assist those living with cancer in

meeting their information needs be rigorously developed with a focus on ensuring that content reflects each of the four characteristics of high-quality information.

Importantly, as identified in Chapter 5 and 6, the internet, and web-page content specifically, provide a clear path to overcoming issues with accessibility. While it is true that barriers to accessing information on the internet exist, such as geographic location, computer literacy, and ability to afford an electronic device that can access internet content (Scantlebury et al., 2017; Zach et al., 2012), it is also true that well designed internet content may be able to overcome many of these barriers such simply being made available in a format that can be printed and mailed to the end-user by a healthcare provider or informal caregiver. Additionally, the ubiquitous use of the Google search engine by study participants in Chapter 5 and 6 suggests that intelligently designed web-page content is likely to be more effective than content presented through custom built apps or social media platforms. In essence, the Google search engine exists as free infrastructure that anyone with internet access can use to create their own informational intervention.

However, just as access to Google is unrestricted, so is the ability to create the content that is indexed by Google and that subsequently appears in search results. This is reflected in the challenges that participants in the research presented in Chapters 5 and 6 experienced when they encountered content of questionable credibility, uncertain applicability, or that was framed in a way that did not help the participants understand what options they had for transforming their reality (Freire & Ramos, 1970/2014). Additionally, while accessing the internet itself and using Google appears to be a challenge for relatively few participants in the study in Chapter 6 were not always able to find content that addressed the challenges they were facing. This may be related to either poor search engine optimization of existing content or simply a lack of existence of truly

helpful content, or both. The findings presented in Chapter 6 provide insights that are likely to help address these issues. In particular, the recommendations for better web-based content (Appendix L) and the development of a template for web-based content informed by both theory and the lived experience of those living with cancer (Appendixes M and N), are likely to support the creation of content that promotes credibility, by being transparent in terms of authorship, that systematically addresses the key orientation questions, including how individuals can help themselves in the situations they are facing, and is structured in a way that enhances Google search engine optimization. But, given the prevalence of unmet information needs in the cancer population and how important the internet is for many on the cancer journey, there is clearly a need for more work to be done, both in terms of research to guide better online content creation and in the creation of high-quality online content that is informed by evidence both in terms of structure and the informational topics presented.

Lastly, both from the findings of the scoping review presented in Chapter 3 and the grounded theory studies presented in Chapters 5 and 6, it is clear that what is truly known about the cancer challenges that individuals face as they navigate the cancer journey is a limiting factor for the development of meaningful informational interventions, including online content. In particular, the temporal relationship between the challenges individuals face on the cancer journey (Table 7 and Appendix K), and the consequences of facing these challenges in an unoriented state (Table 8), highlights the need to better understand the totality of what a cancer diagnosis and the receipt of healthcare introduces into the lives of those affected by malignancy. Incredible advances in scientific research have led to the sequencing of the human genome, identification and characterization of the DNA mutations that drive malignancy, and ultimately novel treatments targeting the cellular machinery that results in malignancy, progression, and death (Hanahan &

Weinberg, 2011). In the same way, the five key concepts (Chapter 1) which lead to my understanding of the knitting problem support that to evolve care in a way that is in keeping Coan ethos of medicine, and the teachings of Hippocrates (Toombs, 2001), understanding the many challenges individuals face on the cancer journey needs to be pursued with the same enthusiasm and commitment as the sequencing of the human genome. By doing so, the same positive transformation that has occurred and continues to occur in terms of biomedical interventions may be seen in how individuals experience life and the cancer journey following a diagnosis.

Future Directions (A Return To the Knitting Problem)

At the start of my journey with the knitting problem, I wondered if a pamphlet provided at the time of consultation with the medical oncologist about colorectal cancer treatment and the risk of peripheral neuropathy would have been a viable solution to address the informational needs of the patient I encountered. Through the work that followed, including what was presented in this thesis, I learned that the knitting problem is not about peripheral neuropathy at all, but how certain parts of the cancer care journey interact with the aspects of individual's identities in ways that are both unique and devastating.

Appreciating that the contemporary context of healthcare delivery is one where biomedical care is prioritized over caring for the global well-being of the individual supports that meaningful and sustainable solutions to the knitting problem will be those that don't attempt to interfere with, but instead compliment biomedical care delivery. As the nurse in the veterans affair study discussed in Chapter 1 indicated: there is simply no time to prioritize things that aren't central to biomedical care (Bokhour et al., 2018). Yet, while not central to contemporary medical practice, caring for the individual in the context of their social lives is part of the ancient tradition of

medicine (Toombs, 2001), and an important part of providing ethical care (Beauchamp & Childress, 2009/1985).

There are still missing threads that need to be found before the knitting problem can be solved. In particular, to understand what information would have been most helpful for the patient I met many years ago, it is important to know what other challenges related to the cancer diagnosis the patient was experiencing at the time they met with the medical oncologist to make a chemotherapy decision (Thiessen, Bouchal, et al., 2022). As the consequences of being unoriented to cancer challenges is cumulative (Thiessen et al., 2020), it is important to understand the sum total of what the patient I met many years ago was up against when faced with an irrevocably life altering treatment decision. This is important both for understanding what sort of intervention, including the types of informational content, might be helpful. The concepts of cancer challenges, consequences of orientation states when facing cancer challenges (Chapter 6), and examples of primary and secondary cancer challenges (Appendix K) are helpful but a comprehensive indexing of the challenges faced during each aspect of the cancer journey, including during an individual's journey with any specific type and treatment pathway of cancer, is needed. Systematically taxonomizing the many cancer challenges faced along the cancer journey, including how they are temporally related, is an important task key for developing informational interventions. This work would inform how to intelligently introduce informational interventions into healthcare delivery, identify what online content needs to be created and how to optimally connect online content through hyperlinks and Google searching, providing insights into what information needs assessment tools need to be developed to guide intervention development.

Additionally, understanding what types of information patients find most accessible in terms of formats would help with delivery of information to address these challenges. While online

information has been identified to be the most accessible for many (Holmes, 2019; Mattsson et al., 2017; Rutten et al., 2005), more granular work needs to be done to identify how to optimize strategies for compassionately conveying complex cancer related information online, including for such topics as treatment options and toxicity. This work will ensure that individuals are able to access the high-quality information that meets their needs, while at the same time not interrupting their routines to do so (Thiessen et al., 2018).

Limitations

The research presented in this thesis adds to the existing literature regarding the health information seeking behaviour of those living with cancer. However, there are limitations that should be mentioned. First, the recommendations for online content creation presented in Chapter 6 (Appendix M and N) are presented as a starting point that will hopefully lead to additional research as well as discourse between patients, informal caregivers, clinicians, researchers, and content creators about how to better create online content to assist those living with cancer. Previous recommendations for online cancer content creation grounded in research, theoretical or otherwise, appear to have been non-existent. The recommendations presented in this thesis should be further developed through iterative research to better characterize how to best create content to address specific situations, such as for specific types of cancer challenges (i.e., initiation of specific cancer treatments), and for specific populations, including, but not limited to those defined by race, gender, sexuality, and disease type.

Regarding the studies presented in Chapters 5 and 6, it should be noted that data regarding race, ethnicity, and culture was not collected. It was recognized by the research team that engagement with specific cultural groups or underserved populations did not occur at any point in the planning of the research work. Therefore, demographic information regarding these population

characteristics was not collected as it was important to avoid the research being interpreted as applicable for any specific group, especially those that are traditionally underserved. Care should therefore be taken in applying the findings from the research presented in this thesis to develop interventions, particularly for underserved populations. In general, any work building on the research presented in this thesis document should involve engagement with the patients, informal caregivers, and the communities aimed to be served in partnerships that first involve identifying which concepts are relevant, applicable, and important to focus on in the work being undertaken.

Lastly, as discussed in Chapter 1, this thesis work was focused on understanding health information seeking behavior and information needs from the perspective of those with lived cancer experience. As such, this thesis did not explore how the theoretical concepts which emerged relate to established work existing outside of the cancer context such as learning theory and pathways for knowledge translation and implementation science. Thus, there are likely important theories that have been developed outside of the cancer context that would provide additional insight into how to assist those living with cancer better navigate the cancer journey through the provision of information. In particular, while learning theories are generally applied within the formal classroom setting, some, such as constructivist learning theory (Bada & Olusegun, 2015) appear to share similar concepts with orientation theory. A rigorous literature review exploring how the theoretical work developed in this thesis aligns with established learning theories may ultimately benefit both those living with cancer and those in more traditional learning environments through the generation of novel high-level theory (Higgins & Shirley, 2000). Regarding knowledge translation, this thesis did not explore how the concepts that emerged could be optimally translated to inform change to current cancer care delivery. As highlighted in the previous chapters, it is recognized that the provision of non-biomedically focused aspects of care

may be challenging to implement (Bokhour et al., 2018) making innovation in how information is provided to those living with cancer an important step for evolving the cancer journey. In keeping with established frameworks for knowledge translation (Graham et al., 2006), work to convert the findings of the research presented in this thesis to real-world change will likely require engagement with healthcare stakeholders at all levels, from administration to front-line clinicians and healthcare recipients, in order to better understand the current state of information provision along the cancer journey, to develop approaches for monitoring progress, and to identify sustainable strategies for implementing evidence based change ("Knowledge Translation," 2016).

Conclusion

Informed by an interaction with a patient who experienced significant damage to their identity as a result of cancer treatment, this thesis has explored how information, identity, and the internet each play an important role in the cancer journey. Recognition that contemporary medical practice, including cancer care delivery, heavily focuses on addressing biomedical issues (Toombs, 2001), often at the expense of an individual's humanity, provides important insights into how to better understand and address the information needs of those living with cancer. Importantly, while unmet information needs are very prevalent in the cancer population (Fletcher et al., 2017), with associated negative impacts on quality of life and emotional state, what is known about the types of information that those living with cancer need to guide their journey is limited and likely influenced by bias from researchers and healthcare providers. Moving forward, work needs to be done to create high-quality informational resources for those living with cancer, that seeks to promote autonomy, minimize harm to the social well-being of individuals, while at the same time requiring few healthcare resources. Beginning this work by further characterizing the many cancer challenges individuals face during the cancer journey and how to optimally deliver content about

complex cancer related topics is an important future direction. But regardless of what is undertaken next, the work must engage with both patients and informal caregivers to identify priorities, processes, and knowledge translation directions that are relevant to the experience of living with cancer. Because, as highlighted in the scoping review results presented in Chapter 3, what is important in the lives of those living with cancer may not always be what is guiding research and healthcare delivery. While the work outlined in this thesis has not solved the knitting problem, hopefully it adds a meaningful thread to the tapestry of work conducted in support of those navigating the cancer journey.

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Appendix A.

Search Strategies for Scoping Review

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily <1946 to November 24, 2021>

Search Date: November 26, 2011

1	(information* or education*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	2393938
2	(assessment scale or questionnaire or survey or instrument).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	1068725
3	(validation or validity or development or reliability).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	3451006
4	(cancer* or oncology* of hodgkin* or neoplas* or lymphoma or leukemia).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	3981125
5	1 and 2 and 3 and 4	3487
6	exp Neoplasms/	3576090
7	exp Patient Education as Topic/	87931
8	exp Data Collection/	2379094
9	exp *"Reproducibility of Results"/ or exp *"Surveys and Questionnaires"/ or exp *Psychometrics/	243139
10	6 and 7 and 8 and 9	661

11	5 or 10	4114
12	limit 11 to (English and journal article and medline)	3434

Limiters: English, Journal Article, MEDLINE

CINAHL Plus with Full Text

Search Date: Friday, November 26, 2021

S1	(TI (cancer* or oncology*) OR AB (cancer* or oncology*)) OR (TI *hodgkin* OR AB *hodgkin*) OR (TI neoplas* OR AB neoplas*) OR (TI lymphoma* OR AB lymphoma*) OR (TI leukemia* OR AB leukemia*)	518,998
S2	(TI information* N2 need* OR AB information* N2 need*) OR (TI information* OR AB information*) OR (TI patient education OR AB patient education)	492,439
S3	(TI assessment scale OR AB assessment scale) OR (TI (questionnaire or survey or scale or instrument) OR AB (questionnaire or survey or scale or instrument))	697,067
S4	(TI (validation or validity) AND AB (validation or validity)) OR (TI development AND AB development) OR (TI reliability AND AB reliability)	69,713
S5	S1 AND S2 AND S3 AND S4	282
S6	(MM "Neoplasms+")	527,065
S7	(MM "Information Needs") OR (MM "Needs Assessment") OR (MM "Patient Education+")	4,583
S8	(MM "Structured Questionnaires") OR (MH "Surveys+") OR (MM "Instrument Construction+") OR (MM "Instrument Validation") OR ((MM "Measurement Issues and Assessments+") OR (MM "Psychometrics"))	259,356
S9	S6 AND S7 AND S8	66
S10	S5 AND S9	346

Limiters: English, Scholarly (Peer Reviewed Journals)

Appendix B.

Data Extraction Tool Developed for Scoping Review

Scoping Review Details

Scoping Review Title: Examining the development of information needs assessment questionnaires in oncology: A scoping review protocol

Review Objective/s: Examine how questionnaires for assessing the information needs of those living with cancer have been developed.

Review Question/s:

1. What questionnaires have been created and validated for evaluating the information needs of people living with cancer?
 - a. What is the stated purpose of each questionnaire?
 - b. What cancer contexts (i.e., cancer type, treatment intent, population) have these tools been developed for?
2. How were the questionnaires developed?
 - a. How were potential questionnaire items identified and finalized?
 - b. How were the questionnaires validated?
 - c. How were patients, healthcare professionals, and informal caregivers involved in the process of developing the questionnaires, including in the identification and selection of questionnaire items?
 - d. How were test and measurement guidelines, such as the COSMIN Checklist, used in the development and reporting of the measure?

Population/Concept/Context Framework**Population** – n/a

Concept - examine how information needs assessment tools have been developed, including the motivation for the development, stages of development, and the process taken to include the expressed information needs of healthcare recipients.

Context - the literature relevant to the cancer context, both in clinical and research settings. It will include published reports describing the development of tools designed for patients, informal caregivers (i.e., friends and family), or both. Literature specific to the paediatric population will be excluded. Non-English language studies will be excluded.

Inclusion criteria

Reports indexed up to date when article searching begins (i.e., post completion of blind protocol peer review).

Reports describing the development OR use of information needs assessment questionnaires specifically for adults living with cancer, including patients and/or informal caregivers.

Reports related to any type of malignancy, including a single or multiple types.

Reports related to any point in the cancer journey, from diagnosis to surveillance or palliation.

Any geographic location.

Exclusion criteria

Non-peer reviewed literature.

Non-English literature.

Reports related to the development of multi-dimensional needs assessment tools (i.e., not focused on information needs).

Reports related to tools designed specifically for the pediatric population, including for adult informal caregivers of pediatric cancer patients.

Reports related to assessing information needs regarding cancer screening.

Details/Results extracted from source of evidence

(in relation to the concept of the scoping review)

Citation Details (author/s, date, title, journal, volume, issue, pages)

Country

Context

Participants

Aim of manuscript

Questionnaire Name

Questionnaire Aim

Intended Context

How are information/information needs described/defined?

Was there a guiding theory/conceptual framework?

What was the process for developing the questionnaire?

How were the patients/informal caregivers/healthcare professionals identified for participation in questionnaire development?

How were patients/informal caregivers/healthcare providers involved in questionnaire item identification/selection? Did the questionnaire items come from a different source?

What were the demographics of the individuals who developed the questionnaire or participated in developing the questionnaire?

What was reported regarding test/measurement guidelines, including testing for structural validity, internal consistency, cross-cultural validity/measurement invariance, measurement error and reliability, criterion validity, hypothesis testing for construct validity, responsiveness, and translation process?

Based on the process used to identify information needs questionnaire items, place an x in the category that best describes the nature of the information needs assessed:						
Questionnaire items reflect:	Normative information needs (i.e., questionnaire items identified and selected by healthcare professionals)	Mostly normative information needs (i.e., some/minimal input from patients/informal caregivers, most influence of item selection from healthcare professionals)	Balanced mix of normative/expressed information needs (i.e., patients/informal caregivers and healthcare providers partnered or were provided relatively equal opportunity for influence on the selection of items)	Mostly expressed information needs (i.e., some/minimal input from healthcare providers, most influence of item selection from patients/informal caregivers)	Expressed information needs (i.e., questionnaire items identified and selected by patients/informal caregivers)	Unable to tell the relative level of influence healthcare providers and patients/informal caregivers had on item identification and selection
X most appropriate:						

Appendix C.

PRISMA-ScR Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	60
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	61
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	64 - 65
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	64 - 65
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	66
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	65
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	66
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	66 – Appendix A
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	67
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	65 - 66
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	66

Critical appraisal of individual sources of evidence [§]	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	n/a
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	66
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	67 – 69
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	71 - 76
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	n/a
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	70 - 81
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	70 - 81
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	81 - 83
Limitations	20	Discuss the limitations of the scoping review process.	83 - 84
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	84
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	85

JB I = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JB I guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

Appendix D.

Data Extraction Spreadsheet Headers

Publication Information					Manuscript Information								
#	Author	Country	Year	Journal	Tool	Tool Development Study	Aspects of Development	Info Defined	Info Needs Defined	Guiding Theory/Framework	Which Theory	Study Objectives (if part of larger work)	Manuscript Objectives

Continued on next line...

Study Details							
Population	Patients vs Informal Caregivers	Curative vs non-Curative	Number of Patients	What did patients do	Informal Caregivers	What did informal caregivers do	Health Care Providers

Continued on next line...

Tools Characteristics (As per Manuscript)											HR PRO Quality as per COSMIN Taxonomy	
Tool Intention	Intended Tool Context	Questions Identified	Question Selection Process	Role of Researchers in Item Selection	Translations	Adapted from a different context?	Influence of HPs	Influence of Patients/Informal Caregivers	What guided psychometric analyses	Tool Developed Guided by guidelines? Which?	Normative Vs. Expressed Needs	Validity

Appendix E.

Intake Questionnaire Used to Guide Selection of Interview Participants

Survey for Patients

We would prefer you to complete this survey at home; Please complete the survey and either email it with your signed consent form to maclean.thiessen@ahs.ca or call 403-521-3276 to make other arrangements.

Date of Birth: _____ Gender: _____

Postal Code: _____

Marital Status:

Single	Married/Common Law	Divorced	Widowed
--------	-----------------------	----------	---------

Education Level:

Some High School	Graduated High School	Some University/ College	Graduated University/ College
---------------------	-----------------------------	--------------------------------	-------------------------------------

Is English your first language?

YES	NO
-----	----

Were you born in Canada?

YES	NO
-----	----

If you weren't born in Canada, how many years have you lived in Canada:

--

Annual Household Income:

Less than \$20,000	\$20,000 to \$50,000	\$50,000 to \$100,000	More than \$100,000
-----------------------	-------------------------	--------------------------	------------------------

I am completing this survey as a:

A cancer patient	Friend of a cancer patient	Family of a cancer patient
---------------------	----------------------------------	----------------------------------

Since the cancer diagnosis, has your family:
Had to alter its plans/goals for the future?

YES	NO
-----	----

Been able to make new plans and goals for the future?

YES	NO
-----	----

Had to change how duties and tasks are divided?

YES	NO
-----	----

Been as reliable with each other as before?
(i.e., make and keep commitments to each other)

YES	NO
-----	----

Were you given enough information **at the time of diagnosis** to plan your life around your cancer treatment?

YES	NO
-----	----

Are there things you wish you would have been told about your diagnosis that you weren't?

YES	NO
-----	----

Are there things you wish you would have been told about your treatment that you weren't?

YES	NO
-----	----

Based on the information you have been given, what is the chance that someone with a cancer like yours will be cured?

Not Curable	Under 25%	25% - 75%	Above 75%	It will be cured	Not Sure
-------------	-----------	-----------	-----------	------------------	----------

Based on what you know, what is the average amount of time someone with a cancer like yours could expect to survive?

Months	Years	Decades	Not Sure
--------	-------	---------	----------

Survey for Family Members of Patients

We would prefer you to complete this survey at home; Please complete the survey and either email it with your signed consent form to maclean.thiessen@ahs.ca or call 403-521-3276 to make other arrangements.

Date of Birth: _____ Gender: _____
 Postal Code: _____

Marital Status:

Single	Married/Common Law	Divorced	Widowed
--------	-----------------------	----------	---------

Education Level:

Some High School	Graduated High School	Some University /College	Graduated University/ College
------------------------	--------------------------	--------------------------------	-------------------------------------

Is English your first language?

YES	NO
-----	----

Where you born in Canada?

YES	NO
-----	----

If you weren't born in Canada, how many years have you lived in Canada:

--

Annual Household Income:

Less than \$20,000	\$20,000 to \$50,000	\$50,000 to \$100,000	More than \$100,000
-----------------------	-------------------------	--------------------------	------------------------

What is your relationship to the patient: (i.e. brother, sister, son, daughter, uncle, aunt, grandmother, grandfather)

--

Since the cancer diagnosis, has your family:

Had to alter it's plans/goals for the future?

YES	NO
-----	----

Been able to make new plans and goals for the future?

YES	NO
-----	----

Had to change how duties and tasks are divided?

YES	NO
-----	----

Been as reliable with each other as before? (i.e., make and keep commitments to each other)

YES	NO
-----	----

Survey For Friends

We would prefer you to complete this survey at home; Please complete the survey and either email it with your signed consent form to maclean.thiessen@ahs.ca or call 403-521-3276 to make other arrangements.

Date of Birth: _____ Gender: _____
Postal Code: _____

Annual Household Income:

Less than \$20,000	\$20,000 to \$50,000	\$50,000 to \$100,000	More than \$100,000
--------------------	----------------------	-----------------------	---------------------

Marital Status:

Single	Married/Common Law	Divorced	Widowed
--------	--------------------	----------	---------

I am completing this survey as a:

A cancer patient	Friend of a cancer patient	Family of a cancer patient
------------------	----------------------------	----------------------------

Education Level:

Some High School	Graduated High School	Some University/College	Graduated University/College
------------------	-----------------------	-------------------------	------------------------------

How long have you known the patient:

Less than 1 year	1 – 5 years	5 – 10 years	More than 10 years
------------------	-------------	--------------	--------------------

Is English your first language?

YES	NO
-----	----

Since the diagnosis, has your friend (understandably) had to alter previously made commitments with you?

YES	NO
-----	----

Were you born in Canada?

YES	NO
-----	----

Since the diagnosis, has the patient been able to be as reliable regarding making and following through on plans with you?

YES	NO
-----	----

If you weren't born in Canada, how many years have you lived in Canada:

Have you been able to be as supportive as you would have liked towards the patient, regarding their diagnosis?

Have you been able to find support to help you cope with the patient's diagnosis?

YES	NO
-----	----

Is there a certain type of information that you did not have access to that you think would have helped you be a more supportive friend?

YES	NO
-----	----

Appendix F.

Initial Interview Guide for Chapter 5

Initial Sample Semi-Structured Interview Guide:

Bolded questions sections will be asked as appropriate. *Italic* text indicates interview script to be stated at the start and end of the interview.

Thank you for agreeing to meet with me/visit over the phone. This interview should take approximately forty-five minutes. It is being recorded. At any point, you are welcome to take a break or stop the interview all together.

Questions for patients only:

Tell me how you learned about the cancer diagnosis?

How has your life changed since the diagnosis?

Were you prepared for these changes?

Some people have expressed that when they are diagnosed with cancer they lose the ability to plan their lives. Did you find this to be true?

Did you find that you were adequately prepared for the impact chemotherapy (and radiation as applicable) had on your life?

What do you consider your work?

How has diagnosis and treatment affected your work?

How far ahead are you making plans right now?

What kind of information helped you plan your life?

Is there any information that you did not receive that would have helped you maintain commitments to friends and family?

What about information to help you maintain your work?

When would the best time to have received this information have been?

What kind of format would have worked the best?

Would receiving detailed information about possible treatments, including schedules, benefits and side-effects, and their duration have been helpful prior to meeting with your oncologist?

Would information about chance of cure and average life-expectancy been helpful to receive prior to meeting with the oncologist?

Questions focusing on information for family (for family and patients):

After the diagnosis, did your family's routine change?

Did attending medical appointments and receiving treatment affect your family's function?

How was it affected? *or* How did you manage to not let treatment and medical appointments affect your family's functioning?

What kind of information did you receive that helped you maintain your family function after diagnosis and through treatment?

How have you been a supportive family member?

How have your family members been supporting you?

Is there any information that you can think of that would help you be more effective at supporting your family members?

Is there any information that would help support you?

What kind of information would have been helpful to support your family in maintaining its ability to function after diagnosis and through treatment?

When would the best time to receive this information be?

What would have been the best way to receive this information?

What are your thoughts on receiving this information perhaps in the mail or outside of the clinic?

Questions for friends only:

After the diagnosis, did you notice any changes in your relationship?

Did any of the plans you had made previously with ‘patient’ change after the diagnosis?

How have you found making plans with ‘patient’ since the diagnosis?

Have you found ways to be supportive? What kind of things to you do?

Is there any information that would help you be a more supportive friend?

Is there any information that would help support you, as the friend of someone living with cancer?

When would you have liked to receive this information?

What would be the best format for this information?

Thanks for taking part in this interview. This concludes your participation in this study. Contact information for myself, my supervisor, and the Alberta Health Sciences Research Ethics Board are listed inside of the consent form if you have any questions, comments or concerns.

Appendix G.

Intake Survey for Chapter 5

- 1) Please complete this survey at the time of completing your consent form. Its purpose is not to exclude individuals, but to ensure a diverse group of people are included in this study.
- 2) This questionnaire uses the term “living with cancer” to refer to individuals that have either received a diagnosis of cancer, supporting someone that is, or has been affected by someone else’s cancer diagnosis.

Year of Birth: _____ Gender: _____

Postal Code: _____

Marital Status:

Single	Married/Common Law	Divorced	Widowed
--------	--------------------	----------	---------

Education Level:

Some High School	Graduated High School	Some University/College	Graduated University/College
------------------	-----------------------	-------------------------	------------------------------

Is English your first language?

YES	NO
-----	----

Were you born in Canada?

YES	NO
-----	----

If you were not born in Canada, how many years have you lived in Canada:

Annual Household Income:

Less than \$20,000	\$20,000 to \$50,000	\$50,000 to \$100,000	More than \$100,000
--------------------	----------------------	-----------------------	---------------------

You are completing this questionnaire as a:

A cancer patient	Friend of a cancer patient	Family of a cancer patient
------------------	----------------------------	----------------------------

Is this your first experience with cancer?

YES	NO
-----	----

Do you have thoughts or ideas about how you could be better supported as someone living with cancer either as a patient, or supporting a patient?

YES	NO
-----	----

Do you consider yourself to be “computer savvy”?

YES	NO
-----	----

Do you use email regularly?

YES	NO
-----	----

Do you use the internet regularly for web searching?

YES	NO
-----	----

Are you comfortable participating in small group discussions?

YES	NO
-----	----

Would you be comfortable participating in an online videoconference (equipment will be provided if you do not already have access to the internet or web-conferencing equipment)?

YES	NO
-----	----

Would you be comfortable providing information through email correspondence?

YES	NO
-----	----

What kind of cancer do you, or the person you are supporting have? (Please fill in the blank)

Is the cancer being treated with curative or non-curative intent?

Curative	Non-curative	Unsure
----------	--------------	--------

For Researcher Use Only

Study Number:

Appendix H.

Initial Interview Guide for Chapter 6

Estimated time: 105 minutes (15 minute introduction, 45 minute sessions, 15 minute nature/refreshment break, 45 minute session)

Introduction – outline background to the project, what the purpose of this project is.

Part 1 Questions (45 minutes):

- 1) Let us go around the room, please share your name, where you are from, and why you agreed to participate in this study?
- 2) When was the very first time you remember being confused or uncertain about something related to cancer? (follow-up questions: Why was that issue important to you? Were you able to find clarity? How did you find it?)
- 3) What kind of challenges does cancer present to your life?

Break – 15 minutes

Part 2 Questions (45 minutes):

- 1) People find different types of information helpful for planning their lives. What kind of information have you used to plan your life around receiving support or supporting someone with cancer? What was helpful, what was not?
- 2) We will now look at some specific examples of informational content that someone with cancer might access or be provided with. Can you tell me how these examples would be helpful? Can you tell me what could be changed to make this content more helpful to help you plan your life? – Show examples of different cancer specific content including websites, handouts, email newsletters, social media posts.
- 3) In seeking to understand how different types of information are useful for planning one's life following cancer, is there anything that you would like to share?
- 4) Let's go around the room, and take turns summarizing today's discussion...
- 5) Have we missed anything? Is there anything that I should have talked about but didn't?
- 6) Is there anything that regarding to informational resources related to living with cancer that we didn't talk about that you feel is important for cancer patients?

At the conclusion of the focus group, participants will be encouraged to communicate any additional thoughts and share examples of helpful resources with the researcher electronically in the next seven days.

Appendix I.

Rigour Statement for Chapter 6

Implementation of eight methods of research practice for enhancing rigor in grounded theory research. Adapted from Chiovitti and Piran (2003)

Suggested Method	Implementation Approach
Let participants guide the inquiry process	Participants were asked to respond primarily to open ended questions, which evolved as the study progressed to explore the concerns of the participants and the role of the internet in addressing these concerns.
Check the theoretical construction generated against participants meanings of the phenomenon.	Throughout the study, and especially as the study approached conclusion, the emerging concepts were reviewed explicitly with the study participants in one-on-one interviews, focus groups, and online forum discussion. Additionally, the emerging concepts were used to guide the development of sample online content with participants, and the feedback from this feedback of the initial drafts was used to revise both the content and to inform the emerging theory.
Use participants' actual words in the theory	Short and long quotes from participants are used throughout the presentation of the theory. Additionally, several of the concepts were either named using participants words (i.e., rabbit holing) or terms that were confirmed as helpful by participants (i.e., validation).
Articulate the researcher's personal views and insights about the phenomenon explored.	The researcher (MT) is a practicing medical oncologist who has a research interest in understanding how to better support those living with cancer through addressing their information needs. This research project was conducted as part of PhD thesis work. He has conducted three previous classic grounded theory studies, exploring how identify is impacted by the cancer diagnosis, what makes quality information, and the variables that define and impact the cancer experience. He tends to view the information that is available to patients and their friends and families as either potentially empowering or oppressing in keeping with the concepts of critical education theory outlined by Paulo Freire.

Credibility

	<p>In general, the analysis of collected data was done within a symbolic interactionist framework informed by identity theory. Based on this, the researcher studied the incidents in the to understand how they related to the individuals journeys to perform within their established social roles.</p>
<p>Audibility</p> <p>Specify how and why participants in the study were selected</p>	<p>The recruitment approach was designed to include a number of individuals with varied cancer experiences, based on their age, cancer types, and roles either as patients or informal caregivers. As a result of the approach used, participants were able to be selected for specific study activities based on their personal characteristics to ensure that concepts were explored with individuals that had varied cancer experiences. In practice, this process involved inviting specific individuals for focus groups and one-on-one interviews based on their responses on the intake questionnaire.</p>
<p>Fittingness</p> <p>Delineate the scope of the research in terms of the sample, setting and the level of the theory generated</p> <p>Describe how the literature relates to each category which emerged in the theory.</p>	<p>Please see Table 6 for sample characteristics. The theory developed can be considered to be a middle range theory.</p> <p>How the main concepts of this theory add to the existing literature is outlined in the discussion section.</p>

Appendix J.

Completed COREQ Checklist

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	142
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	Appendix I
Occupation	3	What was their occupation at the time of the study?	Appendix I
Gender	4	Was the researcher male or female?	Appendix I
Experience and training	5	What experience or training did the researcher have?	Appendix I
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	141
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	141
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	141
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	141
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	141 - 142
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	141
Sample size	12	How many participants were in the study?	143
Non-participation	13	How many people refused to participate or dropped out? Reasons?	143
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	141
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	n/a
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	144
<i>Data collection</i>			

Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	141
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	143
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	141
Field notes	20	Were field notes made during and/or after the inter view or focus group?	142
Duration	21	What was the duration of the inter views or focus group?	143
Data saturation	22	Was data saturation discussed?	142
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	143
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	142
Description of the coding tree	25	Did authors provide a description of the coding tree?	n/a
Derivation of themes	26	Were themes identified in advance or derived from the data?	n/a
Software	27	What software, if applicable, was used to manage the data?	142
Participant checking	28	Did participants provide feedback on the findings?	Appendix I
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	147 - 155
Data and findings consistent	30	Was there consistency between the data presented and the findings?	147 - 155
Clarity of major themes	31	Were major themes clearly presented in the findings?	147 - 155
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	n/a

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix K.

Cancer Challenge Example List

As noted in the manuscript, this list is not exhaustive of all of the challenges related to the cancer journey that individuals experience. It is provided to further illustrate the concept of cancer challenges and was generated from the relevant open codes resulting from the data analysis process.

Direct Challenges

Working with healthcare providers

Understanding who to ask for what

Navigating interactions with unfamiliar providers

Finding information to assist with

Preparing for appointments

Getting needs met despite limited time with providers

Finding strategies for effective information sharing

Trusting healthcare providers

Understanding prognosis

Treatment

Understanding the intent of treatment

Understanding steps in treatment

Understanding the side-effects/toxicities of treatment

Understanding how response is assessed

Is this the right treatment for me/patient?

What are the treatment options?

How will I/the patient be cared for during treatment?

What do I need to do during treatment?

Transitioning between phases of the cancer journey

Managing cancer symptoms

What does this new symptom mean?

Surveillance

What are the signs of re-occurrence?

Minimizing the chances of re-occurrence?

What foods to eat versus avoid?

What supplements can be taken?

What do the test results mean?

Navigating (new) healthcare systems

Where can I find additional supports outside of what my healthcare providers are offering?

Getting to and from medical care?

Parking

Lodging

Travel

Managing emotional well-being

Dealing with being overwhelmed

Living with uncertainty

Fear

Finding and using information

Is this information trustworthy?

Where can I find reliable information?

Secondary Challenges

Coordinating life goals around healthcare provider appointments and treatments

Managing unsolicited/unwanted opinions regarding cancer treatment from friends, family, and strangers

Sharing diagnosis with friends, family, employers

Dealing with employers

Dealing with finances

Minimizing the negative impact of the diagnosis on relationships

Maintaining a household

Helping other cancer survivors

Appendix L.

Infographic For Better Online Content

An Infographic For:
MAKING BETTER ONLINE CANCER CONTENT

Five theory based recommendations to guide webpage content creation in support of people navigating the cancer journey.

BE SPECIFIC, SENSITIVE, AND SYSTEMATIC

Address a specific cancer challenge for a specific population and clearly identify who your content is for. If your content is potentially upsetting, provide an early warning so readers are not caught off-guard.

Systematically address why the cancer challenge happens, what to expect, and what steps the individual can take to have the best outcome.

MAKE CONTENT FOR EVERYONE

The cancer journey doesn't discriminate. Your content shouldn't either. Develop your content into multiple formats, so it can be used and appreciated by the widest audience possible.

A printer friendly version is key, but consider other formats such as a pre-recorded slideshow (e.g., Microsoft PowerPoint), downloadable audio version, or infographic.

TELL THEM WHO MADE IT

Make sure to identify the people and organizations involved in making your content. Content that comes from different sources has a different perspective and will convey different messages.

Being transparent about who made the content and how it was generated will help the end-user understand what perspectives might be missing, and what other types of sources to look for.

AFTERWARDS, SHOW THEM THE WAY

Keep the body of your content clear of hyperlinks. Instead, place links at the end of your content. Include links to content addressing the same/similar challenges to yours, as well as other challenges that the end-user is likely facing at the same time.

This will prevent the end-user from getting distracted (i.e., rabbit holing) and will also help guide them to other helpful content.

MAKE IT GOOGLEABLE

Google search is how most people find online cancer content. Your content may have the power to make a big difference in someones journey, but if it isn't properly indexed on Google people are probably missing out.

Optimize your content for Google using tips from Google's Search Engine Optimization (SEO) Starter Guide (hint: Google it).

For more information about these recommendations, and the project that informed them, go to:
www.cancermaps.ca

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Appendix M.

Five Recommendations for Better Online Content

Orientation theory identifies that the internet plays an important role in helping individuals living with cancer understand the many challenges they face, including what options they have for managing them. Additionally, it identifies that the characteristics of internet content are an important determinant of whether the content is helpful in assist individuals in orienting to a specific cancer challenge (see Figure 1 of the accompanying manuscript). To date, specific guidance for how to optimally design online content to assist individuals on the cancer journey does not appear to have been developed. The following five recommendations are informed by orientation theory and are expected to minimize some of the challenges the participants in the orientation theory study experienced with existing online cancer content.

- 1. Clearly identify the specific cancer challenge being addressed, the specific population the content is for, and the presence of any potentially sensitive information.**

The cancer challenge and target audience the content is designed for should be clearly identified so the end-user can easily determine if the content is applicable to them and whether they want to review the content. Additionally, content should be designed to address the three key orientation questions (i.e., why is this happening, what can I expect, and what are my options), as they pertain to the cancer challenge being addressed. Additionally, the presence of potentially sensitive information such as that related to prognosis should be highlighted to provide caution to the individual and help them decide if they want to navigate through the content.

This recommendation reflects the findings from this study and others (Eysenbach, 2003; Fleisher et al., 2002; Helft et al., 2003) that online health content is not benign and may be a potential source of harm. Without clear clues about the nature of the content and who it is for,

individuals may not be able to discern whether information is relevant to them resulting in unnecessary investment of time used to consume the content or misdirection in terms of the actions they take to navigate the cancer journey. In terms of ensuring the key orientation questions are addressed for each cancer challenge presented, this approach ensures that individuals are able to begin to understand the main aspects of each challenge with each piece of content – and aren't left searching for more content to address one of the orientation questions. Additionally, by highlighting the presence of potentially sensitive information, such as discussions about end-of-life or prognosis, end-users will be given the autonomy to decide whether they wish to further explore the content or avoid the potentially stressful topics for the time being.

2. Content to address a specific cancer challenge should be developed in multiple languages, literacy levels, and audio/visual formats.

Content creators should endeavour to present content in languages and formats that are easily understandable and accessible to the target audience. In addition to meeting increasingly recognized online accessibility standards (Kelly et al., 2009; Lewthwaite, 2014), non-English translations, and printer friendly versions should be made available for content whenever possible. Participants in this study identified that the content they found online was consumed in a number of ways, settings, and was also accessed to provide information to other individuals with a preference of print material – such in the case of adult patients providing information to elderly parents with a preference for print material. Therefore, providing content in multiple formats is likely to make the content more accessible and, in doing so, more helpful. This recommendation reflects the concept outlined by orientation theory of personal factors being a potential barrier to accessing informational sources, including those on the internet. By consistently providing content in multiple formats, individuals will be more likely to identify the format that is most helpful for

them. Additionally, it will serve to minimize the challenge of gathering information from content and sources that are, in and of themselves, challenging for the individual end-user due to issues such as language barriers, learning style, or conflicting priorities.

3. The organizations and individuals responsible for developing the content should be clearly identified, as well as the process for how the content was developed.

Content should clearly identify both the organization and authors responsible for creating it, including relevant credentials and affiliations. This is important because individuals in the orientation theory study identified that, in addition to comparing informational content from multiple sources, they also considered the credibility of the source in terms of weighing the accuracy of the content. This recommendation also aligns with published recommendations for evaluating online health information quality (Silberg et al., 1997). Additionally, the content should clearly identify how it was developed. In particular, the roles and contributions of patient/informal caregivers and healthcare professionals should be outlined. This is important, as those with lived experience will be oriented to the cancer challenge being explored differently than healthcare professionals.

These practices in reporting should not be seen as barriers to content creation for those without professional credentials or organizational affiliations, as these things do not necessarily result in useful content. Instead, they should be considered necessary steps to ensure transparency and to assist individuals consuming content in fully evaluating for themselves what information, and perspectives they will use to navigate the cancer journey.

4. Hyperlinks should be placed at the end of content and should include links to both other sources addressing the same cancer challenge as well as related cancer challenges.

Including hyperlinks to help end-users identify similar and related content elsewhere on the internet is an important part in creating useful online content. Links to content from other sources addressing the same cancer challenge is a key step to helping end-users verify what is accurate, by supporting them in comparing information across multiple sources. Similarly, including links to other cancer challenges that the individual is likely to be facing at the same time (e.g., early on the cancer journey versus when transitioning to surveillance versus when transition to palliative care) will assist individuals in becoming oriented to the other cancer challenges they will be likely to face. The importance of this is described by orientation theory, as it was found that the participants frequently expressed navigating multiple challenges at once, and these challenges could be predictably grouped.

However, an important challenge that the participants faced was that hyperlinks were embedded in online content in a way that was distracting and lead them away from working through the content that was being presented (i.e., “rabbit holing”). To address this, hyperlinks should be placed outside of the body of the content being presented, after the key orientation questions have been addressed. This approach to content design will assist end-users in working through the content, including through the key orientation questions, while also supporting them in discovering content that is relevant to the cancer challenge that they are facing, and other challenges that may be of relevance.

5. Content should incorporate search engine optimization (SEO), especially for Google

Content should be designed to be accessible and discoverable directly through Google searching, in addition to any other internet media platforms. This recommendation reflects the common practices of the participants in the accompanying study for accessing online content as well as the fact that Google has been reported to have over 86% of current search engine market share (Davies, 2021). In comparison to directly accessing content on well-known, reputable, or recommended websites via URL entry or bookmarks, browsing through Google results was identified as the primary strategy for identifying online content by the orientation theory study participants.

While a complete discussion regarding search engine optimization (i.e., SEO) for Google (Cushman, 2018; Google, 2023) is beyond the scope of this document, three key points are worth noting. First, Google's indexing relies in part on keywords used in titles, headings, and hyperlinks (Google, 2023). Therefore, the page title, headings, and hyperlink descriptions should be both concise and describe the cancer challenge. When possible, use language in titles, headings, and text that includes terms likely to be used by the intended audience searching for content on the cancer challenge (Google, 2023). Engaging with patients and informal caregivers to understand what search terms and strategies they would use to find content on the cancer challenge being addressed is a key activity to understanding how to incorporate appropriate terms in titles, headings, and hyperlinks. Lastly, analysis of hyperlinks included in the page being indexed is an important part of Google's indexing algorithm (Google, 2023). Including hyperlinks labeled with descriptive keywords to reputable content will help Google identify when it is appropriate to include the online content that has been created in the search results (Google, 2023).

Appendix N.

Theory Based Explanation of Generated Sample Content

Exploring The Sample Content: Orientation Theory in Action

As part of the orientation theory study, sample content was created to explore the emerging theoretical principles. Importantly, the recommendations described in the main manuscript and elaborated on in Appendix I were informed in large part by the iterative process that resulted in the sample content. This process of content creation was embedded in the methods of the orientation theory. After initial theory development, and the identification of a relevant topic for content creation in collaboration with the participants, an initial draft of the content was developed by the researcher (MT) based on the emerging theoretical concepts. Next, the content was reviewed with the study participants through interviews and focus groups, with the data collected from these study activities being analyzed to guide further development of the emerging theory. In turn, the revised theory informed further development of the sample content, which was subsequently re-reviewed with the participants. This process repeated iteratively until no further revision to the theory were needed as the sample content were identified as well laid out, useful, and complete by the study participants.

The sample content is currently located online ("Sample Content: Preparing For Meetings With Cancer Specialists," 2022). The following sections provide a top to bottom of the sample content with commentary informed by orientation theory and the five recommendations forwarded in the preceding section. Of note, the following sections do not specifically address how the content is informed by recommendations for search engine optimization (SEO) for Google (i.e., recommendation #5, Appendix I). However, it should be noted, that the use of short, concise,

descriptive, titles, headers, and hyperlinks will assist with SEO. Additionally, the inclusion of hyperlinks for both similar and related content are also expected to assist with Google SEO.

Content Panel #1: Orientation Panel

Making The Most of Your Cancer Specialist Visit

Content Advisory: This this page has been developed for adults living with cancer (i.e., patients, and their supporters). It has not been designed to meet the needs of health professionals or children. This page does not contain information about prognosis or other potentially distressing topics.

Page Summary: This page contains information about what to expect and how to prepare for your first visits with a cancer specialist. It has been designed for individual's at the start of their cancer journey. It may be helpful for individuals at any point in their cancer journey. The content was developed with input from people who have experienced cancer in the province of Alberta, Canada, but the content is general so it will likely apply in other parts of the world.

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Contributors: The research participants in the CancerMaps research project

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[QuickReference Worksheet](#)

The orientation panel is positioned at the top of the sample content and provides essential information for the end-user about the content that is to follow. The first three elements orient the end-user to what is being addressed in the content. First, a title makes clear reference to the cancer challenge being addressed (i.e., meeting with a cancer specialist). Second, a content advisory informs the end-user about any potentially sensitive information that may be contained below. Finally, the page summary provides additional details to the end-user about what the content covers, and who it is specifically designed for. These three elements are designed to help the end-user become quickly oriented to the content provided and decide whether they wish to invest further time and energy into navigating it. This first section primarily reflects the principles outlined in recommendation #1, Appendix I.

Next, author and contributor information are included. This content helps end-users who are comparing multiple sources of information make determinations regarding the validity/accuracy of any specific content, especially when inconsistent information is identified.

Including this reflects recommendation #3, Appendix I. This is followed by links to alternate versions of the content. These alternate versions reflect that the heterogeneous personal characteristics of individuals living with cancer result in different needs in terms of content format. Overall, the orientation panel is a key piece of the content, in that it helps orient the end-user to what is included in the following content, how alternative formats can be accessed, and what level of trust they should put in the content.

Content Panel #2: Addressing The Why And What To Expect

Why am I seeing a cancer specialist?

Cancer specialists focus on caring for people living with cancer. Typically, the term cancer specialist refers to a surgical, medical, or radiation oncologists. These are types of physicians who have completed medical training that includes extended training in areas related to cancer care. Surgical oncologists perform surgery to remove cancer, when possible. Medical oncologists use medications that are taken by mouth or are injected to control or cure cancer. Radiation oncologists use radiation which can be administered using external beams, internal implants, or through pills or solutions that are taken by mouth in order to cure or help control cancer.

You likely have been referred to a cancer specialist by another healthcare professional to manage a cancer diagnosis. When a non-cancer specialist suspects cancer often they will arrange for tests or procedures to confirm a cancer diagnosis. These may include biopsies, bloodwork, and imaging tests. When the results of these are available, they will often send what is called a "referral" to a cancer specialist who will work to co-ordinate expert care for the cancer diagnosis.

What can I expect from my cancer specialist visit?

Cancer specialists usually work out of large health centers in major cities. Patients are often referred to a cancer specialist by a family physician, general surgeon, or other healthcare professional involved in the diagnosis of the cancer. Cancer specialists need special resources to do their jobs and have specialized training that they can pass on to learning healthcare providers. As a result, they often work out of large urban centers.

Appointments to see a cancer specialist can take a while to happen. After you are referred to a cancer specialist, it may take weeks before you are contacted with your appointment. You may be given your appointment with short notice. It is normal to feel anxious and frustrated with the time it takes to just find out the day and time when you will be seen. Additionally, the emotions you experience related to being diagnosed with cancer can be overwhelming. When the day of your appointment finally comes, travelling to the cancer center for the first time, finding parking, and then waiting to be seen (which may occur well after your scheduled time) may leave you emotionally and physically exhausted.

Visits with cancer specialists can be stressful. Waiting to find out more about a cancer diagnosis, including how it may impact the other aspects of your life and what kind of treatment is needed can be a stressful experience. There are also a lot of other things about the experience that people find stressful like finding parking, sitting in the waiting room beyond your scheduled time waiting to be seen, and trying to remember everything the cancer specialist has to share. Additionally, you can expect to meet more people than just your cancer specialist, as nurses, trainees, and administrative staff may all be involved in your care. It is not uncommon for people to feel overwhelmed, and even frustrated with the experience.

Orientation theory identifies that, with regards to any specific cancer challenge, there are essentially three key orientation questions that individuals search out answers for: 1) why is this happening; 2) what can I expect; and 3) what can I do. In the first section of the body of the sample content the first two key orientation questions are addressed. Headers are used to identify which orientation question is being answered, with each paragraph addressing a sub-question. Importantly, for this content, the sub-questions were identified based on the data collected from

the participants about what they experienced regarding the specific cancer challenge of meeting with their oncologist.

This approach reflects recommendations #1 and #3 (Appendix I) as the key orientation questions for the cancer challenge are addressed systematically. Additionally, the approach of basing the content on input from those with lived experience speaks to why including multiple perspectives in content creation can enhance the quality of the content. Without the input from the participants, it may have been possible for the author to identify some of the possible sub-questions, however, there were some that were not predicted a priori by the author as important but were highlighted by the participants. Conversely, the author was able to provide details that added to the study participants understanding of the cancer challenge by providing additional insights.

Content Panel #3: Addressing What Can I Do

What can I do to make the most of my visit?

Being prepared for your visit will increase the chances that you will have a positive experience at your appointment. The following sections include tips and advice from people that have been in your shoes as well as from healthcare professionals to help you navigate your first appointment. After you have reviewed the content below, check out the "Quick Reference Guide" at the top of the page for a handy checklist to help get you ready for this important meeting.

Patients and Their Support People Recommend:

Give yourself time to plan and prepare the day before the visit. Whether you are the one that has been diagnosed with cancer, or you are supporting someone living with a diagnosis, give yourself time to prepare before you need to rush out the door to make it to the appointment. Is there information that the specialist will need to care for you, such as a list of medications? Do you have a plan for getting to the specialist appointment? When will you need to leave your house? Do you want to arrive with extra time to eat a snack, find and use the bathroom and figure out where the clinic is before you are expected at your appointment? How are you getting home after the appointment?

Make a list of questions you want to ask ahead of time. There is a good chance that before your first visit with a new cancer specialist you will have lots of questions. Take some time to get organized, perhaps the night before, and identify what questions are important to you. Try to prioritize them in case there isn't a lot of time in the appointment. Of your list of ten questions, which ones are most important to get answers for? At the start of your visit let your cancer specialist team know that you have some questions and ask when the best time to go over them would be. Start with the most important questions. If you aren't able to get helpful answers ask your healthcare providers where else you can go for information.

Plan for the cancer specialist visit to take the whole day. You probably have been given a very specific time for when your appointment will occur, but the time you will need to be at the cancer center is probably longer. Especially if it is your first visit, you might need extra time for unexpected tests or even to see another health professional. Depending on what happens in the appointment, you may also benefit from some extra time afterwards to just decompress and collect yourself. Similarly, if you are scheduled to work or have other commitments around the appointment, it is not a bad idea to let your boss and whoever else know that you need the whole day for the appointment. As you become more familiar with what to expect with your visits, you might find that you can better predict how much you need to put into the meter and when you can return to your other duties—but for the first few visits it won't hurt to play it safe. Check out the link to "How to Navigate Employment and The Cancer Journey" in the "Related Cancer/Maps Content" section below for more information on working with employers.

Lastly, if you are planning on driving or you have someone that is driving you, consider how you are going to deal with parking. Worrying that the meter is going to run out if your appointment takes longer than you expect might cause unnecessary stress. Consider paying for an hour or two more than when you expect your appointment to end, or even for the whole day, until you get a better idea of how long your appointments will take.

Healthcare Professionals Recommend:

Learn and use strategies for dealing with stress in a healthy way. Just like athletes need to relax in the days and hours leading up to a big event to perform their best, taking care of yourself before stressful parts of your cancer journey is important. Taking care of yourself will help you be in a better place mentally and physically to work with your healthcare team and the people in your life that are sharing the cancer journey with you. In addition to getting organized in the days leading up to your appointment, consider taking some time to relax and unwind as best you can. Check out the link in the "Related Topics" section below for content on managing stress, including strategies you can use on your own to help you relax your mind and body when navigating stressful situations.

If you can, bring a team to support you emotionally, physically, and to help gather information. A first appointment with a new oncologist can be incredibly overwhelming. It is not uncommon for patients to remember very little of what is said, such as important information about diagnosis, treatment options, and what to expect in the future. As a result, they may have a difficult understanding what is going on or helping the people in their lives understand what to expect and how they can help. Additionally, if difficult news is shared by the healthcare provider, a patient may not be in a good mental state to travel home alone. A small team of one or two friends or family members who can drive the patient, drop them off at the front doors, figure out parking, take notes, ask the healthcare providers questions, and generally help the patient if they become overwhelmed will make the experience less stressful.

Find a way to record important conversations so that you have the option to review them later or share them with interested friends and family. Research shows that there are many benefits to recording the conversation you have with your oncology specialist. Whether or not you have someone along with you that can take notes of what is said, using a device like your smartphone to record what the cancer specialist is sharing will give you a record you can refer to later to ensure you haven't missed anything. Plus, the recording can be shared with other friends and family who are interested in learning what was said. Many people use the camera/video recording application on their smartphone to record their appointments. Some centers offer a dedicated smartphone app or offer a consultation recording service, but any recording app will work. You can also purchase a handheld audio recorder from most office supply stores that will work well (just make sure you get the salesperson to show you how to use it). Let the know cancer specialist know you would like to record the visit so you don't miss anything that is said and so you can share what is being communicated with the other people supporting you. If you are not able or interested in recording the visit, consider bringing a pen, paper, and something hard to write on so you, or someone accompanying you, can take notes.

After the first two key orientation questions have been addressed, the body of the content moves to address the third orientation question. This section outlines what actions the individual can take to improve their outcome with the cancer challenge. The inclusion of this section reflects the importance of addressing all three key orientation questions in content tackling a cancer challenge. Without it, individuals may be left wondering what they can do, or unknowingly taking actions that make their experience worse. This again reflects recommendation #1 (Multimedia Appendix I) and the importance of ensuring that all key orientation questions are systematically addressed.

Additionally, this section also is divided into what the participants in the study recommended and what healthcare professionals recommend in terms of making the most of a cancer specialist visit. Here again, the different orientation that individuals have to a specific cancer challenge is important and highlighted. The recommendations generated by the participants in the orientation theory are very different from those that came directly from the author, who is a practicing medical oncologist. Additionally, this speaks to the importance of clearly identifying who informed the content, in keeping with recommendation #3 (Appendix I) as end-users may wonder why recommendations for navigating cancer specialist visits differ from other sources ("What to Expect in Your First Meeting with Your Cancer Doctor | Dana-Farber," 2019).

Content panel #4: Hyperlinks

Content From Other Sources on This Topic:

[Working with your healthcare team](#) - Content from the Canadian Cancer Society

[Making the Most of Your First Appointment with Your Oncologist](#) - Content from the Memorial Sloan Kettering Cancer Center

[What can I do BEFORE my first appointment with the oncologist?](#) - Content from OncoLink/University of Pennsylvania

Other Topics You Might Be Wondering About:

[Coping With Anxiety and Stress](#) - Content from the Canadian Cancer Society

[Understanding Your Lab Test Results](#) - Content from the American Cancer Society

[Cancer and Work](#) - Content from McGill University, Montreal Canada

Supporting Scientific Articles That Are Free to Access:

[Association of Mindfulness-Based Interventions With Anxiety Severity in Adults With Cancer: A Systematic Review and Meta-analysis.](#) JAMA network open, 3(8), e2012598

[Prime Time for Consultation Audio Recordings: Supporting Shared Decision Making During and After the COVID-19 Era.](#) JCO Oncology Practice 2021 17:4,161-163

[Patient participation in the cancer consultation: Evaluation of a question prompt sheet](#) Butow, P.N. et al. Annals of Oncology, Volume 5, Issue 3, 199 - 204

The placement and content of hyperlinks in the sample content reflects recommendation #4 (Appendix I). Regarding placement, orientation theory identifies that one of the challenges with internet content is that hyperlinks can be distracting and direct individuals away from thoroughly reviewing content related to a cancer challenge. Therefore, to avoid this, hyperlinks should be placed after the key orientation questions have been addressed.

Regarding the specific links, it was identified in the study that resulted in orientation theory that the participants often verify the information they come across, including that from the internet and from healthcare professionals, by reviewing content from multiple sources. Therefore, the sample content includes links to similar material from other sources, in an effort to connect the end-user with content from other sources so they can verify for themselves what is accurate and obtain additional perspective. Lastly, as individuals face multiple cancer challenges at once, hyperlinks are included for other cancer challenges they may be facing at the time of their first visits with the cancer specialist.

The links to peer-reviewed articles that are relevant to the cancer challenge is in keeping with concepts described by orientation theory. Some participants expressed a preference for reading, if not simply being able to access, relevant scientific, peer-reviewed, articles for the cancer challenges they were facing. This reflects both the unique personal characteristics of individuals informing what formats are useful (e.g., recommendation #2, Appendix I), as well as the importance of credibility in helping individuals trust the information they are encountering in the orientation process.

Content Panel #5: How To Find A Real Person

How Can I Get Help from a Real Person?

Your healthcare team, including your family physician, cancer specialists and any nurses involved in your care team are likely good people to talk to if you have concerns about your appointments. Additionally, many cancer centers have counsellors and other people who can help you navigate the many challenges of the cancer journey, but you may need to ask your cancer specialist how to contact these people. Proceed to your nearest emergency department or call an ambulance (911 in Canada and the United States) if you feel that you or a loved one is in danger.

For ways to connect with a real person for additional supports, that do not require a referral from your healthcare providers, check out: [The CancerMaps Real-People Resources Directory](#)

It was identified in the orientation theory study that the internet is often accessed when individuals cannot access their healthcare team, or, alternatively, are uncomfortable asking a

member of their healthcare team for information about the cancer challenge they are facing. These issues did not always reflect a preference for internet information, and it was not uncommon for the participants to express that they would have preferred to have been able to access a healthcare provider that they were confident and comfortable asking their question to, in a timely manner. Therefore, this panel works to address the issues by providing end-users with access to resources where they can find additional information about their cancer challenge or other challenges through interacting with a real person. Like the text addressing the key orientation question of “what can I do” (see: Content panel #4), this section provides the end-user with another option in terms of managing their cancer challenges.

Content Panel #6: Publishing Information

Publishing Information:

First Published: April 21, 2022 Revised: June 26, 2022

Initial Development: Content based on a data collected and analyzed as part of the CancerMaps research project. Iteratively reviewed with study participants until content and study results finalized.

Date Reviewed: No formal review/update has take place to date.

[Click here](#) for more information about the CancerMaps project, findings, and how to use the CancerMaps format.

Lastly, this panel includes information about initial publication dates, time of updates and more details about how the content was developed. Publication dates, and dates of review were identified by some participants as important, but not as consistently as the other elements of the content and were unable to be clearly linked to orientation theory. The additional details about how the content was developed were endorsed as adding some value by a few participants, and were initially in the first content panel. However, they were subsequently placed at the bottom of the page to make the first content panel more concise in keeping with participant feedback.

Appendix O.

Permission to Include Unpublished Manuscript

The signatories below agree that the, yet unpublished, manuscript entitled “Examining the Development of Information Needs Assessment Tools for Use in The Cancer Context: A Scoping and Critical Review”, may be included in this thesis.

Daranne Harris: _____ Date: _____

Patricia Tang: _____ Date: _____

Shelley Raffin Bouchal: _____ Date: _____

Shane Sinclair: _____ Date: _____