Oncology Patients’ Experiences of Using Electronic Patient Portals and Other Online Tools to Support Care and Treatment

by

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A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Nursing

Faculty of Nursing

University of Alberta

Abstract

With the current proliferation of clinical information technologies in Canada, patient portals and other online tools are becoming increasingly adopted in healthcare. Many people use the Internet for health-related purposes to connect with peer support groups and read about their medical conditions and prescribed medications. Research studies show that oncology patients have a keen interest in portals, as they often require more comprehensive health information when compared to the general population. In Canada, patient portal technology is relatively new and evidence on the benefits of portals is limited. Moreover, research has not been conducted in Canada regarding the use and effects of patient portals in oncology practice. This qualitative descriptive study employed individual semi-structured interviews with oncology patients and/or their family caregivers to explore patient experiences of using portals and other online tools for care and treatment. Eleven participants were enrolled in the study. Interviews were audio-recorded and transcribed verbatim. Using thematic analysis, the following themes were identified: (i) experiencing doubt and the desire for transparency; (ii) becoming an informed and active member of the healthcare team; (iii) encountering complexity; and (iv) emphasizing the importance of the patient-provider relationship. Although participants considered online tools as beneficial, it was unclear whether they actually fostered feelings of empowerment; thus, further research is needed to clarify this association.

Preface

This thesis is the original work done by Amanda Santos. The qualitative research study, “Oncology Patients’ Experiences with Novel Electronic Patient Portals to Support Care and Treatment: A Qualitative Study with Early Users and Non-users of Portals in Alberta, Canada,” received ethical approval from the University of Alberta Research Ethics Board (Pro00098299) in August 2020. This qualitative research study is a component of a larger longitudinal study being conducted by Dr. Petrovskaya.

Chapter 2 of this thesis has been published as Santos, A., Caine, V., Robson, P. J., Watson, L., Easaw, J., and Petrovskaya, O., “Oncology Patients’ Experiences with Novel Electronic Patient Portals to Support Care and Treatment: A Qualitative Study with Early Users and Non-users of Portals in Alberta, Canada” in the JMIR Cancer. I was responsible for the literature review, enrolling participants, data collection, data analysis and writing the manuscript. Both Dr. Olga Petrovkaya and Dr. Vera Caine assisted with data analysis and contributed to the manuscript. Dr. Olga Petrovskaya was the original creator of the concept and ethics application forms.

Acknowledgements

I would like to thank my supervisory committee: Dr. Olga Petrovskaya and Dr. Vera Caine, as well as Dr. Susan Sommerfeldt who was my examiner during the proposal defense. I cannot express enough thanks to Dr. Petrovskaya and Dr. Caine for the continued support and for providing me with this tremendous learning opportunity. A special thank you to Dr. Petrovskaya for challenging me throughout the process and more importantly for believing in me as a student, and to Dr. Caine who helped alleviate my stress and gave me the confidence to complete my thesis. Dr. Caine, your encouragement when the times were tough was duly noted. My heartfelt thanks to the both of you.

A special thanks to the Senior Leadership at Cancer Care Alberta for supporting this study, to the manager of patient engagement at Cancer Care Alberta who facilitated the recruitment process and to the participants of the study. This study would not have been able to take place without their assistance.

Thank you to the following scholarship foundations for helping support my graduate studies: the Alberta Graduate Excellence Scholarship, the Helen Rollis Prize for Excellence in Advanced Nursing Practice, the Scott Family Graduate Scholarship, and the Lowry Award from Edmonton Community Foundation.

Finally, to my remarkable and loving father, my deepest gratitude goes to you. You encouraged me to pursue my career in nursing and taught me the true meaning of compassion. To my mother, thank you for inspiring me to become a diligent worker. I would not be where I am today if it wasn’t for the both of you.

Table of Contents

List of Abbreviations

Abbreviation	**Unabbreviated**
AHS	Alberta Health Services
eHealth	Electronic Health
EHR	Electronic Health Records
EMR	Electronic Medical Records
ICT	Information and Communication Technology
IT	Information Technology
mHealth	Mobile health
MAC	MyAHS Connect
MADI	MyAlberta Digital ID
MPR	My Personal Records

CHAPTER 1: INTRODUCTION

In Canada, electronic healthcare (eHealth) has become an integral part of healthcare delivery and its use continues to grow rapidly (Canada Health Infoway, 2020). eHealth uses the Internet and technologies, such as computers, to help deliver healthcare services more effectively and efficiently (Doak et al., 2020). The Internet and digital medical technologies assist in expediting access to medical information for both patients and healthcare providers. For example, online patient portals are being implemented in the Canadian healthcare system, as an increased number of physicians, clinics and hospitals have adopted this type of technology (Canada Health Infoway, 2020). Portals, an extension of the electronic medical record (EMR) that stores health information generated and controlled by the provider's organization, give patients the opportunity to access the majority of their personal health information (Kildea et al., 2019). Personal health information includes: patient's medical history, laboratory results, medications, allergies and diagnostic results. Portals also serve as a communication tool (e.g., via secure messaging) for patients and healthcare providers; thereby, encouraging patients to be more involved in the management of their health (Powell & Myers, 2018). Furthermore, some portals may also permit patients to book appointments with their healthcare providers and refill medication prescriptions (Gheorghiu & Hagens, 2017). Today, Albertans can access their personal health information via two patient portals. In addition to portal technology, many people use social media and the Internet to obtain health-related information.

As transparent and convenient as sharing health information on portals may be, there are risks associated with its use. First, sharing patient health information online may jeopardize patient safety if an instance were to occur where information was made available to a third party either accidentally or intentionally. Second, test results may be misinterpreted by patients who lack the understanding and medical knowledge to interpret them accurately. This inability to comprehend their medical results could cause intensified levels of anxiety; thereby, increasing the demand on healthcare professionals to provide constant reassurance to their patients (Winget et al., 2016). Despite the aforementioned risks, portals are considered to be beneficial to healthcare providers, patients and health systems (Antonio et al., 2020). This is because the use of portals augments patient engagement, empowerment, knowledge and can improve overall health outcomes (Kildea et al., 2019). Moreover, using portals encourages patients to adhere to medical advice, assists with the accuracy and the completion of healthcare records, results in fewer inpatient visits and provides patients with an additional method of communication with their healthcare providers (Graham et al., 2020).

The Canadian Cancer Society (2019) predicts that approximately 1 in 2 Canadians will be diagnosed with cancer in their lifetime, and about 1 in 4 will die of the disease. In Alberta, cancer is also a critical health problem for numerous people, as the same statistics apply for its residents (Surveillance & Reporting, 2015). With the increase of cancer diagnoses, patient portals are becoming more desirable to augment the coordination of care for oncology patients (Coughlin et al., 2018). Studies conducted in other countries have demonstrated that oncology patients use portals, as they often require in-depth health information in comparison to the general public (Kuenzel et al., 2018). In the United States, multiple studies have shown that utilizing portals can be beneficial to oncology patients. They often provide oncology patients with additional support systems and allow them to manage multiple treatment plans more easily (Rodriguez, 2018). Due to the recent implementation of patient portals in Alberta, there is a lack of understanding about portal use and effects among oncology patients. Similarly, it is not known how and why Albertans diagnosed with cancer use the Internet and social media to search for health-related information. Therefore, it is imperative to explore patient practices and experiences of using online tools for care and treatment to obtain a better understanding of portal use and to address unforeseen obstacles in the province.

Literature Review

eHealth in Canada

eHealth refers to the application of digital health technologies and includes telehealth, virtual care, mobile health (mHealth), big data systems, health information technology (IT) systems, consumer health IT data, electronic health records (EHRs) and electronic medical records (EMRs) (Canada Health Infoway, 2020) (Refer to Appendix A for definitions of various eHealth tools). In Canada, eHealth continues to be readily adopted in the healthcare industry and has become an essential part of healthcare delivery (Canada Health Infoway, 2020). eHealth uses medical data and information and communication technology (ICT), such as mobile devices to augment healthcare services (Doak et al., 2020). The Internet and communication technologies can assist in delivering quality care by educating and empowering its users, making healthcare more equitable by extending services, expediting access to medical information and ensuring the information provided is evidenced-based for both patients and healthcare providers. Furthermore, eHealth is transforming the way patients and providers communicate and establish rapport, as patients have immediate access to medical information and are able to attend virtual medical appointments with various healthcare professionals (Eysenbach, 2001). In Canada, the objective of using eHealth is to encourage Canadians to live healthier by offering a system that securely connects its users with valid, up-to-date health information and allows citizens to better understand and manage their own health (Canada Health Infoway, 2020).

For patients in Canada, using eHealth tools means having self-confidence in scheduling medical appointments electronically, as well as accessing personal health information and other health information independently. For Canadian healthcare providers, using eHealth is believed to improve patient safety while prescribing medications electronically and consult other specialists more conveniently (Canada Health Infoway, 2020).

As the use of eHealth continues to evolve in Canada, the more patients and healthcare providers are recognizing the benefits it can offer (St-Denis, 2017; Canada Health Infoway, 2020). Canadians, in particular, are eager to have electronic access to their personal health information and have expectations to manage their own health in today's digital world. For example, one study found that only 11% of patients utilized their physician as a first source to obtain health information, whereas 49% of patients used the Internet as their initial source (Zychla, 2017).

Patient Portals in Alberta. Currently, Albertans can view their personal health information via two online portals accessible through the Government of Alberta website under the aegis of MyHealth Records: 1) MyAHS Connect, an EMR-tethered patient portal offered through Alberta Health Services (AHS) settings (Graham et al., 2020; AHS, 2020) 2) MyPersonal Records, a citizen portal (Government of Alberta, 2020). A patient portal is a protected computerized application that distributes personal health information and allows patients and healthcare providers to interact securely. This clinical information technology is believed to create a patient-centered environment that encourages patients to become more self-aware and involved in the management of their care (Zychla, 2017). Patient portals are being adopted and implemented around the nation by an increasing number of physicians, clinics and hospitals. Access to patient portals is controlled by the organization that collects and stores the information within an EMR, EHR or hospital system. Patients are provided with a secure login enabling them to review their personal health information, book medical appointments, send messages, request medication prescription renewals and communicate with their primary healthcare provider. Furthermore, some portals may allow patients to upload their own health information (Gheorghiu & Hagens, 2017). For some patients today, a portal may be the 'cornerstone' for assessing and evaluating their medical health status (Zychla, 2017). Occasionally, the term patient portal is used synonymously with the term personal health record; however, these tools are different. A personal health record is typically untethered from organizations and controlled by patients (Archer et al., 2011; Innovatemedtec, 2020).

In March 2019, Alberta's Ministry of Health (Alberta Health) released a province-wide electronic portal called MyHealth Records allowing all Albertans aged 14 years and older to access their health information online including medication history, immunization records and common laboratory results. More recently, a list of lab results available via this portal was expanded and other functions added to the portal, such as secure messaging with select providers.

In an attempt to provide healthcare workers across Alberta with a single access point to patient information, in November 2019, Alberta Health Services (AHS), the province's integrated health authority, launched wave one of the clinical information system, Connect Care, a partner of Epic Systems Corporation, at some Edmonton zone locations. Connect Care implementation is an ongoing process and AHS prepares to launch wave three in 2021. As an extension of Connect Care, AHS also introduced their own portal software called MyAHS Connect (aka MyChart). Through the use of computers, smartphones, tablets and smartwatches, patients registered with AHS facilities are able to access their health information, such as medical history, immunizations, self-book appointments, and communicate with their healthcare providers using secure messaging (Alberta Health Services, 2020).

It is often claimed that portal technology will resolve challenges regarding the aging population, increase in numbers of people living with chronic health conditions and rise of healthcare expenses. Conversely, some literature shows that most systems tend to run a higher budget than originally planned. This is due to a lack of preparation and challenges that organizations face while implementing newer technology. Thus, it is imperative that organizations are diligent in monitoring where funding is invested and that they understand the actors and events involved during each phase to allow for better future planning and successful employment of investments in IT systems (Avdagovska et al., 2020).

Benefits and Barriers of Patient Portal Use. In Canada, the adoption of patient portals is relatively new, and research to demonstrate its impact on the Canadian healthcare system is emerging. In addition to international research studies, the majority of available Canada-specific research suggests that there are benefits to using portals (Zychla, 2017). The advantages most widely agreed upon by patients using portal technology is having access to personal health information and the secure messaging feature to initiate conversations with their primary healthcare providers (Powell & Myers, 2018; Graham et al., 2020). Patients value portals, as it provides them with more detailed information about laboratory results and allows them to compare it with the previous trends of data. Furthermore, being able to schedule appointments, request medication prescription renewals and access medical information makes patients feel more involved in the management of care; consequently, making them feel more empowered (Powell & Myers, 2018). In a study conducted in Alberta during the pilot stage preceding the launch of Connect Care, patients were typically satisfied with MyChart portal. Patients described the portal as an easy to use, efficient tool, that improves accuracy of data sharing and allows for easier communication with healthcare professionals (Graham et al., 2020).

Healthcare providers have also reported benefits of using online portals. Many providers believe that portals give patients the opportunity to actively participate in the management of their care. Moreover, they report that prior to face-to-face appointments, patients are more self-aware and better prepared when portals are adopted, as they have additional time to look up medical results and ask pertinent health questions (Powell & Myers, 2018). Although research evidence is inconclusive as to whether portals disrupt clinical workflow (Antonio et al., 2020; O'Leary et al., 2016), in one study, healthcare providers reported that portals had minimal distraction to their everyday work and were integrated in a routine work schedule. Healthcare providers also reported that portals were efficient and allowed them to be more productive. Instead of having to track patients down to relay messages, portals made this process much simpler for them (Powell & Myers, 2018).

The implementation of online patient portals can benefit the overall healthcare system. Some studies have shown that patients are more willing to comply with medical advice and more competent with refilling medication prescriptions; thereby, reducing the number of yearly inpatient visits (Canadian Medical Protective Association, 2017; Powell & Myers, 2018). In addition, early experience with portal use in Edmonton showed changes in the way people accessed healthcare services, such as the reduction of missed clinic appointments, or no-show rates (Graham et al., 2020).

Although patient portals are reported to produce positive effects on patients, healthcare providers and healthcare systems, there are barriers and challenges to its implementation and use. One significant barrier is patients' lack of literacy, including health and digital literacy. This creates concern for increasing health inequities and further marginalizing selected population groups (Antonio et al., 2019). Given that diverse populations exist within oncology practice, for example, those who speak English as a second language, some patient groups may lack self-confidence and hesitate to use the tool. A second obstacle recognized by healthcare providers is the transparency and delivery of medical information. Some healthcare providers have a negative attitude towards patient portals because they are concerned about receiving more questions and phone calls from their patients. Finally, healthcare organizations are concerned about having limited resources to meet the demand of portal use. Resources are fundamental to the success of implementing patient portals, as it ensures continuity of healthcare services (Kooij et al., 2018).

Future research needs to gain a deeper understanding of patient, provider, and system-wide benefits and drawbacks of using online portals, as there is limited Canadian research in this area. In particular, to increase the value of generated evidence, researchers are encouraged to clearly outline technical characteristics and functions of specific portals they study and describe socio-political and organizational contexts of portal implementation and use (Antonio et al., 2020).

Prevalence and Epidemiology of Cancer in Canada and Alberta

Cancer is the leading cause of death in Canada. Cancer is responsible for 30% of all deaths across the nation and the numbers continue to rise each year (Poirier et al., 2019). In Canada and other industrialized countries this is mainly attributed to both the growing and ageing populations (Brenner et al., 2018). By the end of 2020, it was predicted that there would be 225,800 new cancer diagnoses and 83,300 cancer related deaths in Canada; an increase of 5,400 when compared to the estimated number of new diagnoses for 2019 (Canadian Cancer Society, 2020). To really put things in perspective, the Canadian Cancer Society (2019) estimates that about 1 in 2 Canadians will be diagnosed with cancer in their lifetime, and approximately 1 in 4 Canadians will die from the disease. Despite this alarming probability, five-year net survival rates have increased since the 1990s from estimates of 55% to current rates of 63%. These five-year net survival rates vary drastically depending on the type of cancer. For example, thyroid cancer five-year survival rates are 98%, whereas lung cancer rates are as low as 19% (Canadian Cancer Society, 2020).

In Alberta, there are 162,000 people living with cancer and 18,400 new diagnoses each year. Furthermore, there are 93,000 systemic treatments and 128,000 radiation treatments done annually (Alberta Health Services, 2019).

Although cancer can occur at any age, it mostly affects individuals who are 50 years and older. Males are more likely to develop cancer in their lifetime in comparison to females. Also, females are more likely to survive cancer than males. Based on 2019 statistics, almost half of the population who develops cancer are diagnosed with either lung, breast, colorectal or prostate cancer (Poirier et al., 2019). Breast cancer is the leading form of cancer in females and prostate cancer is the most prominent in males. Lung cancer is accountable for more cancer deaths than any other type of cancer previously mentioned (Canadian Cancer Society, 2019). It is projected that by 2042, the number of people diagnosed with colorectal cancer will surpass those diagnosed with lung cancer. This is largely due to people being less physically active and more overweight (Brenner et al., 2018; Poirier et al., 2019).

The projected annual spending associated with cancer is approximately $7.5 billion in Canada. This extensive cost is mainly due to physician fees and hospital expenditures (Poirier et al., 2019). Given the substantial health and economic burden of cancer, it is imperative that decision-makers re-assess resources needed, health policies be re-evaluated and cancer research be prioritized. Focusing on health policy, resources and cancer research will inform health promotion activities and assist with early detection of cancer (Canadian Cancer Society, 2019). Knowing the epidemiology of cancer is essential to protecting and improving the health of Canadian citizens. Understanding the incidence of cancer can assist in decreasing the burden and inform prioritization of preventative services (Poirier et al., 2019).

Patient Experiences of Living with Cancer

Advancements in cancer treatment, paired with continuous developments in medical technologies have allowed oncology patients to live longer. Nevertheless, cancer has become a chronic disease requiring extensive ongoing treatment; consequently, impacting patients' and their families' quality of life (Sibeoni et al., 2018). Navigating fragmented healthcare services can be a difficult task for the average person. For an individual diagnosed with a complicated condition, such as cancer, this complexity is compounded. Oncology patients are provided with vital, but voluminous information and are required to make significant, time-sensitive decisions, often after receiving what may be the worst news of their lives (Watson, 2008).

For oncology patients, receiving a cancer diagnosis is often overwhelming and life changing. Moreover, it can drastically impact an individual's mental health and overall well-being (Niedwiedz et al., 2019). One of the most common symptoms that oncology patients report is physical pain; it is also the symptom that many patients fear most. Studies have found that although numerous patients experience physical discomfort, seldom is it due to the disease itself. Instead, patients report a connection between their physical pain and the internal struggles and treatments that they endure (Quinn, 2018). Oncology patients frequently experience adverse effects from the treatments they receive. Common side effects include nausea, vomiting and fatigue. Additionally, patients report sensory effects including tastelessness, hair loss, weight loss and/or weight gain (Sibeoni et al., 2018). These adverse effects tend to have a profound impact on the patient's everyday quality of life.

Although physical symptoms are more frequently reported than any other symptoms, oncology patients also report feelings of defeat, separation and loneliness. After receiving a life-altering diagnosis, patients often endure a sense of loss. This may be related to a lack of certainty and loss of control over their lives. Facing this sense of loss can then lead to feelings of isolation and loneliness. Patients may feel separated from others due to changes in lifestyle, and feelings of distress that accompany the diagnosis (Quinn, 2018). Even with good support systems in place, oncology patients report feelings of loneliness. Family and friends are crucial to improving oncology patients' well-being; however, it is often described that the people providing support can only empathize with the patient to a certain extent given that they themselves have not lived through a cancer diagnosis. As a result, patients often feel secluded, as they believe that no one will ever understand the grief they endure. In addition, thoughts of isolation may stem from the oncology patient, feeling as if they have become a voiceless component of the healthcare process, instead of being an integral member of the care team (Quinn, 2018). A cancer diagnosis may also have a significant impact on a patient's mental health. Studies have shown a higher prevalence of anxiety and depression among oncology patients when compared to the general population. Mental health is an important consideration, as it has shown to correlate with a patient's recovery and survival (Niedzwiedz et al., 2019).

Although the majority of patients have described the experience of being diagnosed with cancer as emotionally devastating, they have also attributed some positive aspects to their diagnosis. Many patients identify an activity or a particular relationship as having renewed importance to them. Building strong relationships facilitates oncology patients' ability to maintain a better quality of life, often long after the cancer treatment is complete. The presence of family and friends is essential for everyone, as it promotes feelings of being supported and cared for. Furthermore, establishing good rapport with a primary healthcare provider, positively impacts a patient's disposition and fosters a sense of trust in the healthcare system (Sibeoni et al., 2018).

The Use of Online Tools in Oncology

Health Information Seeking Using the Internet. Over the past decade, cancer treatment has undergone several significant changes, two of which include: a reduction in the duration of acute-care admissions and an increase in outpatient care services. Consequently, patients spend less time in hospitals and more time at home as a direct result of these changes. Although increasing outpatient care services may be beneficial for oncology patients emotionally and financially, they may however, find it challenging to manage their own care. Subsequently, patients seek out additional health information by utilizing the sources that are available to them, such as the Internet. This relatively new ability to access health information has allowed oncology patients to become more empowered and self-determined in organizing their care (Mattsson et al., 2017). However, the notion of offloading responsibility to the patient with the assumption that they can confidently access online resources and thereby self-manage their disease is distressing for some patients. This concern is due to patients having inadequate access to the Internet or limited health literacy (Wahlstedt & Ekman, 2016).

As the Internet connectivity and coverage improves, it is considered a vital source of information for many oncology patients today. The Internet offers extensive access to health information and interactivity (Mattsson et al., 2017). Health-related Internet activities include health information seeking, social interacting, communication with healthcare providers and online medical purchasing (Jiang & Liu, 2020). Oncology patients may use the Internet to visit different online support groups, blogs and social networks (Mattsson et al., 2017). For this population, Internet health information seeking involves looking up information to better understand symptoms, diagnosis, prognosis and the effectiveness of various treatments. As oncology patients become more adept at navigating the Internet, they are better equipped to use online services, more cognizant of wide-spread health resources and more likely to participate in Internet health information seeking (Jiang & Liu, 2020).

Internet-based technologies, such as websites, applications and portals, have made it possible for oncology patients to have immediate access to accurate health information including personal health information contained in the provider's EMR. Researchers in Sweden found that oncology patients have a greater desire to actively research health information immediately after being diagnosed, when compared to the later stages of their treatment (Mattsson et al., 2017). Furthermore, Mattsson et al. (2017) found that having a university degree and being younger is often associated with increased health-related Internet searches. Overall, Internet health information seeking is the most commonly reported health-related activity on the Internet by oncology patients. Despite the ease with which the Internet can be accessed, some oncology patients still prefer to receive health information from their healthcare providers so as to ensure that the information they are receiving is reliable (Jiang & Liu, 2020).

'Spontaneous internet use' in oncology patients continues to evolve (Lleras de Frutos et al., 2020). Historically, the Internet was used as a source of gathering information; however, presently the Internet is often used for support and social networking. Patients now play a more active role in the management of their care, whereas previously, patients took on a more passive role and simply collected the information that was provided to them by healthcare providers. A literature review, conducted in Spain, has shown that gathering information from the Internet positively correlates with decreased mortality rates and lower levels of anxiety and depression (Lleras de Frutos et al., 2020). Although Internet use is considered beneficial for many, this vulnerable population group requires special attention in order to reduce their levels of distress and maintain a better quality of life. Some commentators suggest that healthcare professionals should provide oncology patients with the skills needed to effectively locate accurate health information on the Internet (Jiang & Liu, 2020). Professional guidance regarding the utilization of the Internet may assist with issues pertaining to security and confidentiality (Lleras de Frutos et al., 2020).

Patient-Provider Relationships in the Digital Information Age. Effective communication and establishing a good rapport between patients and healthcare professionals are imperative to the provision of quality care (Tarver et al., 2018; Weiner & Biondich, 2006). Without effective communication and good rapport, the management of chronic disease can be challenging (Tarver et al., 2018). These objectives are of particular importance, as people with cancer are living longer. Oncology patients often deal with physical, psychological and social stressors on a daily basis; thereby, increasing the significance of maintaining effective communication with their healthcare providers (Jiang et al., 2019). Patients' use of the Internet and information and communication technology (ICT), such as online portals to view their laboratory results, can transform communication and relationships between oncology patients and healthcare providers. On a positive note, ICT and the Internet have changed the way people communicate, offering various means of communication, such as email, instant messaging and video chat. Some studies have found a positive association between the utilization of ICT and health outcomes in patients (Tarver et al., 2018).

On the contrary, Tan and Goonawardene (2017) raised concerns about Internet health-information seeking and the negative effects it can have on patient-provider relationships. Online health information can lead to patient's being misinformed; thus, causing them to be distressed. This feeling of anxiety may result in patients having more questions and requests for their healthcare providers. Secondly, online findings may conflict with information provided by healthcare professionals. Consequently, patients may be dissatisfied and seek a second opinion from another healthcare provider (Tan & Goonawardene, 2017).

The recent proliferation of ICT has enabled online patient-provider communication to occur more frequently. For the last few years, communication between patients and providers via online tools has been acknowledged for its benefits.; for example, online communication increases patient access to quality health information, as it offers patients an additional way to reach out to their providers. It also decreases healthcare-associated costs for patients by reducing transportation needs and time away from work to make medical appointments. Moreover, online communication expands accessibility to healthcare for those living in remote areas, as these patients can interact with their providers via email, phone or through online portals (Jiang et al., 2019). Online communication is especially beneficial to oncology patients, as the management of their care is often complex and overwhelming, causing them to feel anxious and depressed. Exchanging information and the establishment of a trustworthy patient-provider relationship is said to enhance patient engagement and advance cancer survivorship (Jiang et al., 2019).

Over the past decade, online communication has significantly increased. In the United States, it has increased from 9.7% to 36.6% over the past 10 years; email being most commonly utilized (Jiang et al., 2019). Socio-economic factors, such as gender, age, poor health, having a history of cancer and living in urban areas are associated with increased usage of online communication (Jiang et al., 2019; Tarver et al., 2018). Men access the Internet more often than women; however, women are more likely to email their healthcare provider and access the Internet for health information (Tarver et al., 2018). Younger people and those with poorer health are more likely to communicate with their health providers online (Jiang et al., 2019). Finally, research shows that online communication is statistically higher in patients with a history of cancer and those living in urban areas (Jiang et al., 2019; Tarver et al., 2018).

Online patient-provider communication must be implemented in a way that respects the needs of all users (Weiner & Biondich, 2006). Older patients, those with lower levels of education and without Internet access or computer skills, may prefer traditional communication channels (in person or over the phone). For this reason, ICT implementation and use should be guided by principles of health equity to overcome health disparities so as to ensure that the needs of patients are met and to build more effective relationships (Antonio et al., 2019; Jiang & Liu, 2020).

Patient Experiences with Portals. Patient portals are becoming more prevalent throughout healthcare; especially in oncology settings (Alpert et al., 2019). Existing American literature suggests that oncology patients typically place a higher value on having electronic access to their personal health information when compared to people who are healthy; thereby, implying that oncology patients are more likely to use portal technology (Alpert et al., 2019; McNamara et al., 2015). Oncology patients find it beneficial to have online access to their symptom lists, diagnosis, treatment, side effects and prognosis (McNamara et al., 2015). Patients access their personal health information via personal devices and in some cases, they can request medication refills, send messages and schedule clinic appointments.

Patients often report being satisfied with the use of portal technology (Alpert et al., 2018). Having access to their personal health information assists patients in understanding their medical condition; for example, the provision of reference ranges with their phlebotomy results helps to interpret blood tests. The impetus behind the portal technology is a belief that as patients understand their condition better and gain the ability to actively track their symptoms using portals, they will be more inclined to follow medical advice. Additionally, some patients consider portals to be a convenient method of gathering and storing information in one place. Patients report that having access to their health record allows them to be better prepared for visits with their oncologist; therefore, encouraging patients to take a more active role in the management of their care. Patients have expressed that portals make them feel more in control of their situation and give them more opportunity to advocate for their needs (Alpert et al., 2019). Moreover, patients noted that portals provide them with an additional means of communicating with their providers (Alpert et al., 2019; Rodriguez, 2018).

In contrast with the majority of oncology patients who view portals as beneficial, there are some who have reservations. When oncology patients review their results, they have the potential to discover that their cancer has metastasized. Therefore, patients have reported concerns about having access to this information, as they do not fully comprehend the consequences. Furthermore, given the implications of living with cancer, oncology patients are often viewing these results during times of despair, thereby, compounding ever-present feelings of fear and uncertainty (Alpert et al., 2018). The amount of access to information varies between oncology patients. Some studies have found that oncology patients whose cancer had metastasized preferred having access to less information, when compared to patients who did not have a change in their condition (McNamara et al., 2015). Patients who are already diagnosed and being treated for cancer typically feel comfortable using portals and see the benefits of the technology during or after treatment. However, healthy individuals have expressed concerns about being made aware of a new cancer diagnosis through the portal (Alpert et al., 2018).

Several studies found that many patients preferred having access to additional information, whereas other studies reported that patients experience anxiety or distress when given access to information (Alpert et al., 2018; McNamara et al., 2015). Overall, this area of research is an emerging field, with mixed findings. In Canada, patient portals are relatively new, and no studies exist about the implication of portals in oncology settings. Therefore, more research is needed to gain a deeper understanding of patient experiences with portal use in cancer settings.

Oncology Provider Perspectives on Patients Using the Internet and Portals. Nowadays, patients are choosing or feel persuaded to become more conscious of the management of their care. As an increased number of patients participate in the decision-making process, patients are actively searching the Internet for health information and are given easier access to their personal health information to make them feel more involved in their care. While this access may be seen as beneficial to patients, healthcare providers express concerns about the accuracy and reliability of information in public search engines. The possibility of patients viewing abnormal results and/or discovering a new diagnosis is a common fear shared among oncologists (Alpert et al., 2018; Winget et al., 2016). Having immediate access to results prior to meeting with a physician or other primary healthcare provider may be harmful to some patients, especially for those patients with life-changing diseases. Given the diversity of education levels, patients might misinterpret or misunderstand the results available to them (Winget et al., 2016). For this reason, patients are more likely to experience feelings of distress and less likely to adhere to medical advice. Although healthcare providers are cautious about patient access to abnormal results, they typically agree that patient access to normal results is beneficial and broadens patients' knowledge base (Alpert et al., 2018; Winget et al., 2016).

A qualitative study in California with 82 oncologists, concluded that many healthcare providers are concerned about the compromised quality of care that patients receive when given immediate online access to their personal health information (Winget et al., 2016). As a strategy to improve the quality of care and to help mitigate feelings of distress, oncologists and other healthcare professionals express the importance of meeting with patients in person prior to relaying serious health information (Alpert et al., 2018; Gerber et al., 2017; Winget et al., 2016). Face-to-face interactions and scheduled meetings are considered imperative when discussing the implications and results of laboratory and radiology tests (Alpert et al., 2018). However, some physicians and nurses' express concerns about the additional, sometimes unbillable, workload related to an increase in patient demand for communication to clarify health information and that more staff is required to answer patient's messages in a timely manner (Winget et al., 2016). Some nurses, however, prefer patient portal use, in some situations, as it decreased their workload by providing them with more time to respond to nonurgent matters (Gerber et al., 2017).

Patient safety and expectations also surfaced as main concerns by both nurses and oncologists (Gerber et al., 2017; Winget et al., 2016). Living in a digital era where text messaging has become the new norm, many patients expect instant responses to their inquiries. Nurses are concerned that patients will attempt to use portals as a communication tool to report medical emergencies to healthcare providers. Given that portals are not designed to be used as a communication tool for medical emergencies, there is a risk that the patients will not be attended to in a timely manner; thereby, putting their health at risk (Gerber et al., 2017).

Although there are many concerns regarding the use of portals, many healthcare providers describe these technologies as valuable tools for many patients. Portals provide patients with an additional information resource, educate them regarding medication use, enable them to make appointments online, enhance communication and help patients feel more empowered (Gerber et al., 2017; Powell & Myers, 2018).

Gap in the Literature

In summary, as the use of the Internet and ICT increases globally, many people use these tools when pursuing health information to inform their care. Research into these practices has been growing over the last decade; however, after a rigorous review of numerous databases, I was able to determine that the amount of research on the effects of patient portals in Canada is limited. Moreover, there hasn't been any research conducted on the use of patient portals in oncology practice within Canada. This gap in the literature is significant, given that the Alberta healthcare system recently adopted patient portals. It is important for nurses to be familiar with oncology patients' and their family caregivers' experiences of using this technology and other digital information tools for health-related purposes. It was necessary to address this gap in the literature, as it can affect patients' overall well-being, relationships with their providers and utilization of healthcare services. Acquiring this knowledge allows us, as healthcare providers, to better support and treat oncology patients.

Purpose

The purpose of this qualitative study was to explore and describe how oncology patients and/or their family caregivers use electronic patient portals available in Alberta and other digital information tools for treatment and care.

Research Question

My research question was: what are the experiences of oncology patients and/or their family caregivers when using electronic patient portals and other digital information tools for health-related purposes?

Methodology

I used a qualitative descriptive approach. In the discipline of nursing, this approach has been summarized by Margaret Sandelowski (2000) as the preferred method to describe the phenomena of interest. Although she made it clear that she was not the creator of this approach, her outline of key principles is useful. The qualitative descriptive study that I conducted was a component of a larger longitudinal study conducted by Dr. Petrovskaya. The ethics approval for the study was granted (Pro00098299). All consent forms, recruitment strategies and material were developed by Dr. Petrovskaya. I reviewed the University of Alberta's Research Ethics Board application and supplementary material to learn about the ethical requirements for conducting research involving participants. My independent component of this study included the following: assisting with participant recruitment, screening for inclusion/exclusion criteria, obtaining verbal informed consent, data collection, data management, data analysis, ensuring rigour, and dissemination.

What is Qualitative Description? Why Qualitative Description?

Qualitative description is a methodology that describes a particular phenomenon of interest. This design is useful to inform policy and clinical practice. The goal of this methodology is to provide a wide-ranging summary of events of the phenomena understudy. Hence, it is important that the researcher conducting the study, stays close to the data. Qualitative description differs from interpretive description for the very reason that researchers are not expected to move far from their data (Sandelowksi, 2000). The design features included within this study are maximum variation sample, data collection from individual interviews and qualitative content data analysis (Sandelowksi, 2009). Of the design features listed, our study included maximum variation sample to obtain a rich view of the phenomenon and semi-structured interviews to facilitate open discussion. Thematic data analysis was used instead of content analysis. In thematic data analysis, the data produced is detailed and qualitative in nature, whereas in content analysis, data can be analyzed both qualitatively and quantitatively (Vaismoradi et al., 2013). Thematic data analysis is described in further detail in the data analysis section.

Sample

A convenience sample of eleven people diagnosed with cancer and/or their family caregivers were recruited in Alberta. This is a type of non-probability sampling that involves subjects who are readily accessible to the researcher (Wu Suen et al., 2014). It is common for qualitative studies to involve smaller sample sizes to facilitate in-depth engagement with participants and the topic. Participants included eight females and three males, all of whom were residents of Alberta and spoke English. All of the participants had been diagnosed with some form of blood-borne, tissue, organ and/or lymphatic cancer, with the exception of one family caregiver. All participants reported level of education above high school, with six possessing university degrees. Nearly half of the participants had previously worked in healthcare or were currently working in the field.

Seven participants were enrolled in and used a portal: one person used both My Personal Records (MPR) and MyAHS Connect (MAC); five used MPR only, as MAC was not launched at their healthcare facilities yet; and one person used MyChart in the past (precursor to MAC) and was in the process of creating her MyHealth Records/MPR account.

Participant Recruitment

Patients and/or their family caregivers were recruited in August-November 2020 via three strategies. First, a recruitment email was sent to 118 members of the CancerControl Alberta Patient and Family Advisor Network. The manager of patient engagement at CancerControl Alberta facilitated the process. Patients and families who were interested in participating contacted Dr. Petrovskaya or myself directly via study email or phone.

Inclusion/Exclusion Criteria

The inclusion criteria were as follows: adult oncology patients (over 18 years of age) regardless of gender and type of cancer; residing in Alberta; able to read, understand and communicate in English; and access to an active phone number through which they could be contacted. If a patient preferred that a family member interacted with the research team or if the oncology patient was deceased, then the family member was invited to participate in the study. In order for the family member to participate, they had to meet all of the inclusion criteria with the exception of a cancer diagnosis. Inclusion was limited to residents of Alberta because valid provincial ID documents are required to access MyHealth Records portals. The exclusion criteria included the absence of a phone connection and inability to communicate in English. None of the exclusion criteria were based on gender, ethnicity or health status.

Data Collection

Once consent was obtained, I employed semi-structured interviews with patients and/or family caregivers. Interviews lasted on average 48 minutes (range 27-68 min) and were audio-recorded. An interview guide (see Appendix C) was used to facilitate an open discussion about participants' experiences of using patient portals and other digital information tools for health-related purposes. I documented oral informed consent (written consent was waived by the Ethics Board during the COVID pandemic) and took field notes while interviewing participants to record my reflections. My goal was to explore how patients use electronic/digital sources of information to inform treatment and care.

Data Management

I recorded personal identifiable information shared by participants during the initial communication and consent process on my personal laptop. Immediately after the conversation, I transferred the information into a Word-processed Master list where the personal identifiable information was linked and assigned a code number. The electronic Master list was kept on a secure, password-protected University of Alberta Faculty of Nursing drive. All documents were deleted from my laptop and hand-written notes were destroyed.

Interviews were initially recorded on a voice recorder, then transferred to the University of Alberta Faculty of Nursing drive, and deleted immediately after data transfer, following each interview. These audio recordings were then transferred to the University of Alberta Faculty of Nursing drive. Only a limited number of people, the Principal Investigator, I (the Co-Investigator) and a trusted transcriptionist, were allowed access to these recordings.

Data Analysis

Interviews were transcribed verbatim. Data analysis occurred simultaneously with data collection. Initially, I read and re-read interview transcripts. Then, interview transcripts were thematically analyzed using an inductive approach. Thematic analysis allowed me to recognize, analyze and report patterns within the data (Braun & Clarke, 2006). I coded the data without trying to fit the information into pre-established categories. That is, this form of thematic analysis was data-driven. The analytical steps included: familiarizing myself with the data; generating initial codes (based on recurring patterns, but also based on outliers in the data); searching for themes (collating codes into potential themes, gathering all data relevant to each potential theme); reviewing and defining themes; and refining the overall story and the analysis details (Braun & Clarke, 2006). Themes were reviewed and finalized in consultation with my supervisor and co-supervisor.

Rigour

The trustworthiness of a qualitative study contains 4 key components: credibility, dependability, transferability and confirmability. Typically, qualitative interview studies require 6 to 30 participants; but the most important indicator is being able to achieve data saturation. By the 9th interview I noticed recurrent themes which was when I knew it was about time to stop collecting information and to begin analyzing the data. I examined the accuracy of data collected and clarified participants' responses to ensure credibility and dependability of the results (Korstjens & Moser, 2018). Even though our sampling technique (convenience sampling) contained some risk of selection bias, our recruitment mechanism assisted in the achievement of maximum variation sample; for example, patients with various diagnoses and different levels of health literacy and computer skills were invited to participate. Ensuring that the sample reflected a diverse group of patients, improved the transferability of the study to other settings (Korstjens & Moser, 2018). Last, recording reflective notes while interviewing participants ensured that the study was confirmable, as I was more conscious of my personal beliefs and subjectivities

(Ortlipp, 2008). Select interviews were analysed independently by each of my co-supervisors and me to achieve investigator triangulation.

Dissemination

My goal was to prepare and submit a manuscript for publication. In addition, I will present at academic conferences, such as the Faculty of Nursing Research Day and/or Canadian Nursing Informatics Association (CNIA) conference, and to non-academic stakeholders, such as Cancer Care Alberta leadership, clinicians and patient groups. It is expected that the findings of this qualitative descriptive study will enhance the quality of care for, not only oncology patients, but also for all patients who utilize portal technology. Furthermore, the findings might inform the implementation of patient portals during the subsequent rollouts of Connect Care throughout the province of Alberta.

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CHAPTER 2: PUBLICATION

Oncology Patients' Experiences with Novel Electronic Patient Portals to Support Care and Treatment: A Qualitative Study with Early Users and Non-users of Portals in Alberta, Canada

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Abstract

Background: With the current proliferation of clinical information technologies internationally, patient portals are increasingly being adopted in health care. Research, conducted mostly in the United States, shows that oncology patients have a keen interest in portals to gain access to and track comprehensive personal health information. In Canada, patient portals are relatively new and research into their use and effects is currently emerging. There is a need to understand oncology patients' experiences of using eHealth tools and to ground these experiences in local sociopolitical contexts of technology implementation, while seeking to devise strategies to enhance portal benefits.

Objective: The purpose of this study was to explore the experiences of oncology patients and/or their family caregivers when using electronic patient portals to support their healthcare needs. We focused on how Alberta's unique, two-portal context shapes experiences of early portal adopters and non-adopters, in anticipation of a province-wide rollout of a clinical information system in oncology facilities.

Methods: This qualitative descriptive study employed individual semi-structured interviews and demographic surveys with 11 participants. Interviews were audio-recorded and transcribed verbatim. Data were analyzed thematically. The study was approved by the University of Alberta Human Research Ethics Board.

Results: Participants currently living with non-active cancer discussed an online patient portal as one among many tools (including the Internet, phone, videoconferencing, print-out reports) available to make sense of their diagnosis and treatment, maintain connections with healthcare providers, and engage with information. In the Fall 2020, most participants had access to one of two of Alberta's patient portals and identified ways in which this portal was supportive (or not) of their ongoing healthcare needs. Four major themes, reflecting the participants' broader concerns within which the portal use was occurring, were generated from the data: (i) experiencing doubt and the desire for transparency; (ii) seeking to become an informed and active member of the healthcare team; (iii) encountering complexity; and (iv) emphasizing the importance of the patient-provider relationship.

Conclusions: Although people diagnosed with cancer and their family caregivers considered an online patient portal as beneficial, they identified several areas that limit how portals support their oncology care. Providers of healthcare portals are invited to recognize these limitations and work toward addressing them.

Keywords: patient portal; MyChart; Health Information and Communication technology; eHealth; personal health information; oncology; cancer care; Canada; qualitative; context of technology implementation

Introduction

Clinical information technologies and consumer eHealth tools are becoming an essential part of healthcare delivery. Patients are eager to have electronic access to their personal health information, and expectations to manage their own health have increased [1]. eHealth refers to the application of digital health technologies and includes telehealth and remote monitoring, the use of mobile devices, ePrescribing, health information technology systems, electronic health records (EHR) and more [2]. The use of eHealth and the Internet has the potential to augment healthcare services by educating and empowering patients, making health care more equitable by extending services, expediting access to medical information, and ensuring the information provided is evidence-based [3]. Furthermore, eHealth is transforming the way patients and providers communicate, establish rapport, and receive care, as virtual medical appointments become more commonplace (a movement catalyzed as a result of the COVID-19 pandemic) and as patients have immediate access to medical information.

Patient portals are secure computerized applications that give citizens access to some of their personal health information stored in health providers' EHR, via electronic devices such as computers, cellphones and tablets. Personal health information available via portals typically includes lab results, medications, immunizations, allergies, diagnostic results, and medical visit notes [4]. Other portal features include secure messaging with healthcare providers, appointment self-scheduling, and requesting medication refills. Different jurisdictions may choose to enable different portal features and set restrictions (i.e., immediate test result release versus embargo period).

In addition to portals, digital platforms, including the Internet, enable access to health-related information and peer support groups. The Internet is often used as a primary source of health-related information, generating concerns about misinformation among healthcare providers [1]. To address this concern, patient portals that provide hyperlinks to credible information (e.g., medication side effects, explanation of laboratory tests) have been suggested as a preferred source of information.

In Canada, patient portals are becoming more available, but the actual use is challenging to estimate. In Alberta, a Canadian province with a population of more than 4.4 million people, two province-wide patient portals were launched in 2019, MyHealth Records and MyAHS Connect (described later in the paper). As of March 31, 2021, approximately 565,000 Albertans had created a MyHealth Records account and more than 38,000 Albertans had access to MyAHS Connect portal [5]. The latter figure denotes the total number of patients who could *potentially* activate portal accounts as the portal was gradually becoming available across the healthcare sites these patients visited.

The patient portal use in Alberta may not necessarily be representative of the overall population in Canada. For example, in 2019, the Canadian Medical Association reported that virtual care and online patient portals were used by 1% of Canadians [6]. The same year, researchers at the University Health Network (UHN) in Toronto, Canada reported the annual adoption rate of approx. 65%, with 43,000 'myUHN' patient portal registrations during the first 14 months [7]. Attempts to reconcile these numbers should be made with caution. On the one hand, reports of portal adoption are often based on a non-conservative definition of portal use, meaning activating a portal account and/or logging in once. On the other hand, all sources from 2019 cited above, reflect a pre-COVID-19 pandemic situation. During the pandemic, virtual care and portal adoption have been on the rise.

Canadian research to demonstrate the impact of patient portals is emerging. Similar to international studies, Canadian research suggests that there are benefits to using portals [1]. Patients often value portals, as this technology provides them with detailed information about their health and stimulates and informs conversations with their healthcare providers [8,9]. Furthermore, being able to schedule appointments, request medication prescription renewals and access medical information, allows patients to feel more involved in the management of care [9]. Healthcare providers comment that portals give patients the opportunity to actively participate in the management of their care and that patients are better prepared for medical appointments, as they have additional time to look up medical results and develop pertinent questions [9]. Portals may also benefit healthcare systems, as patients might be more willing to follow medical advice and more diligent with refilling medication prescriptions [9,10].

Despite these benefits, there are barriers to portal implementation and use. Limited health- and digital-literacy and lack of computer or internet access increase health inequities and further marginalize selected population groups [11]. Test results may be misinterpreted by patients, generating anxiety and increasing the demand on healthcare professionals to provide reassurance and clarification to their patients [12]. In addition, healthcare organizations have reported concerns regarding limited financial resources to implement patient portals [13].

Patient portal use is known to be the highest among patients diagnosed with cancer. The Canadian Cancer Society [14], predicts that approximately 1 in 2 Canadians will be diagnosed with cancer in their lifetime, and about 1 in 4 will die of the disease. With the steady year on year increase in cancer diagnoses, online patient portals are becoming more desirable to augment the coordination of care for oncology patients [15]. Cancer treatment and the cancer diagnosis, in and of itself, results in a wide range of self-management challenges, such as monitoring side effects and scheduling numerous medical appointments. Oncology patients have a keen interest in portals, as they require comprehensive health information, have blood work done regularly and often are, or are expected to be, active participants in managing their condition [15,16]. They report that using portals allows them to feel more in control of their situation, be better prepared for medical appointments, and provides them with the opportunity to advocate for their needs [17]. Yet, some oncology patients view portals with reservations. For example, with the immediate release of laboratory and imaging results via a portal, patients may discover that their cancer has metastasized. Given the implications of living with cancer, oncology patients are often viewing these results during times of despair, thereby, compounding feelings of fear and uncertainty [18].

The objective of this study was to explore how patients diagnosed with cancer use online resources for care and treatment in the Canadian province of Alberta. Specifically, we were interested in patients' awareness and use of the novel electronic patient portals in Alberta's unique, two-portal context.

The Context and Setting of this Study

When reporting research on patient portals, it is important to clearly outline characteristics and functions of specific portals and describe socio-political and organizational contexts of portal implementation and utilization [19]. Below we describe the complicated context of portal implementation in Alberta, Canada, where this study was situated.

In March 2019, Alberta's Ministry of Health (Alberta Health) released a provincial patient portal called MyHealth Records (later its component called My Personal Records became a patient portal *per se*) allowing all Albertans 14 years and older to access some of their health information online, most notably immunization records and common laboratory results [20]. MyHealth Records requires a multi-step process to create an account and authenticate (as described in detail below). All patient information is supplied to MyHealth Records from a provincial Electronic Medical Record (EMR) called Netcare. Although useful to healthcare providers, Netcare EMR is a 'view only' system.

In November 2019, Alberta Health Services (AHS), the province's integrated health authority, launched Wave One of the clinical information system, Connect Care (AHS' name for its project to implement the EPIC system), in some acute care teaching hospitals and ambulatory clinics in Edmonton. Connect Care implementation is an ongoing ambitious process consisting of nine waves (from 2019 to 2023), with three waves already launched, aiming to achieve the *one patient one record* goal for the province. Unlike clinical information systems implemented in a single healthcare facility or across a few facilities, Connect Care is envisioned to span the entire province with the population of more than 4.4 million people and to replace existing fragmented EMRs. One of the future waves will include oncology facilities across the province. As a component of Connect Care, AHS offers a tethered patient portal called MyAHS Connect (known as MyChart during the pilot stage, as described below) to enable patients registered with AHS facilities to access their personal health information [21].

In preparation for Connect Care launch, from 2015 to 2019, the AHS tethered patient portal called MyChart (EPIC) was piloted in select Edmonton clinics. Patients who used MyChart during the pilot stage were mostly satisfied with the portal and described it as an easy to use, efficient tool that improved accuracy of data sharing and allowed for easier communication [8,22]. Although a sign-up process presented initial challenges for some patients, overall, it was easy to create a MyChart account, including obtaining proxy access. With Wave One of Connect Care in 2019, AHS initially made an arrangement for existing MyChart users to be 'grandparented' into the new, Connect Care-enabled patient portal. However, due to the tensions between the two macro-level portal implementers, access to the portal for these existing users was interrupted either temporarily (they had to create a new account) or permanently (for some parent-proxies who accessed their children's information). In early 2020, MyChart was renamed MyAHS Connect and the access to this portal was streamlined with the Government's MyHealth Records patient portal, which affected the ease of enrolment for AHS patients, as described below. A chronology of major events in Alberta, up to April 2019, leading to the unique, two-portal context in the province is presented in Avdagovska et al. [23].

Thus, at the time of our study in the Fall of 2020, Albertans who were patients attending AHS facilities could enrol to view their personal health information via one or both online portals accessible through the Government of Alberta website under the aegis of MyHealth Records: 1) a provincial citizen portal My Personal Records linked with a 'view only,' legacy EMR; and 2) MyAHS Connect portal tethered to a Connect Care-enabled EMR. (Refer to Multimedia Appendix for a table comparing portal features in Alberta. Portal functionalities are categorized based on Ammenwerth et al. [24] with adaptations).

To sign up for MyHealth Records, citizens must access the Government of Alberta website, register for a MyAlberta Digital ID (MADI) and confirm their identity by uploading an Alberta driver's license or Alberta ID card. Within 10 days, one receives a verification code in the mail and is able to complete MADI registration online. A person then has to provide their personal health number (each legal resident has this number to access the Canadian publicly funded healthcare system), to set up access to My Personal Records portal. In order to access MyAHS Connect portal, in addition to the above steps, a patient must be attending an AHS healthcare facility that has launched Connect Care, be offered or indicate their interest in becoming a portal user to the facility's personnel, who will provide further instructions (i.e., a website link to enter personal information to get access to MyAHS Connect) [25].

Of note, AHS facilities, in which Connect Care is being implemented, include hospitals, outpatient clinics, continuing care facilities, cancer centres, mental health facilities and some community health sites across the province. In contrast, some primary and community care sites, and family physicians are not officially part of AHS and additional efforts will be required to link these sites to Connect Care.

As is evident from the above description, for the public, major challenges in accessing Alberta's portals include: a complicated sign-up process; terminological confusion with many variants of official and colloquially used portal names and abbreviations; significant challenges with proxy access for parents of sick children (as children under 14 years of age cannot have a MADI account); and what appears as the existence of two parallel portals.

Apart from a few studies conducted during the MyChart pilot stage [8,22], there is limited understanding of the use and effects of patient portals in Alberta. The research question guiding this study focused on patients diagnosed with cancer to explore their experiences of using online resources to support their cancer treatment and care, and in particular patients' awareness and use of the novel electronic patient portals in Alberta, Canada. We sought to understand how Alberta's unique, two-portal context shapes experiences of early portal adopters and non-adopters, in anticipation of a province-wide rollout of a clinical information system in oncology facilities.

Methods

Design

This qualitative descriptive study [26] involved in-depth semi-structured interviews with oncology patients and/or their family caregivers to provide a comprehensive summary of the phenomenon under study. Broadly, our theoretical assumptions informing the study relate to the *technology-in-practice*, *sociomaterial* perspective [27,28]. This perspective conceptualizes technologies as active artefacts whose role and effects can be better understood in their relation to other human and non-human actors in a person's situated reality. The technology-in-practice perspective helps to avoid both the uncritically enthusiastic rhetoric of technological progress as always beneficial and an equally unwarranted negative technological determinism (e.g., cold technology eliminates warm human touch). Rather, a researcher is guided to study how technological objects are used or not used in everyday life *in connection* with other human and non-human actors; what human actors do with those objects; and what those objects *do*, what effects they produce. Ethical approval for this study was obtained from the Research Ethics Board at the University of Alberta (Pro00098299).

Sample and Recruitment Strategy

Using convenience, purposive sampling, we recruited 11 participants who had been previously or were presently diagnosed with cancer and/or their family caregivers, were residents of Alberta and spoke English. Our primary interest was the experiences of patients diagnosed with cancer. However, it is well known that in the context of oncology care, family involvement (e.g., informal and unpaid caregiving provided typically by close family members) can be significant. Thus, we reasoned that eligibility criteria inclusive of family members of people diagnosed with cancer may attract more than one person from the same family unit. For instance, a patient in an active stage of cancer might choose to participate with the assistance of a family member. As described below, only one participant in our sample self-identified as not diagnosed with cancer but as a family caregiver with past experiences of caregiving, and rather than excluding this person, we interviewed him and clearly marked his data in the findings as provided by a family caregiver.

A recruitment email was sent twice, one month apart, to more than 100 members of the Cancer Care Alberta Patient and Family Advisory Network. This Network is a group of volunteers, often retired professionals, actively interested in providing their opinion to Alberta Health Services on various health-service related topics. We reasoned that the Network is a group of accessible informants with direct experience with cancer, who moreover are likely to be aware about the novel patient portals. The portals have not been widely advertised in the province, and thus we targeted a group who is generally more informed about health service innovations in Alberta. Interested individuals contacted the lead author (AS) directly over email or phone to schedule the initial consent meeting. All 11 respondents who took part in the individual consent meetings agreed to participate in the study.

Data Collection

From August to November 2020, each participant completed an online demographic survey and took part in a semi-structured interview over the phone. We developed the interview guide to be aligned with the technology-in-practice perspective. That is, rather than asking participants who self-identified as portal users to explain how the portal is helpful and why it is good, we asked a broad opening question about using (or not) online tools and resources while living with a cancer diagnosis. We further asked participants to describe situations in which they used the Internet or the portal, e.g., “What happened that you needed to use an online tool? What did you look for? How did you use the information?” An interview guide was used to evoke detailed responses from all participants [29]. Interviews ranged from 27 minutes to 68 minutes in length, with an average time of 48 minutes, and were audio-recorded and transcribed verbatim. During the interviews, the interviewer (AS) took reflective notes to enhance credibility and trustworthiness of the study, as personal beliefs and preconceived notions were brought forth [30]. The interviewer did not know and had no interaction with the participants prior to the study.

Data Analysis and Rigour

Inductive thematic analysis was undertaken [31,32]. Transcripts were coded by the lead author. All codes and associated quotes were compared and contrasted to identify similarities and differences across the data set. Codes were then grouped into preliminary categories and themes, and were finalized once all codes and preliminary categories were reviewed and discussed with two other members of the research team (VC, OP) until a consensus was achieved, ensuring the qualitative rigor of the study [33]. Data analysis occurred simultaneously with data collection until no new codes were identified.

Saturation, or the point in the data collection process when participants provide similar information [34], was reached at diverse points for different themes. For example, by the 5th interview all participants talked about the uncertain future they face once diagnosed with cancer and how they searched the Internet for health-related information and how they desired transparency when communicating with health care providers. These ideas are expressed in what we identified as Theme 1. By the 9th interview we had consistently heard that most portal users were trying to gain independence by being able to access information via a portal, using the portal to prepare for appointments, and disliking incomplete information and poor organization of the portal webpages. This too shaped subsequent themes.

One of the trustworthiness criteria in qualitative research relates to the expertise and experiences of researchers [34]. To present a compelling account of the phenomenon under study, researchers need to strike a balance between possessing knowledge of the field of study (e.g., to create data collection tools, understand the context) and delineating between their own assumptions and participants' experiences. Our research team brought relevant expertise and self-awareness to this study: one of the members of the research team had received cancer care recently, adding an important patient perspective during team discussions. Another academic member of the research team (OP) focuses on eHealth and portal technology implementation, contributing expertise in this area. Authors from Cancer Care Alberta (Alberta Health Services) include a member of the Executive Leadership Team (PR), a scientist (LW), and an oncologist (JE), each of whom have interests and experience in exploring innovations in models of cancer care.

Results

Participants included eight females and three males within the age range from mid-20s to late-70s. Most participants were 60 years old and above. Except for one family caregiver, all of the participants had been diagnosed with some form of blood-borne, tissue, organ and/or lymphatic cancer. All participants reported level of education above high school, with six possessing university degrees. Nearly half of the participants had previously worked or were currently working in health care. All participants spoke English as their primary language, and nine self-identified as white. Every participant classified themselves as proficient users of computers, who employ Internet daily for a variety of purposes such as emailing, online banking, shopping, and health information seeking.

Seven participants were enrolled in and used a portal: one person used both My Personal Records (MPR) and MyAHS Connect (MAC); five used MPR only, as MAC was not launched at their healthcare facilities yet; and one person used MyChart in the past (precursor to MAC) and was in the process of creating her MyHealth Records/MPR account.

Only two of seven portal users originally learned about the portals from the public sources such as newspapers and media, whereas the majority learned about the portals from volunteering on the patient advisory committees for health services. Three participants were not aware of the portal(s) prior to the study. The only participant who did not sign up for a MPR provincial portal despite being aware about it, had frequent follow-up meetings with his oncologist where blood work was reviewed, which seemed sufficient in terms of accessing personal health information for this participant.

At the time of this study, all participants experienced relatively stable health (i.e., active cancer treatments were completed), and the participants used the portals from a couple of times per month to once every few months. Four participants reported having other chronic conditions which also motivated some of them to use a portal regularly.

In the interviews, participants discussed an online patient portal as one among many tools (including the Internet, phone, videoconferencing/telemedicine, print-out reports) available to make sense of cancer diagnosis, treatment, and prognosis, maintain connection with healthcare providers, and interact with the information. Thematic analysis of interview transcripts generated four key themes *reflecting the participants' broader concerns within which the portal use was situated*: 1) experiencing doubt and the desire for transparency, 2) seeking to become an informed and active member of the healthcare team, 3) encountering complexity, and 4) emphasizing the importance of the patient-provider relationship.

Theme 1: Experiencing Doubt and the Desire for Transparency

Several participants described using portals and the Internet to reveal what they believed was the '*hidden truth*' about their condition. Experiencing doubt and the desire for transparency were articulated through the following subthemes: (a) an uncertain future and (b) transparency of health information versus withholding information.

Subtheme 1A: The Uncertain Future

Many participants voiced their concerns about not knowing what their future held. They used a patient portal and the Internet to look for certainty. For example, when participants were asked what one was looking for or hoping to achieve while using the Internet, a family caregiver replied, "*My uncle I think was just wanting to know what other people had to say, what was the collective wisdom on this… am I gonna survive it*?" Similarly, a woman in her 20s said the following about accessing information on social media:

> *There's just so many people out there like you and sometimes it inspires a sense of hope, these people survived, I can do it too type of thing, but other times … it can cause some harm because if you see a really sad story, you're like shoot, what if that happens to me?*

Most participants found patient portals useful for accessing personal medical information, particularly test results. The words of a 60-year-old woman who used My Personal Records (MPR) exemplify an attitude of several participants: "*The way I'm wired, I freeze if I don't know the information; I freeze. Information keeps me moving forward …* [this] *is the best way to summarize how I use the portal, and how I use the internet.*" To clarify medical terminology encountered in the portal and to search for additional information, all participants commonly turned to the Internet; for example, the Mayo Clinic and WebMD websites. Participants' preferences varied: some used Wikipedia as a starting place and then triangulated information from various sources; others sought out open-access scientific research.

However, participants realized that neither generic nor personal medical information, such as test result numbers in the portal provide definitive answers or allow them to understand the prognosis of their illness. For this, participants relied on their healthcare providers and were very sensitive to what their providers disclosed and withheld.

Subtheme 1B: Transparency of Health Information versus Withholding Information

Access to medical information via a portal addressed only a fraction of what participants living with cancer felt was necessary for them. Participants often equated transparency of information with openness of their healthcare providers. The majority of the participants stressed the importance of receiving clear and unambiguous health information. A 64-year-old woman emphasized this notion by saying:

> *When you've got an oncology patient, for the most part, ... those people really have to buy-in to the healthcare system, they're there for a long time, not a good time, and they want full knowledge, they want to be able to get confirmed ... what's the word I want ... full consent, knowledgeable consent.*

Comparably, a 68-year-old woman disclosed how she used nonverbal cues to attain openness during a telehealth videoconference: "*When I asked him* [oncologist] *a question, I could look to see if he was covering anything, you know, if he was trying to protect me from some information, I could tell that on his face*." (This video call was enabled by other technology, not via the portals, as MPR does not provide video visits with healthcare providers). Participants implied that honesty and full transparency are inextricably intertwined; both are paramount to the provision of care and to the development of trustworthy patient-provider relationships. As a 72-year-old man stated,

> *We don't want secrecy, we want openness. The health system is all about the patients and without the patients you don't have a business. ... If you've got an open thing of information on both sides of the conversation, you can overcome objections so much more honestly.*

It is noteworthy that many participants wondered if their healthcare provider was withholding information from them as a means of protection. A 45-year-old woman said, "*Because you know, you always think that maybe, are they* [healthcare providers] *telling you everything? Are they hiding something?*" As a result, some participants relied on the portal and other online sources, such as social forums and websites that provide cancer specific information, to uncover the '*hidden truth.*' A 60-year-old man used the Internet to verify if the information he was given by his doctors was true:

> *I was getting statistics on the type of treatment that I was going to get and it had a success rate of well over 90% and sometimes it's the old saying, that if it sounds too good to be true than it probably is, well I guess I checked it* [the Internet] *to cross reference that and to make sure that they are telling me the truth about it.*

Another 60-year-old participant echoed the aforementioned concern and described how she used MPR to cross-check the information she received from her doctor:

> *You* [the patient] *do get left behind and I think what the portal can do … is make sure I'm asking the right questions, like why is that high and* [the doctor is] *not mentioning it? … to say I don't trust the system is too extreme, but I don't trust that people don't make mistakes.*

Most of the participants acknowledged the importance of having truthful information, often obtained from a combination of sources, that assisted them during decision-making processes.

Theme 2: Seeking to Become an Informed and Active Member of the Healthcare Team

Much-noted benefits of patient portals was having access to laboratory test results and a medication list. Participants wanted to use portals to become well-informed and better prepared for medical appointments with their oncologists; however, they felt that having access to limited information supplied via the portal prevented this from occurring. Although the portal allowed participants to feel more in control of their situation, it did not necessarily equip them to be full participants in their care because of limited information provided in the portal. Subthemes for this category included: (a) seeking control through independence, (b) accountability for managing one's health, and (c) preparation for medical appointments.

Subtheme 2A: Seeking Control through Independence

Prior to the adoption of portals, participants received relevant personal health information entirely through their healthcare providers. Portals allowed them to access test results independently and thereby made them feel more in control of their situation. A 64-year-old woman who used My Personal Records (MPR) said,

> *Until some of these portals were coming up, I kept a written log, I asked for copies of lab results, especially when they were abnormal. And that's not necessary now, it's all there online, and it is fully accessible in Alberta*. [She continued] *I guess it* [a portal] *just gives you a sense of control which I think, when you're a patient you often feel like you don't have a lot, so even just giving you that sense so you really felt like you were part of the team.*

Reiterating this point, another participant familiar with MPR, who in the past was a family caregiver, spoke hypothetically about how portals might be helpful for oncology patients:

> *Portals would help them* [family/friends with cancer] *feel more in control of what can sometimes feel like a situation where you don't have any control. Cause you know, you're always waiting for somebody else to tell you what's next, and how this is gonna go, was your scan clear, was there something on it? You can go and check them yourself.*

Subtheme 2B: Accountability in Relation to Managing One's Health

Many participants believed that being a self-advocate and taking ownership for their own health was part of their responsibility as a patient. An online patient portal both required and promoted self-responsibility. A 64-year-old woman said,

> *One of the things I have found dealing with long-term residual results from cancer treatment is: if you're not your own advocate, if you don't stay on top of it yourself, then*

> *... you can get lost in the shuffle. And so, to me, there is a personal responsibility for keeping on top of everything.*

Although all six of the participants who accessed MPR appreciated having the ability to independently look up their laboratory results and immunization records, many found it particularly challenging to track their health status, as the information provided to them within the portal was fragmented. A 68-year-old woman said with irony in her voice: "*We want people to take responsibility for their own health and yet we are not giving them all the information*." Many participants wanted to be able to read unredacted clinic-visit summaries, doctor's notes, referrals, and diagnostic results in full detail—regardless of how harsh those details were. However, at the time of the study, the amount of information supplied to MPR patient portal from Alberta's EMR was very limited.

A man in his 70s shared that one of the reasons he did not access this portal was because of missing information (at the time of the study in the Fall 2020): "*PSA* [prostate-specific antigen] *is not available and for prostate cancer people that are in active treatment the first thing that the patient will look at is, what's my PSA?*" On the other hand, a woman who had access to both portals, appreciated viewing diagnostic imaging reports such as scans and X-rays provided through MyAHS Connect (whereas they were unavailable in MPR). This participant found that printing out her imaging report for a muscular-skeletal injury she had been dealing with recently, and taking the report to her physiotherapist, made communication easier for her with her care provider. It also increased accuracy of information conveyed.

Many of the participants recognized inequality in the distribution of health information. A 68-year-old woman stressed: "*If we really think patients are part of the healthcare team then we need to give them the same information as the other members.*" Being their own advocate and having equal access to medical information were considered essential components in terms of managing one's health. Yet, most of the participants felt that MPR, in its current form, was "*lacking in execution.*"

Subtheme 2C: Preparation for Medical Appointments

Given the time constraints of medical appointments with oncologists, participants really valued their appointments. For example, a 64-year-old woman said: "[A portal] *allows me to be more knowledgeable when I go into a meeting or an appointment because I have specific pinpoint questions, so that I'm not wasting their* [oncologists'] *time.*" Many participants used the portal and other online sources as a means of preparing for their appointments. A 74-year-old man shared his perception of the Internet's potential: "*It is all intended to help the individual become more conscious of their situation ... so that they can be more effective in their dialogue with their oncologist.*" The portal and Internet sites allowed participants to assume a more active role during their appointments, as having access to information prior to the meeting fostered meaningful dialogue with their oncologist. A 45-year-old woman discussed how she used MPR to prepare for her appointments, "*When you go see an oncologist the time is very short .... So, if I go in and I already know, ok my test results were good, then my set of questions are gonna be this.*"

In contrast, some participants felt that the information provided to them via MPR neither prepared them for their appointments nor promoted conversations within the multidisciplinary healthcare team. For example, a 39-year-old woman disclosed that having access to incomplete information did not increase her confidence going into an appointment:

> *It* [the portal] *didn't really give me that ability to come into the appointment ready, which is what I would want out of this, is for me to come into appointments more knowledgeable, for me to be able to talk with my doctor more back and forth versus him coming in with all the information.*

Theme 3: Encountering Complexity

All participants encountered multiple complexities when navigating the portal technology and when piecing together information. Due to the difficulty of comprehending medical jargon and unexplained information in My Personal Records (MPR) portal, all six participants who used this portal turned to the Internet to gather information about their medical condition. During the interviews, it was apparent how challenging the portal names were for participants, not to mention the fact that there are two different portals housed on the same My Health Alberta Government website. One woman felt exasperated trying to make sense of all the names, official and colloquial, she previously heard as being used (often interchangeably) to refer to a website with patient's health information: *"my health Alberta; my health; my health records; my personal records; mhr; portal; my ahs connect; my ahs; mac…"* And this list does not include a mobile app version for MyAHS Connect called "MyChart by Epic." A sense of encountering complexity and feeling lost were expressed through the following subthemes: (a) a counter-intuitive tool and (b) difficulties comprehending information.

Subtheme 3A: A Counter-intuitive Tool

The majority of the participants who accessed MPR discussed diverse difficulties they experienced, such as poor organization of the webpage and non-intuitive navigation. A 39-year-old woman, who reported using the portal since early 2019 when it was launched, described it as "*not patient-friendly.*" She elaborated by describing the layout of the page with medication prescriptions: "*It had dates, but it didn't really seem like they were in order or I couldn't really determine what the order was supposed to be, it didn't really make sense*." Similar problems were reported by a 60-year-old woman: "*Occasionally I want to check* [my medications], *especially the one-off prescriptions, the ones you have to spend hours digging through the data to find out what you were prescribed, like when I had a bladder infection*."

The way lab results were displayed in MPR garnered even stronger criticism: "*It just sucks*," mentioned one participant and then elaborated:

> *You can't just pick a test and then get the entire bit of information … Like my mom is following her one blood test every month … If she wants to track how that one test is doing, she has to keep a written log because otherwise she has to keep going back and searching, and searching through all of the multiple blood tests she gets … I think it* [My Personal Records] *was designed by a computer programmer who didn't understand how people used their data.*

Similarly, a 68-year-old woman, who used to work in health care and self-identified as highly computer literate, described her attempt to make sense of the lab results page: "*You can't just look at it and see it on one page; that really frustrates me. And if I recall correctly, it's organized in a weird way.*"

Due to the perception of poor organization of the webpage and its 'cluttered' interface, participants described the portal as difficult to navigate. A 68-year-old woman quoted above, summed up her frustration: "*There's too much stuff on it and so you have to kind of figure things out.*" She continued, "[Unlike MPR] *I like nice, simple, clean… here's what I'm looking for, click on that, ok there it is.*" Navigating the complicated interface deterred a 39-year-old woman from using MPR: "*I found it pretty hard to navigate …. I just didn't find it helpful, near as helpful as I expected it to be or hoped it would be, so I haven't really gone back.*"

In addition, participants described the multi-step sign up process as being somewhat "*cumbersome.*" Waiting for a code to arrive in the mail felt to some like a *"drag."* Further, a 45-year-old woman shared:

> *I had trouble signing in when* [the portal became available] *because you were supposed to scan your driver's license or something, I don't know, something wasn't working so I actually had to try about three or four times.*

Although most of the participants felt that the sign-up process was disconcerting, many appreciated, from a security standpoint, how careful the Government was at protecting information. As one person expressed, "*It was worth it to go through the steps to know it was secure.*"

Only three participants considered MPR as "*easy to navigate*" (one of these individuals was also referring to MAC, MyAHS Connect), while others expressed the need for a simpler portal. "*The biggest thing is that they're* [portals should be] *intuitive.*" Another individual said, "*They* [should not] *be difficult, portals are only as good as they've been created and set up and if it's difficult to maneuver through it, it's gonna turn people off.*"

Subtheme 3B: Difficulties Comprehending Information

All seven participants who used a portal, encountered unfamiliar medical terminology and/or incomplete information and relied on the Internet at some point, to fill the gap. A 77-year-old woman, who previously worked as a healthcare provider, described having difficulty interpreting radiology reports within MAC: "*Some of these radiology words are a bit challenging and I've got a healthcare background, so if I can't figure it out, what about the general public?*" Comparably, a 39-year-old woman said, referring to a disjuncture between vaccine's names commonly used in colloquial language and vaccine's scientific names used in the portal: "*I didn't know … the technical name of the immunization … was that flu shot, was that Twinrex, was that the things that we call them, the layman's terms. It was … too technical for a patient, it wasn't patient friendly.*" The same participant, who self-identified as health literate and computer-savvy and came across as very articulate, nevertheless mentioned the following about lab results: "*It would be great if I could see all of them, or if I could understand them.*"

As a consequence of encountering medical jargon and incomplete information, participants either gravitated towards the Internet to understand the information or turned away from the portal altogether. For example, a 68-year-old woman described a situation in which she used the Internet to understand why a lab result was abnormal: "*That's when I would go to Wikipedia* [as a starting place] *and I would check to see why my GFR* [Glomerular Filtration Rate] *was low.*"

The main difference between the information provided within the portal and on the Internet, however, was that the portals did not generate suspicions of falsification. As a 72-year-old man said,

> *The patient portal is a reflection of what's actually happened to you. The internet is a morass of good information and misinformation and it depends on your intellect or the space you're in mentally as to how you interpret that.*

When navigating the portal, participants noted fragmented and often perplexing information, but knew that the information within the portal was about them.

Theme 4: Emphasizing the Importance of the Patient–Provider Relationship

Perhaps paradoxically, patient access to their personal health information via portals and an increased sense of independence, have generated a greater emphasis on the value of patient-provider relationships. Although many participants voiced concerns about healthcare providers potentially withholding information as a means of protection or *"sugar-coating"* (as one participant has put it), participants still trusted and valued their professional advice. While the findings did not directly suggest that trust influenced patient portal use, they did highlight the importance of in-person interactions and having healthcare providers assist patients with interpreting information from the portals and other online sources. The subthemes for this category include: a) trust and the essence of in-person interactions and b) the need for additional information.

Subtheme 4A: Trust and the Essence of In-person Interactions

Although participants appreciated having access to their personal health information, they did not want portals to replace the relationship they had with their oncologist, family doctor, or a nurse. The development of a trusting relationship between the patient and health provider was mainly attributed to in-person interactions. A 68-year-old woman stated, "*I wouldn't want it* [the portal] *to replace my relationship with my physician.*" She continued, "*I feel like I need to trust them. That relationship really matters and I'm not somebody who prefers to use technology for my relationships, I prefer it face-to-face.*"

Participants described the importance of in-person interactions when receiving unpleasant news. A 72-year-old man rhetorically asked, "*You should never have an internet message saying— 'you've got stomach cancer, report to your doctor'— that should never happen; that's a human touch, right?*" Comparably, a family caregiver said, "*How it* [a message] *gets delivered, who you're hearing it from, how you're hearing it, makes a big difference in how you're going to build your own frame of reference to go forward.*" She continued, "*They're* [healthcare providers] *trained, they know how to deliver news like that and how to support people.*"

Subtheme 4B: The Need for Additional Information

Most of the participants relied on their physician and nurses to provide them with necessary information, or to explain its significance, to understand and manage their medical condition. A 45-year-old woman shared: *"My neutrophils, whenever I'm on my medication, is low. It doesn't alarm me* [when I see it in the portal] *because I know my doctor's seen it so if he was concerned about it then he would tell me.*" Some of the participants did, however, recognize that their healthcare providers are also busy attending to other patients. A 60-year-old man said, "*I found the doctors I was dealing with were also dealing with hundreds of other people.*" Not having a healthcare provider available to interpret information significantly impacted the participants' lives. A woman in her 20s who did not have a portal account, shared her reality:

> *They'll* [healthcare providers] *take weeks to get back to you and I think running on such high anxiety levels is simply something I can't do. It really hinders every aspect of my life; I can't function normally until I get the clear you know? It's like debilitating fear.*

Enlisting the help of formal supports, such as their oncologist, helped alleviate anxiety. A family caregiver shared, "*She's got a great family physician who will get all of her results and interpret them for her so when she actually talks to the oncologist she's already in a state of receptivity, she's more relaxed.*" Similarly, another participant described her reaction to reading the word 'metastases' on a radiology report within MAC: "*It made me very nervous.*" She continued, "[but] *now I know to ignore that because my doctor says, no, that's not the case."* Participants acknowledged the importance of attending their medical appointments; for example, one woman stated, "*That's why we go to the specialist, to tie it all together.*"

Discussion

Summary of Key Findings

The aim of this study was to explore the experiences of oncology patients and/or their family caregivers with electronic patient portals available in Alberta for health-related purposes. As far as we know, this is the first empirical study set in the unique context of a two-portal system in Alberta, Canada, that illustrates how the tensions between the macro-level portal policymakers [23] are manifested in patient experiences with portal technology. At the time of the study, the provincial Government's webpage with the access to MyHealth Records housed two portals. A provincial portal My Personal Records (MPR; implemented by the Government *per se*) was available to adult Albertans, and most participants in our study used it. On the other hand, a provincial health authority's (AHS) clinical information system Connect Care (EPIC) and its MyAHS Connect patient portal (MAC; known as MyChart in 2015-2019 during the pilot stage and implemented independently from the Government) had not been launched across Alberta's oncology facilities. However, some oncology patients attending other clinics for concomitant health concerns, might have had access to MAC through those non-oncology facilities. One participant in our study used both portals.

One concern raised frequently by the participants was the lack of awareness of the portals in Alberta. Many pointed out that the portals were not well advertised. In fact, three participants who did not use the portals didn't know they existed until enrolling in the study. Further, the overall terminological morass with portal names and an excessively complicated sign-up/authentication process are characteristics of the two-portal context in the province. This influences the public perception and creates a barrier to portal adoption.

Our data do not permit robust comparison between the two portals (e.g., webpage layout, navigation, filtering of test results); however, participants expressed frustration about the existing layout of MPR, while MAC was appreciated for proving access not only to lab tests but also to diagnostic images.

Findings of this study point to patients' desire for transparency. Although portals and other digital platforms were considered as beneficial tools in accessing health information, these tools did not provide its users with direct information regarding their prognosis and future. Many of the participants used these tools as a means of triangulating or supplementing the information provided by their healthcare providers. Several participants wondered if their healthcare providers were withholding information from them as a means of protection; therefore, they used the portals and the Internet to cross-check the information. Although the majority of participants felt that having access to health information enabled them to be more knowledgeable, prepared and in control, some felt that having limited access to information prevented them from becoming active participants of their health. Moreover, many of the participants described how personal interactions had profound effects on the development of trusting patient-provider relationships and that they did not want portals or any other online tools to replace that.

Participants in our study did not regard searching for health information or using a portal in separation from their ongoing lives as people living with cancer. Related to the *technology-in-practice* perspective [27,28], we found that the portal joins the net of relations consisting of healthcare providers (especially oncologists and nurses), information, medical visits, diagnostic tests, prescribed drugs, family life, etc. The usefulness of portals (or not) is weighed by their ability to answer questions, link pieces of information, offer continuity through displaying comprehensive information, and make communication effortless. The organization of portal webpages and their content produce multiple and shifting effects such as increasing or alleviating anxiety, positioning a portal-user as a tech-savvy or 'illiterate', and enhancing or undermining trust in health services.

Comparison with Other Literature

Supporting our findings, Kooij et al. [13] noted a significant tension between the aims of protecting information privacy versus facilitating portal uptake among end users. In the Netherlands, a portal sign-up for patients that requires the use of the Government-issued unique Digital Identifier and a multi-step authorization and verification, is a notable barrier to portal uptake and use [13].

The evidence on the implementation and uptake of patient portals is unequivocal about the facilitating factors, such as creating awareness about the portal, easy sign-up process, intuitive navigation, explanation of medical terms and the use of lay language [19]. Yet, all these facilitators were lacking at the time of the study.

Participants in our study emphasized the importance of the patient-provider relationship; a parallel finding to Alpert et al.'s [18] study from the United States. In our study, the majority of the participants relied on their family doctor or oncologist to interpret information from the portals or the Internet and to try to resolve feelings of uncertainty and distress. Similar findings were reported by Baudendistel et al.'s [36] study in Germany, where healthcare providers shared their concerns of patients developing anxiety and uncertainty during the absence of professionals to interpret results presented within portals. Several participants preferred in-person interactions for communicating about their condition. The importance of communication in oncology is equally emphasized in several other American studies [9,37,38].

At the time of our study, participants lived with non-active cancer, had infrequent diagnostic tests, and accessed the portal occasionally. With the exception of one person, they did not report situations when they viewed abnormal test results in real time, before their oncologist evaluated the results and had a chance to follow up with them. In contrast, the research literature is replete with examples of concerns expressed by patients and healthcare providers about immediate result release. For example, the overwhelming majority of oncologists in an outpatient department at Stanford Cancer Care Center felt that patient online access to abnormal results had negative consequences, but opinions were mixed for normal results [12]. Furthermore, half of the oncologists reported that sharing online results had worsened their communications with patients [12]. In another study, the timing of result release was identified by oncologists and nurses in a cancer care centre in New York as particularly important for patients as some results may indicate the recurrence or progression of disease, generating patient anxiety [35]. Physicians were clear about the necessity to quickly aid patients in interpreting test results to prevent or reduce anxiety [12].

Numerous studies suggest that electronic portals improve patient health outcomes [39,40]. Patient empowerment facilitated by the use of portals and other online tools is a recurring theme in the literature [3,9,39,41,42]. It is said that the provision of health information, especially laboratory results, allows patients to feel more involved in the management of their care; thereby, empowering them [9,43]. Our findings complicate and add nuance to the aforementioned literature. Similar to findings reported in Ammenwerth et al. [24], portals did not necessarily foster feelings of empowerment. Participants spoke of the challenges they encountered when attempting to become an informed and active member of the healthcare team. While access to health information allowed participants to prepare for their medical appointments and feel in control [18,44], many of them struggled to make sense of the fragmented information. Moreover, many of the participants discussed the need for access to information to self-manage in their daily life. Therefore, to foster feelings of empowerment, other conditions should be in place in addition to having access to one's personal health information. It is possible that the language of empowerment is preferred by researchers; but people living with cancer seem to describe their experiences in other ways.

Recommendations for Research

Contrary to some existing research, in our study, participants who used a portal did not describe feelings of empowerment. We wondered: do portals and other online tools actually foster feelings of empowerment or does this notion stem from the development of knowledge about one's condition and health-visit preparation skills? The interchangeable use of the terms engagement and empowerment has further added to the complexity of measuring this concept [43]. Future research might explore both engagement and empowerment and clearly define how these terms are understood.

Further, ethnographic fieldwork is promising for understanding why portals are used or abandoned by patients and involves examining whether and how patients use health technology in daily life, what practical arrangements (consisting of people and things) they create to support living with chronic health conditions, and how technology can support what Jeannette Pols calls a *good life* for patients [45]. Talking about *good* life with technology, Pols, a social scientist, philosopher, and health care researcher, means that the new health technology (e.g., a portal) is not inherently good. Its effects and outcomes are not pre-determined but instead are produced as the result of interactions among various human and non-human elements in everyday life. This draws attention to particularities [46], and to the necessity for accommodations, the ability to undertake and undergo small changes and adjustments from/by technological systems, humans, healthcare practices, and policies. What Pols might ask of portal implementers, policymakers, healthcare organizations, and researchers interested in the success of eHealth tools is to—amidst the focus on healthcare standardization, "generalizable outcomes," "universal values," and "general trends" [46]—make space to attend to particularities of patients' lives to understand what arrangements make a portal valuable versus meaningless.

A noteworthy finding of the study was that some participants used the portal and the Internet to counter the lack of transparency perceived in health care. Future studies can explore how trust can be developed and sustained within online environments. Transparency is seldom discussed in health care despite being a common concern and potential ethical issue that directly impacts patient care [47]. Full disclosure of information may promote better quality care, augment trust and promote better health outcomes [48].

Future research could also examine portal platforms and compare them across Canada, as some provinces work with different vendors and develop their own portals. Comparing portal implementation across the country could assist with the identification of best practices and help guide improvement strategies to reduce costs and maximize benefits.

Once Connect Care is launched within Alberta cancer care facilities and patients receive access to MyAHS Connect, it will be essential to understand patients' experiences with the two-portal terrain as well as health professionals' perspectives working within the context of oncology care. Some areas that will need to be considered include access to the portal (ensuring an easier sign-up process) and ways to balance transparency with the potential psychological impact of information that is distressing, unclear, or can be misinterpreted. With increased portal use and the expansion of the potential information that can be accessed by both the patient and their families via a proxy access, further questions arise. These questions also highlight the ease of use and the security of the data.

Recommendations for Practice

One key recommendation is to improve public awareness and healthcare providers' awareness about portals and their ability to promote them. Further, developing an education program (e.g., video tutorials and posters) can facilitate portal uptake. Healthcare providers also require portal training, as it may allow them to assist patients who require further support with accessing supplementary resources and navigating portals. Education programs aiming to increase citizens' digital and health literacy may assist patients to develop confidence, critically analyze health information and allow them to make informed decisions that optimize their health [49]. Healthcare providers are at the forefront of patient education and might be in the optimal positions to tailor education sessions to individual capacity [50]; however, healthcare providers require organizational support and would need to co-design educational materials with patients and family members.

Our study did not include perspectives of oncology service providers; however, it is well known that the collection, storage, and analysis of patient-reported quality of life and outcome measures is an ongoing process in oncology context. Patient portals provide a convenient venue to support these organizational goals, making it easier for patients to complete before and after-visit questionnaires. The success of this undertaking depends on patient's uptake on the portal technology. Our findings indicate that even highly educated and literate individuals with computer skills might be deterred from the difficult-to-navigate portals containing fragmented information.

Recommendations for Policy

A patient-friendly version of the portal with a simpler interface, and one that is designed with understanding of *how* patients use information, is needed. However, explaining the significance of laboratory values and providing direction on what to do after being informed about an abnormal result lies beyond the portal's affordances; it is the role of the clinician. Portal policies should be developed with the appreciation of the role of clinicians, who often need to mediate between the patient and the portal.

It will be interesting to observe how the Alberta Government's My Personal Record and the health authority's MyAHS Connect co-evolve and how this process shapes experiences of portal users. Another important consideration is the timing of releasing test results into the portals. Many oncology patients prefer discussing the results with the oncologist first to prevent feelings of distress. Lastly, an essential recommendation for practice and policy is that portals cannot streamline or replace the patient-provider relationship, as this relationship can provide both trusting and individualized care [51].

Limitations

There are a few limitations to this study. All participants spoke English as their primary language; therefore, this study did not account for challenges that may have been faced by individuals who speak English as an additional language, or who are unable to speak English. Further, our convenience sample was comprised of individuals from Alberta Patient and Family Advisory Network for oncology. These tend to be well educated individuals (often former healthcare professionals) who regularly use computers and the Internet and are active participants in managing their health. Lastly, our recruitment relied exclusively on email invitation (with one reminder). This approach may have excluded individuals and groups who don't use computers and who, by extension, will likely not be able to use portals.

The strength of this study was a sample comprised of individuals of diverse age, from the 20s to the late 70s. Further, patient portals are new to Alberta, Canada, and it is informative to learn from the experiences of early adopters. The detailed description of portal features and the context of portal implementation provided earlier in this paper will help readers judge the degree of transferability of our findings. Indeed, we want to stress that the differences in portal features and design across jurisdictions should be taken into consideration in research on portals.

Conclusion

In Canada, the objective of using eHealth is to encourage Canadians to live healthier by offering online tools that securely connect its users with valid, up-to-date health information to augment understanding and management of personal health [2]. With the growth of cancer diagnoses today, patient portals are becoming more desirable to strengthen the coordination of care for oncology patients [12]. Although literature foregrounds the benefits that portals can offer patients, the findings of this study suggest that more effort is needed to move from the portal deployment to making it an integral tool in the lives of people living with cancer. It is noteworthy that patient portals cannot replace the patient-provider relationship, but rather, serve as an additional means of accessing information and assisting oncology patients to cope with their condition.

Acknowledgements

AS' graduate studies were supported by the Helen Rollis Prize for Excellence in Advanced Nursing Practice and the Scott Family Graduate Scholarship, as well as the Lowry Award from Edmonton Community Foundation.
OP acknowledges with gratitude funding she received from the Social Sciences and Humanities Research Council of Canada (SSHRC IDG).
OP, PR, LW, JE are thankful for the Endowment Fund for the Future from the Faculty of Nursing, University of Alberta, Canada.
VC has not declared a specific grant for this research from any funding agency in the public, commercial, or not-for-profit sectors.
Survey data were collected and managed using REDCap electronic data capture tools hosted and supported by the Women and Children's Health Research Institute at the University of Alberta, Edmonton, AB, Canada.
The authors would like to thank Ms. Debora Allatt, Manager, Education and Patient Experience, Cancer Care Alberta, Alberta Health Services, for her assistance with distributing recruitment emails.

Authors' Contributions

OP led conceptualization of the project and with AS submitted the ethics application. OP drafted the original version of the survey and interview guide. AS conducted participant recruitment, data collection, the initial data analysis, and drafted early version of a manuscript. AS and OP contributed equally to the substantive content of the original manuscript. AS, VC, OP helped refine data analysis. VC provided necessary guidance to AS throughout the process and helped revise interview guide and manuscript drafts. PR, LW, JE were involved in project conceptualization, grant funding application, and survey development; they also added substantive content to the original draft and reviewed subsequent versions. OP led a revision process, executed by her and VC with input from AS and PR. All co-authors approved a final version.

Conflicts of Interests

None declared.

Multimedia Appendix

Table

Abbreviations

AHS: Alberta Health Services
EHR: Electronic Health Record
EMR: Electronic Medical Record
MAC: MyAHS Connect (AHS' Connect Care portal)
MADI: MyAlberta Digital ID
MPR: My Personal Records (Alberta Health (government) portal)

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CHAPTER 3: IMPLICATIONS, RECOMMENDATIONS AND REFLECTION

This chapter includes a brief summary of the research findings, implications for nursing practice and recommendations for future research. A personal reflection is also provided. Reflective writing is fundamental to the concept of learning from experience. A personal reflection enhances critical thinking, facilitates creativity, contributes to new insight of problems and allows for self-improvement (Jasper, 2005).

Brief Summary of the Findings

I identified four themes that describe oncology patients' and/or their family caregivers' perspectives of using electronic patient portals and other online tools for health-related purposes. Themes that emerged from the interviews were: experiencing doubt and the desire for transparency, becoming an informed and active member of the healthcare team, encountering complexity, and emphasizing the importance of the patient-provider relationship.

Experiencing doubt and the desire for transparency were expressed through the following subthemes: the uncertain future and transparency of health information versus withholding information. The majority of the participants valued portals and other online tools, as it provided them with access to personal and general health information; however, these tools rarely made it easy for them to understand the prognosis of their disease. Many participants expressed concerns about the possibility that their primary healthcare providers (i.e., oncologist) may be withholding information from them, and explained it as the doctors' desire to protect them. As a result, some of the participants used portals and other online tools to gain further insight.

The subthemes of seeking control through independence, accountability in relation to managing one's health and preparation for medical appointments, demonstrated how portal technology and other online tools made it challenging for patients to become informed and active participants in their care and treatment. Although the majority of participants felt that having access to health information enabled them to be more knowledgeable, prepared and in control, some felt that having limited access to information prevented them from becoming active members of the healthcare team.

The experience of encountering complexity was expressed through the following subthemes: a counter-intuitive tool and difficulties comprehending information. All participants encountered some difficulties when navigating the novel portal including poor organization of the webpage and non-intuitive navigation. Furthermore, many of the participants mentioned that the information provided was both fragmented and difficult to understand. Consequently, all of the participants who used portals relied on the internet at some point to make sense of the information.

Despite patients' ability to access their personal health information via portals, they placed greater emphasis on the patient-provider relationship. This notion was brought forth through the subthemes: trust and the essence of in-person interactions and the need for additional information. Majority of the participants enlisted the help of their primary healthcare provider, such as their oncologist to interpret health information. Moreover, many participants described how personal interactions had profound effects on the development of trusting relationships and that they did not want portals or any other online tools to replace that.

Implications to Nursing Practice

As the use of eHealth tools including portals continues to evolve in Canada, understanding the effects they have on patients is paramount to the provision of quality nursing care. Nurses often play an active role in the employment of portals, as they triage patients' secure messages, educate patients about portal benefits and use, and act as intermediaries between clinician and patient communication. Therefore, it is necessary that nurses understand the impact of portals on unique patient groups. Since oncology patients have greater needs for health information, it would be beneficial for nurses to encourage portal use, as it offers patients additional access to information (Kuenzel et al., 2018). Furthermore, portals may facilitate communication and connection between oncology patients and nurses, as some patients may struggle to access health services on a regular basis. Given that this study has shown how online portals can augment self-control and reduce anxiety in oncology patients, the implementation of portals, paired with ongoing research into areas of concern for this population is significant to nursing, as it may support nurses in the delivery of care (Kildea et al., 2019; Rodriguez, 2018). Developing a more comprehensive understanding of why oncology patients use the Internet and other online tools may allow nurses to provide more tailored support and alleviate possible anxiety (Mattsson et al., 2017). Nurses can ensure that health education includes discussion on how to access credible sources on the Internet (Haase et al., 2019). As Escriva Boulley et al., (2018) have stated, digital health tools can allow patients “to cope better with cancer and treatment side effects, and to enhance psychological wellbeing, leading to faster recovery” (p. 2684).

In general, the findings of this study can assist nurses to recognize barriers and challenges associated with portal use and will thereby facilitate improvement strategies. One significant barrier that was identified in this study, as in other studies, was having limited digital and health literacy (Kooij et al., 2018; Antonio et al., 2019). About half of the participants recognized that this barrier existed because of the diverse populations that used portals; for example, older adults and individuals who spoke English as an additional language will likely experience this barrier. A nurse can make patients aware about resources, such as portals, however, if patients do not understand medical terminology, then the portal, as it currently exists in Alberta, is of little use to them. It is well recognised that portals need to be user-friendly and easy to navigate to engage diverse patient groups (Antonio et al., 2019; Antonio et al., 2020) and encourage them to be more involved in their overall health (Pirschel, 2020; Thomas et al., 2014). In Alberta, both the Government and AHS should increase the visibility of their respective portals and advertise them to the public. Developing an education program (e.g., video tutorials and posters) for Albertans is fundamental to portal uptake. Healthcare providers also require portal training, as it may allow nurses and other healthcare providers to assist patients who require further support with accessing supplementary resources and navigating portals. Other education programs, those aiming to increase digital and health literacy, may also assist patients to develop confidence, critically analyze health information and allow them to make informed decisions that optimize their health (Nutbeam et al., 2010).

Nursing values a patient-centered, humanizing approach. Digital health tools can sometimes hinder this practice and inadvertently interfere with the meaningful relationships that nurses strive to develop with their patients (Cuchetti & Grace, 2019). Technology has an enduring presence in modern nursing practice; thus, nurses should develop critical awareness about the effects that technology has in healthcare and explore patients' perspectives of using these tools to ensure optimal experience (Cuchetti & Grace, 2019). The influence of technology as well as its consequences and benefits on patient care, should be taken seriously while delivering nursing care (Cuchetti & Grace, 2019). Nurses should not assume that all patients will use technologies exactly as they are designed, as everyone shares different values. Instead, nurses need to inquire into how patients use digital health tools in their daily lives to sustain the benefits that technologies can offer.

Recommendations for Future Research

Contrary to some existing research, participants in this study, who can be considered early adopters of patient portals in Alberta, did not describe feelings of empowerment. Future research can assess how empowerment is being measured and to clarify the association of patient empowerment and the use of portals (Risling et al., 2018). Do portals and other online tools actually foster feelings of empowerment or does this notion stem from the development of knowledge about one's condition and health-visit preparation skills? The interchangeable use of the term's engagement and empowerment has further added to the complexity of measuring this concept (Risling et al., 2018). Another research direction that is more promising involves understanding whether and how patients use digital health tools and portals in daily life, what practical arrangements (consisting of people and things) they create to support living with chronic health conditions, and how technology can support *good life* for people (Pols, 2012).

Best evidence suggests that when portals are being designed, their prototypes be tested with the intended users. Such studies can examine how information can be presented and modified (e.g., lay language) within portals so as to ensure that patients can fully comprehend the information provided. Future research could also examine portal platforms and compare them across Canada. Each Canadian province, and even each health authority in some provinces, work with different portal vendors and develop their own portals. Comparing portal implementation across the country could assist with the identification of problems and help guide improvement strategies to reduce costs and maximize benefits. In addition, research could explore patients' and caregivers' perceptions surrounding ethics and privacy to protect personal information and foster trusting relationships between healthcare providers and patients. As Lovatt et al., (2017) purport, "New technologies and platforms are likely to change how trust manifests, so researchers should be responsive to technological change and how this might affect trust and sharing [information] online" (p. 11).

What is clear from the findings of this study is that some barriers exist to patient portal use. Consequently, future research should explore barriers and opportunities for the adoption of portals. Critical digital literacy skills should be explored in greater detail. Examining if portal use is linked to other issues of health inequities, such as ethnicity and gender should also be considered in future research. Furthermore, patient engagement of portal use should be measured over time. Future research should assess whether portals and other online tools can have a more expanded use and not just be used during times of uncertainty.

A unique finding of the study was that, for some of the participants, portal technology and other online tools were used as a way to counter the lack of transparency perceived in healthcare. Future research should explore what transparency means to the patient and what changes they would like to see in order to feel like an active and informed member of the healthcare team. Research should examine how clarity of information can be achieved in healthcare and whether clinical information technologies can assist with transparency of information. Moreover, exploring how trust can be developed and sustained within online environments should also be considered. Transparency is seldom discussed in healthcare despite being a common concern and potential ethical issue that directly impacts the care that patients receive (Clarke et al., 2012). Full disclosure of information may promote better quality care, augment trust and promote better health outcomes (Oettgen, 2017).

Personal Reflection

For the past 7 years, I had the ambition to do my Master of Nursing. I have always admired people who have become experts in their field of practice and obtained their PhD. For this reason, I have chosen to pursue my Masters as a stepping-stone towards achieving my PhD.

Ever since I worked as a research coordinator for Dr. Rowe at the University of Alberta Hospital, I have appreciated research. Now, after having conducted my own study, I appreciate the research process even more. I recognize that not many students write their thesis while in the Nurse Practitioner stream of the Master's program, but I truly believe more students should consider this option. Choosing this stream and writing my thesis has really transformed my nursing career, as I now recognize the value of implementing current research into practice. I have always cherished human interaction and building deeper connections with patients, especially during times of need. Conducting qualitative research has increased how much I value empathy and has given me a deeper understanding of patients' perspectives. Writing my thesis has required perseverance and commitment and despite its difficulty, I am forever grateful for the experiences it has brought me.

I have worked on my thesis for almost 3 semesters, and over the course I have grown as a writer and learned a great deal about the research process. Writing my thesis has not only made me a stronger writer, but it has taught me how to think independently and how to find the answers to questions I was unsure of. When I reflect back on the process, I think about my lack of confidence in writing and how meeting Dr. Petrovskaya transformed that. She provided me with the opportunity and challenged me to take on this endeavor. Dr. Petrovskaya's interest in eHealth and my passion for oncology joined perfectly to develop this thesis. At the very beginning, I established specific strategies for finding relevant information. When conducting my literature review, I became proficient at navigating library databases. I learned how to refine my searches by combining key words and using the asterisk key. I was surprised with how often I had to move outside of my discipline to find sufficient sources. Moreover, I was astounded by the length of the research ethics application and realized how much thought and effort goes into conducting a study.

While conducting the interviews, I found myself reflecting on the death of my father. I recognized how his death from cancer shaped my experience of conducting this research. It allowed me to empathize with the patient and family caregiver in ways that are difficult to explain. While reading through the transcripts and listening to the audio-recordings, I couldn’t help but to relate to my experience of when my father was sick. Many of the participants felt like their primary healthcare provider was withholding information from them as a means of protection. While reading this, I surprisingly found myself reflecting back to when I was 17 years old and in the hospital with my father. I remember feeling as if everyone was withholding information from me because I was young and couldn’t handle receiving such devastating news. I truly believed that everyone knew what was going to happen to my father, and so just like the majority of participants, I remember searching for answers. I remember enlisting the help of my aunt to find out the truth because I knew she would tell me everything that I needed to know. Establishing trust and the knowledge that someone is being fully transparent helps to foster trusting relationships. To this day, I value the trusting relationship that I have built with my aunt. The same could be said for the patient and healthcare provider in that full transparency can significantly improve trust and the overall relationships patients have with their healthcare providers. Furthermore, portals can work to further strengthen the patient-provider relationship by ensuring that all information is readily accessible to the patient.

Since engaging in this qualitative study, I have reflected on the importance of having strong mentors. What seemed impossible at times was accomplished with the help of my mentors. Being mentored by Dr. Olga Petrovskaya and Dr. Vera Caine was not only essential to the knowledge and skills I acquired during this process, but also to enhance my chances of success.

Upon completing my thesis, I now recognize the importance of understanding how digital technology, such as EHR and portals are used in practice. Clinical information technologies can be fundamental to the procurement of knowledge and to the development and protection of trusting patient-provider relationships. Like a participant said, *"Technology is the way of the [new] world";* therefore, healthcare providers need to "recognize both the both the promises and pitfalls of information technologies so as to use them wisely on behalf of ethical patient care" (Cuchetti & Grace, p. 1).

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Appendix A

Types of eHealth Tools

eHealth Modality	Definition	Explanation
Telehealth or Telemedicine	The distribution of medical information and services to patients and healthcare providers via information and communication technology	Telemedicine focuses on the curative aspect of care while telehealth focuses on disease prevention, health promotion and curative care
Virtual Care	Any real time connection made between patients and healthcare providers using a video or audio device to facilitate care	Virtual care can assist patients living in remote areas or those with busy schedules
Mobile Health (mHealth)	The practice of public health and medicine via portable devices, such as smartphones and tablets	Used for educational purposes, diagnostics, treatments, data collection, remote monitoring, disease tracking and telehealth
Big Data Systems	The use of data science techniques across many industries to collect and examine intricate datasets	Handling large volumes of data to augment patient outcomes and business platforms
Health Information Technology (IT) Systems	Electronics used to store and distribute medical information and knowledge	Health IT systems such as, medical imaging and computer-assisted diagnostics allows physicians and other primary healthcare providers to make precise diagnoses and treatments for patients
Consumer Health Information Technology (IT) Data	Consumers are able to collect, manage and share their personal health information along with other health-related data	Refers to a wide-range of web-based applications such as, telehomecare and portals, to allow patients to participate in their own care
Electronic Health Record (EHR)	A digital system that stores an individuals' health information	Includes patient information, such as demographics, medical history, medications, allergies, immunizations, laboratory results, vital signs, etc.
Electronic Medical Record (EMR)	Part of a pre-existing EHR; a digitized version of the paper chart	A narrower view of an individuals' medical history found in clinics and hospitals

Retrieved from Innovatemedtec (2020)

Appendix B

Time Line for Research Project

Date	**Activity**
February 2020- March 2021	Ongoing Meetings with Dr. Olga Petrovskaya and supervisory committee
May- June 2020	Co-supervisor (Dr. Vera Caine) and committee member (Dr. Susan Sommerfeldt) selected
June 2020	Submit Thesis Proposal to the Faculty of Nursing
July 2020	Oral Examination of Thesis Proposal and Ethics Approval
August- November 2020	Interviews with Participants
December- February 2021	Data Analysis & Writing Chapters of Thesis
May 2021	Present at the Canadian Nursing Informatics Association (CNIA) Conference
October 2021	Present at the Alberta Cancer Research Conference
November 2021	Manuscript published in the JMIR Cancer
January 2022	Final Defense of Thesis

Appendix C

Interview Guide

Hello and thank you for agreeing to be interviewed. My name is Amanda, I am a Registered Nurse and a Master's student in Nursing at the University of Alberta.
In our last phone conversation, you provided your oral consent to participate. Do you remember?
(Wait for participant's positive response)
This time, I would like to have your permission to audio-record our conversation and I will again remind you what the study is about and what I will ask you to do. Can I turn the recorder on?
(*Wait for participant's positive response*)

I will be begin with a brief introduction to remind you about the study in general:
This study is done by a researcher from the Faculty of Nursing at the University of Alberta, Dr. Olga Petrovskaya. This study has received ethical approval from the University Ethics Board.

The purpose of this study is to explore how people like you—people living with cancer or their family caregivers—use different online sources of information to learn about their health condition and for treatment and care. In other words, we are interested to find out whether and how **you** use Internet, social media such as Facebook groups, various websites, and other online information for health-related purposes, to help you deal with your condition.

Many people use the Internet and social media to search for health-related information, for example, to read drug information, learn about their health conditions, or connect with peer support groups. "Doctor Google" has become a source of health information for some people. What is very interesting, Albertans now have secure online access to their personal health information like lab results through the patient portal called MyHealth Records and MyAHS Connect. If you use it, I will ask you about this. If not, I will tell you about these portals.

The interview is audio recorded and also, I will also take notes in the process. You can choose not to answer any questions that make you uncomfortable. The interview can last an hour or a bit longer, but if you feel you need to take a break, tell me and we will either take a break, or stop and book another interview to continue. If you feel tired, please let me know—I can't see you and will be helpful if you tell me how you feel and if we need to stop.

Your answers will be kept confidential and not shared with anyone, including the research team or your healthcare providers. Only myself and Dr. Petrovskaya will have access to the raw, personally-identifiable data.
Another important point is that I am interested in what is really happening. Not so much in "how things should be," but in "how they really are" from your perspective and in your life. I am not judging you and not evaluating the quality of care.

Do you have any questions at this point? Can we start an interview?

[These are sample questions; actual questions will emerge in the process of interview depending on what participant says. It is not necessary to ask all questions.]

Can you tell me about how you use the Internet for health-related purposes?

(The interviewer will be quiet and wait for a response; encouraging sounds will be made – "go on", "tell me more about this...",

probing questions will be asked about specific digital information sources – websites, Facebook groups, electronic patient portals etc.

What online information does a patient access?

Why—what is the patient looking for or hoping to achieve?

How is this information used?

Does a patient share this information with an oncologist? What is the outcome?)

For participants who did not complete an online survey, the following two areas will be addressed (note: ***not all*** *listed questions will be asked during the interview—these are sample questions):*

1) Demographic questions:

Your name (First, Last)
Your year of birth
Your geographic location (name of city, town)
Your gender:
- ☐ Male
- ☐ Female
- ☐ Other

Your highest level of education:
- ☐ Elementary
- ☐ High School
- ☐ College, trade school, diploma or degree
- ☐ Undergraduate Degree
- ☐ Post-Graduate Degree
- ☐ Other: _____________

Employment/Occupation status:
- ☐ Retired
- ☐ Unable to work (e.g., due to disability)
- ☐ Homemaker
- ☐ Student
- ☐ Working full-time
- ☐ Working part-time
- ☐ Unemployed
- ☐ Other: ________________

Is your employment/occupation in the healthcare field? YES NO
Is English your first language? YES NO

Your ethnic background (to which ethnic or cultural groups did you or the majority of your ancestors belong to on first coming to Canada? List more than one if necessary):
- ☐ White [Caucasian]
- ☐ South Asian (e.g., East Indian, Sri Lankan, etc.)
- ☐ Chinese

☐ Black
☐ Filipino
☐ Latin American
☐ Southeast Asian (e.g., Vietnamese, Cambodian, etc.)
☐ Arab
☐ West Asian (e.g., Iranian, Afghan, etc.)
☐ Korean
☐ Japanese
☐ Aboriginal (e.g., North American Indian, Mètis or Inuit, etc.)
☐ Refused
☐ Don’t know
☐ Other: _______________________

How would you describe your computer skills?
Very confident/use computer regularly, for advanced things
Intermediary level / use for simple things
A hesitant user
I don’t use computer

What is your diagnosis?
What type of cancer?
When were you diagnosed?
What treatments did you have?
Where do you see your oncologist?
How frequently do you visit this clinic (number of visits last year):_____________
How would you describe your health status?
How are you feeling no?
(Prognosis? Social networks/caregivers?)

1) Usage of Alberta’s patient portals if the participant is aware / uses them:

Do you use MyAHS Connect or MyHealth Records?
How did you decide to start using it?
Did your doctor inform you about the portal? What did he/she say?
Do you remember when you signed up? Tell me about the process of signing up
So, how many months you are using it now?
How often do you use it?
How do you use the portal? What are the occasions? What information do you look up?
Do you find this information easy to understand? What do you do if you do not understand something? Where do you obtain needed information?
Are your family members also using the portal?
Have you ever sent a direct message to the clinic via MyAHS Connect? What happened next?
Has the portal changed anything for you?
What do you do now that you did not do before this portal was in place?
Are you satisfied with how the portal works?
What do you get out of the portal?
What works well? What is most useful about it?
What does not work? What is most frustrating about it?

If you could change something about this portal, what would that be?
How are clinic appointments scheduled for you? What will be different if parents self-schedule via the portal?
In what kinds of ways do you use the portal to see benefits?
In the literature, there are positive evaluations of patient portals, and yet not everyone uses them.
Do you have a sense of why parents are using or not using the portal?
Do you have a sense of why physicians (nurses, etc.) are using or not using it?

[A researcher will thank a participant at the end of the interview and inform that a $20 gift card will be sent via email. If a participant prefers a "hard" card, they will be asked to provide their mailing address.

If this was a follow-up interview that lasted more than 20 min, a researcher will thank a participant at the end of the interview and inform that a $10 gift card will be sent.]

Appendix D

Selected Information from the Ethics Application

Informed-Consent

In accordance with the AHS, University and Government of Alberta's directives put in place to maintain continued research while also preventing exposure and transmission of COVID-19, our research team had requested approval for waiving written consent, as it was not practical to obtain at the time. For that reason, oral consent was procured.

Honorarium

As an honorarium, all participants were given a $20 e-gift card from Amazon. If a second, "member checking" interview was needed to clarify information provided in the first interview (exceeding 20 min in length), the participant was givens another $10 gift card.