

EVALUATION OF A WEB-BASED TOOL DESIGNED TO PREPARE PEOPLE FOR
TREATMENT DECISIONS AND ADVANCE CARE PLANNING: APPLICABILITY IN
ONCOLOGY

by

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Abstract

Health care delivery is structured around patient-centered care and the expectation that patients will exercise autonomous medical decision making, however many oncology patients who access health care have no preparation for making informed treatment decisions or engaging in advance care planning (ACP) conversations. Engagement in ACP conversations facilitates patient-centred care that is consistent with the care and treatment the patient wants and enables in-the-moment medical decisions during treatment and at end of life. Patient engagement in ACP is associated with a measure of high quality care delivery by legal standards, clinical guidelines and ethical consensus. The majority of Canadians acknowledge the importance of ACP, but do not benefit from it because they are not engaging in ACP discussions or documentation. This study addressed the need to find an acceptable and relevant means to engage cancer patients in ACP.

PREPARE is a promising web-based intervention aimed at preparing patients to engage in ACP discussions that was developed with community dwelling seniors in the United States. It had not been evaluated for use with an oncology population. The purpose of this qualitative descriptive study was to evaluate the acceptability, applicability, and understandability of PREPARE for cancer patients. Data was collected via cognitive interviewing, followed by a brief semi-structured interview with 21 participants to gather a meaningful account of their experience with the PREPARE website. Content analysis resulted in a comprehensive summary of what the participants liked and did not like about the resource, as well as suggestions for change.

The active cancer treatment patients enrolled in this study indicated that the PREPARE website was acceptable, applicable, and understandable for an oncology population. Importantly, this was the case for both older and middle aged participants.

Some participants had difficulty with the life limiting language of “life not worth living or worse than death” and this requires follow-up in order to determine whether changes to the resource are needed. However, overall, PREPARE was found to be a useful reflective resource for cancer patients that merits further consideration for implementation.

Preface

I played an extensive role in the planning and execution of this thesis project, including an extensive literature review that was foundational to the structure and strength of this pilot study. I independently promoted this project to the varying departments at the Cancer Centre and enlisted their help in successfully recruiting participants for this study. I organized and conducted all interviews for this study and collected all data in both written and audio formats. I was responsible for all drafts associated with this thesis, and participated in the repetitive content analysis processes. My supervisory committee assisted with the broad design of the research project, data analysis, and revisions of the drafts of the thesis.

This research study was approved by the University of British Columbia Behavioural Research Ethics Board, and received harmonized ethics approval, certificate # H14-01537.

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Thank you to my husband David and to our extremely talented and wonderful children, for giving me the time and space to experience new adventures, and allowing me to re-invent myself in the process. This has been a long journey for all of us, one that included undergraduate, clinical and graduate studies, and you have been patient and accepting of all these changes and transitions. I would like to think that we, as a family, remain strong and stand united in meeting the challenges that life can unexpectedly bring our way. Hugs and kisses to my grandbabies.

Dedication

In loving memory of my father Arlington Matthew Frey,

(1925-2010)

Dad was an amazing upbeat gentleman

Who, with faith as his compass, navigated a cancer journey

&

To others living and walking this path.

Chapter One: Introduction

This thesis reports on a study designed to explore the acceptability, applicability, and understandability of a promising advance care planning (ACP) resource for oncology patients. The web-based resource prepares patients to engage in ACP conversations and has not been tested for use within cancer care.

ACP is a voluntary process of conversations between patients and their close family or friends and health care providers, where patients consider and share their values and beliefs regarding their preferred health care options and goals of care, and choose a substitute decision maker to help them voice their wishes should a time come when they are unable to speak for themselves (British Columbia Ministry of Health, 2012; Robinson, 2011; Romer & Hammes, 2004). ACP was originally conceptualized as part of palliative and end-of-life philosophies of care that asked patients to make future decisions about whether they would want to receive medical procedures, such as cardiopulmonary resuscitation (CPR) or mechanical ventilation, and document these wishes in a written advance directive (Sudore, Knight, McMahan, Feuz, Farrell et al., 2014; Sudore & Fried, 2010). However, rather than focusing on future decisions alone, ACP has recently been broadly re-defined as a facet of good health care that plays an important role toward supporting informed patient and family in-the-moment treatment decision making (Sudore et al., 2014). Even though health care delivery is structured around patient-centered care and the expectation that patients will exercise autonomous medical decision making, many patients who access health care have little or no preparation for engaging in ACP conversations or understand their role in making informed treatment decisions (Zaloni & Slota, 2015). Autonomous patient decision making can be difficult to achieve within the complexities of clinical communication between patient

and physician (Samara, Larkin, Chan & Lopez, 2013; Yeh, Cheng, Chung & Smith, 2014; Zalonis & Slota, 2015).

The benefits of early patient engagement in ACP result in patients making decisions and receiving care that is right for them, spending less time in the hospital and intensive care units and more time with their families (Mack & Smith, 2012). Research by Temel, Greer, Muzikansky, Gallagher, Admane et al. (2010) found that when patients diagnosed with metastatic lung cancer were provided with both active treatment and palliative care early in their diagnosis, including pain and symptom management and the promotion of self-determination, they experienced longer survival times and improved quality of life, compared to those who received standard treatment care alone. In addition, research drawn from palliative and end-of-life populations identifies the benefits of early ACP discussions, including improved patient and substitute decision maker satisfaction and comfort with care, improved adherence to patient wishes, and increased completion of written advance directives or advance care plans (Canadian Hospice Palliative Care Association, 2012; Cohen & Nirenberg, 2011; Green & Levi, 2009). However, the majority of Canadians do not engage in ACP discussions or documentation (Canadian Hospice Palliative Care Association, 2012; 2013; 2015). And only 10-20% of the population in the United States, Canada, and Australia have completed any type of ACP documentation (Canadian Hospice Palliative Care Association, 2012). This lack of engagement in advanced planning can lead to important medical decisions being made impetuously during a health crisis, and the delivery of aggressive or palliative medical care that is inconsistent with an individual's values, wishes or desired care (Canadian Hospice Palliative Care Association, 2012; Green et al., 2009).

This qualitative descriptive study provided an opportunity to recognize some of the background associated with the development of ACP, acknowledged existing barriers that

prevent engagement in ACP within oncology, and identified the importance of this engagement within a health care system that recognizes patient decision making as best practice. The PREPARE website (www.prepareforyourcare.org) is an innovative resource that was designed to address the problem of engaging patients in ACP (Sudore et al., 2014). PREPARE was originally designed and piloted with older adults experiencing multiple chronic illnesses, and has demonstrated promise in influencing behaviour change toward engagement in ACP conversations (Sudore, Schickendanz, Landefeld, Williams, Lindquist et al., 2008; Sudore et al., 2014). This study explored oncology patients' perspectives about this unique web-based tool. The purpose of this qualitative inquiry was to assess the acceptability, applicability, and understandability of PREPARE as a resource for oncology patients. The aim of the study was to determine whether revisions to PREPARE might be necessary before the site would be suitable for oncology populations, and if so, identify what changes might be required to engage cancer patients in ACP conversations.

Background to Advance Care Planning

The background portion of this chapter will outline the history associated with the development of ACP and its impact on the promotion of patient self-determination. It will include a discussion about the relationship between ACP and a death denying society, and present the efforts of Canadian ACP initiatives, as well as initiatives found within the province of British Columbia.

Historical Development of ACP

A cross-sectional survey by Downar, You, Bagshaw, Golan, Lamontagen, et al. (2015) indicates that ACP might be the answer to nonbeneficial medical treatments delivered within a dichotomized health care system. Nurse and physician survey respondents, who provide direct patient care in acute medical wards or ICUs across Canada, viewed improved

ACP and staff communication training as a promising solution to reduce nonbeneficial or futile medical treatments. Nonbeneficial treatments were defined as “advanced curative/life-prolonging treatments that would almost certainly result in a quality of life that the patient has previously stated that he/she would not want” (p. 273). Discourse around ACP, palliative care, death and dying began to circulate in the United States (US) in the 1950s and 1960s. Similar to practice today, these discourses were driven by a dichotomised medical system (Zimmermann, 2007). “Traditional medical models view active treatment and comfort measures as mutually exclusive rather than integrative, as the illness progresses” (Pere, 2012, p. 13). The aim of active medical treatment continues to be facilitated by advancements in technology and new treatment options, focusing on curing disease and prolonging life (Wright, Zhang, Keating, Weeks, & Prigerson, 2014; Downar et al., 2015). Whereas palliative or comfort care views dying as a natural process supported by pain and symptom management and non-curative care that enhances quality of life and family coping. Within the field of health care, palliative care has been conceptualized as an exclusive system of care delivered by specialists at the end of life, rather than being introduced in the early stage of a life limiting disease alongside treatment choices and life prolonging medical interventions (Pere, 2012).

Generally, ACP can be viewed as one facet of a palliative approach to person-centred care that encourages autonomous patient decision making, and supports open communication between patient, family, and care providers, regarding the patient’s prognosis and illness trajectory (Samara et al., 2013; Walling, Lorenz, Dy, Naeim, Sanati et al., 2008; Zalonis et al., 2015). A person-centred philosophy underpinning health care services facilitates cooperation in patient decision making, and care that provides individuals with an awareness of treatment options, respects choices based on what matters most to that individual, and

supports peoples' rights to consent or refuse treatment and care (Canadian Hospice Palliative Care Association, 2012; Cook, Rocker & Heyland, 2013).

Robinson (2011) states that initially ACP was based on a document driven approach in response to the 1990 United States (US) *Patient Self Determination Act* (PSDA) and accreditation standards. ACP initiatives were supported by the bioethical principles of patient autonomy and personal freedoms, which underpin ethical decision making and the idea that patients should be able to exercise self-determination even at end of life when they might not be able to speak for themselves. The aim was to facilitate a 'good death,' as seen through the eyes of the patient (Canadian Hospice Palliative Care Association, 2012).

The principle of autonomy is widely accepted in Western countries, such as Canada and the United States (Bergum & Dossetor, 2005; Zalonis et al., 2015). "An autonomous person possesses a set of values and goals, deliberates, arrives at a decision, and then communicates this decision to others" (Zalonis et al., 2015, p. 707). The PSDA requires US hospitals, nursing homes, and health plans to provide some assistance with the completion of advance directives, and to place either pre-existing or new documents within the patient's medical record. This document driven approach met with multiple challenges, including the completion and appropriate placement of these documents into the patient's chart, outdated documentation outlining the patient's treatment preferences, and an inability of these documents to influence the patient's clinical care (Collins, Parks & Winter, 2006; The SUPPORT Principal Investigators, 1995). Others have argued that the document-driven approach to ACP was limited by its focus on documenting medical interventions, such as cardiopulmonary resuscitation and levels of care, rather than attending to the overarching patient values and goals that underpin end-of-life care preferences (Robinson, 2011; Samara et al., 2013). The clinical lack of completion of ACP documentation by individual patients

suggests that “current techniques of discussing ADs [advance directives] may not be focusing on what patients really want to talk about” (Prommer, 2010). Research indicates that patients do not engage in ACP for its potential medical outcomes, but rather for its social function in strengthening family communication, function, and relationships (Robinson, 2011; Singer, Martin, Lavery, Thiel, Kelner et al., 1998; Tilden, Tolle, Nelson, & Fields, 2001).

In response to the failure of the document-driven approach to ACP, the field evolved into a person-centred process focused on patient values and preferences, which were elicited over a series of facilitating conversations intended to inform care, particularly at end of life. A key attribute of this relational process is the involvement of all stakeholders, including family members, in ACP conversations. When medical decision making becomes an actively lived experience within family relationships in the context of illness, it involves both an independence from family, by focusing on an individual’s own values and beliefs, as well as a dependence upon family to support and facilitate individual choices (Bergum et al., 2005). This relational ACP process is exemplified by the Respecting Choices Programme, which engages patients, families, and substitute decision makers in conversations that elicit key patient values and beliefs, verifies accurate knowledge about health situations, discusses options for end-of-life care, documents patient preferences, and revisits these preferences often as circumstances change. Research targeting palliative populations found this process of engaging patients in ACP is successful in improving end-of-life care (Brinkman-Stoppelenburg, Rietjens & van der Heide, 2014; Collins et al., 2006; Robinson 2011). However, this particular multi-step, whole system ACP programme is a cost intensive model that is not readily duplicated, requiring skilled certified facilitators, dedicated clinicians and clinical time, and engagement of all the key decision makers (Barnes, Jones, Tookman & King, 2007; Briggs, Kirchhoff, Hammes, Song, & Colvin, 2004; Robinson, 2011).

Despite advancement in the field of ACP, engagement in the process remains a challenge. Population studies from Canada and the United States indicate that people have a substantial lack of knowledge and understanding around what ACP is (Canadian Hospice Palliative Care Association, 2013; Zhou, Stoltzfus, Houldin, Parks & Swan, 2010). A 2012 Ipsos-Reid national poll found that 86% of Canadians had not heard of nor understand what ACP is, over 80% had not completed traditional documentation, less than half of the population had had health care discussions with their family or friends, only 46% had designated a substitute decision maker, and only 9% had followed through and spoken with a healthcare provider about their wishes for care (Canadian Hospice Palliative Care Association, 2015).

Death Denying Society

Robinson (2011) and others propose that ACP limitations continue to challenge palliative care services across Canada (Carstairs, 2010; Canadian Hospice Palliative Care Association, 2012). Such limitations include varying provincial legislation, limited public awareness around ACP, a lack of integrated services that provide public education, and a reluctance of families and health care professionals to discuss death and dying.

Carstairs (2010) provided a report to the Canadian Senate, stating that Canadians view death as an unnatural experience, and avoid thinking and speaking about it. However, when these taboo conversations become unavoidable, discussion often revolves around a war-like scenario, where death is to be fought and conquered at all costs (BC Cancer Agency, 2015). Carstairs claims Canadians are a death denying society that cling to the belief that one's own death will be quick, painless, and perhaps occur in sleep. This belief stands in contrast to the 90% of Canadians who will spend many months or years living through the dying process.

A study by Tanuseputro, Wodchis, Fowler, Walker, Bai et al. (2015) examined end of life use and costs of health care sectors in Ontario Canada during the timeframe of 2010 and 2013. Statistically, decedents who constituted 0.67% of the population, consumed approximately 10% of Ontario's total health care budget annually, with end-of-life in-patient costs rising sharply in the last 120 days prior to death. Their study indicated that only 9.1% of patients hospitalized in the last year of life were admitted with palliative care as the main responsible diagnosis. These authors suggested that introducing interventions that reduce acute care admissions for palliative patients, when unwarranted, would potentially reduce costs incurred at end of life and simultaneously improve the dying experience of end-of-life patients who prefer to spend their last days of life at home.

Both acute medical treatment and palliative or comfort care philosophies of care now recognise the benefits of interventions that engage patient and families in ACP with their health care team (Downar et al., 2015), the outcome of which is thought to improve end-of-life comfort care, respect patient's beliefs and values, and achieve a fiscal societal responsibility in the spending of health care dollars (Bernacki and Block, 2014; Smith & Hillner, 2011; Tanuseputro et al., 2015). Mack et al., (2012) state: "At a time of controversy about a sick and aging population and fiscal constraint, honest communication about choices and outcomes represents an important solution" (p. 2715).

Canadian ACP Initiatives

Canadians are an aging population and it is estimated that 20% of the population, 8 million Canadians, will be over the age of 65 by the year 2026, with seniors accounting for 75% of deaths each year. These estimates predict a demand for an integrated health care system that provides improved access to quality palliative care and eventual end-of-life care in every province and territory. National ACP initiatives began to take shape after the

Quality End-of-Life Care: The Right of Every Canadian (2000) report was received by the Canadian Senate. This report was a catalyst for government action and the development of a community voice for hospice and palliative care. In 2002, the Canadian Hospice Palliative Care Association (CHPCA) was joined by the newly formed Quality End-of-Life Care Coalition of Canada, composed of approximately 20 national organizations at that time. This collaboration created a stronger unified voice to lobby for improved end-of-life care (Carstairs, 2005).

Following the 2000 senate report, the Honourable Senator Sharon Carstairs received the first Appointment of a Federal Cabinet Minister to be responsible for palliative care in Canada. In addition, a Secretariat on Palliative and End-of-Life Care was established within Health Canada to support Carstairs' appointment. The Secretariat, in collaboration with 150 federal, provincial, and territorial representatives and researchers, developed the 2002 Canadian Strategy on Palliative and End-of-Life Care. This strategy outlined five priorities, including the concepts of best practices, research, public information and awareness, surveillance, and education for professional health care providers (Carstairs, 2005).

These priorities gave rise to a National Framework for ACP (2012), which was developed by the Advance Care Planning in Canada: National Framework Project Task Group. The Task Group included representatives from national professional organizations and non-governmental groups concerned with ACP. The Task Group, along with experts in ACP, used a national consultative process to articulate common principles that underlie ACP, within the complex systems, jurisdictions, and professions that are responsible for health, justice, and social services across Canada. The Framework is broad, giving guidance to how ACP could be operationalized within a health care system with defined provincial boundaries and limitations (Canadian Hospice Palliative Care Association, 2012).

Additionally, in support of the Canadian ACP initiatives, the “Speak Up” campaign (<http://www.advancecareplanning.ca/>) was launched and is targeted toward facilitating communication and enhancing public knowledge around ACP. This web site provides a venue for non-specific as well as cancer-specific resources relevant to ACP, making these resources available to the general public, patients, families and professionals. The focus of the site is to start conversations about end-of-life care.

ACP initiatives within British Columbia. On a provincial level and from an organizational or systems perspective, as of September 2011 new incapacity or personal planning legislation has contributed to the urgency of implementing clinical interventions to prepare patients to engage in ACP conversations within the province of British Columbia. This legislation has brought ACP to the forefront of clinical practice by enabling capable adults to document the health care treatments they consent to or refuse, based on their wishes. Health care organizations and providers in British Columbia, must comply with this legislation by inquiring about and complying with patient directed medicalized health care planning (British Columbia Ministry of Health, 2011; British Columbia Ministry of Health Advance Care Planning, 2015; British Columbia Ministry of Justice, 2011; Public Guardian and Trustee of British Columbia, 2014). In support of this new legislation, the British Columbia Ministry of Health (2012) has developed an ACP teaching guide and documentation focused booklet called *My Voice*, distributed widely throughout the province (<http://www.health.gov.bc.ca/library/publications/year/2013/MyVoiceAdvanceCarePlanningGuide.pdf>). *My Voice* offers a guide, workbook pages, and legally valid forms to help individuals consider and document an ACP that suits them. The booklet is designed to help patients plan for and receive the care they want during a time of incapacity.

However, there is an absence of resources that prepare Canadians to engage in ACP conversations and complete the *My Voice* documentation process. A 2014 Harris/Decima poll confirms that while Canadians acknowledge the importance of end-of-life conversations when they are healthy, they are quick to find excuses for not doing so. The top three reasons Canadians use to avoid ACP conversations include being afraid of death, not wanting to upset family, or by being ‘creeped out’ by the conversation (Canadian Hospice Palliative Care Association, 2013).

Summary

Patient understanding of and engagement in ACP and treatment decision making is considered limited in Canada and the United States, even though this engagement is recognized as a measure of quality and supportive care by legal standards, clinical guidelines, and ethical consensus. Population studies from Canada and the United States indicate that people have a substantial lack of knowledge and understanding around what ACP is and the benefits it provides for their care (Canadian Hospice Palliative Care Association, 2013; Zhou et al., 2010). ACP can be viewed as one facet of a palliative approach to person-centred care that encourages autonomous patient decision making, and supports open communication between patient, family, and care providers, regarding the patient’s prognosis and illness trajectory (Samara et al., 2013; Walling et al., 2008; Zalonis et al., 2015). Within the field of health care, palliative care has been conceptualized as an exclusive system of care delivered by specialists at the end of life, rather than being introduced in the early stage of a life limiting disease alongside treatment choices and life prolonging medical interventions (Pere, 2012). Rather than focusing on end-of-life decisions alone, ACP has recently been broadly re-defined as a facet of good health care that plays an important role toward supporting informed patient and family in-the-moment treatment decision making (Sudore et al., 2014).

A study by Downar et al. (2015) indicated that those who deliver acute medical care across Canada see early engagement in ACP, alongside medical interventions, as a promising solution to reduce futile medical treatments. The outcome of the early integration of ACP into active treatment can improve end-of-life comfort care, respect patient beliefs and values, and achieve a fiscal societal responsibility in the spending of health care dollars (Bernacki et al., 2014; Smith et al., 2011; Tanuseputro et al., 2015).

Hammes (2003) describes ACP as a process of building relationships, “to explore and to discuss what it would mean to care about each other if a life changing medical problem occurred” (p. 5). Romer and Hammes (2004) suggest that each and every adult should have opportunities to engage in ACP. The success of an ACP program is not measured by the number of individuals who choose to participate in it, rather its success is found in offering appropriate opportunities to do so. This study explored the acceptability, applicability, understandability and usability of a promising ACP web-based resource called PREPARE (www.prepareforyourcare.org). This website resource prepares patients to engage in ACP conversations and had not been tested for use within cancer care. PREPARE introduces the topic of ACP to its viewers and invites/teaches patients and families to engage in self-directed ACP conversations with each other and their health care team.

Chapter two will include a summary of the literature related to Canadian’s engagement in ACP processes, identify the importance of this engagement within oncology care in Canada and the United States, and explore various approaches and interventions intended to increase engagement in ACP early in the cancer patient’s trajectory of care.

Definition of Terms

Advance care planning (ACP): ACP is a voluntary process of conversations between patients and their close family or friends and health care providers, where patients consider and share

their values and beliefs regarding their preferred health care options and goals of care, and choose a substitute decision maker to help them voice their wishes should a time come when they are unable to speak for themselves. ACP was originally conceptualized as part of palliative and end-of-life philosophies of care, but has recently been re-defined as foundational process in supporting patients with curative and non-curative treatment decision making (British Columbia Ministry of Health, 2012; Robinson, 2011; Romer et al., 2004; Sudore et al., 2014; Sudore et al., 2010).

Palliative care: Palliative care regards dying as a natural process and includes the management of symptoms and pain, clarification of prognoses and the promotion of self-determination, enhances the patient's quality of life, and offers patient and family psychosocial support. Traditional medical models of care have placed palliative care within the timeframe of end-of-life patient care (Pere, 2012; Temel et al., 2010). However, new guidelines promote palliative care as being appropriate at any stage of a serious illness, and can be provided together with curative treatment (American Society of Clinical Oncology, 2012).

Palliative care team: A team of doctors, nurses, and other specialists who work with the patients other physicians/oncologists to provide an extra layer of support by providing palliative care (American Society of Clinical Oncology, 2012).

Chapter Two: Literature Review

Chapter one of this thesis provided a historical context to the development of ACP, and acknowledged the important role ACP conversations play in achieving patient-centred or self-determined care that is consistent with the care and treatment the patient wants, which ultimately facilitates a ‘good death,’ as seen through the eyes of the patient (Canadian Hospice Palliative Care Association, 2012). Chapter two will provide a literature review that is describe within the following categories: engagement in ACP; ACP within oncology care; and, interventions targeting increased engagement in ACP conversations.

Engagement in ACP

Even though Canada and the United States have had ACP initiatives for decades the public’s understanding of ACP and their engagement in it remains low. A 2004 Ipsos-Reid population survey found that eight out of ten Canadians agree that people should start planning for end of life while they are still healthy, and yet 70% of those polled had not done so (Canadian Hospice Palliative Care Association, 2015). A second national Ipsos-Reid poll conducted in 2012 found that 86% of Canadians had not heard of ACP and did not understand what it entailed. Over 80% had not completed traditional documentation; less than half had had health care discussions with their family or friends; only 46% had designated a substitute decision maker; and, only 9% had followed through and spoken with a healthcare provider about their wishes for care (Canadian Hospice Palliative Care Association, 2015). A 2013 Harris/Decima poll confirmed that while Canadians acknowledge the importance of end-of-life conversations when they are healthy, only 45% of the sample had done so, whether healthy or not. The top three reasons Canadians use to avoid ACP conversations include being afraid of death, not wanting to upset family, or by

being ‘creeped out’ by the conversation (Canadian Hospice Palliative Care Association, 2013).

Engagement in ACP is now being recognized as a measure of quality of supportive care by legal standards, clinical guidelines, and ethical consensus (Loberiza, Swore-Fletcher, Block, Back, Walling et al., 2008). However, when diagnosed with a serious illness, Canadians bring their avoidance behaviours and misconceptions surrounding ACP into treatment with them. These avoidance behaviours and misunderstandings influence readiness to engage in ACP conversations and exercise self-determined care options. ACP has been conceptualized by health care leaders as being suitable for everyone and especially relevant throughout an illness, such as cancer (Canadian Hospice Palliative Care Association, 2012; Hedlund, 2013). Billings and Bernacki (2014) state that different preferences are expressed when healthy people are presented with abstract, hypothetical choices about a distant future, compared to their preferences when they become seriously ill. This suggests that while it is good practice to begin ACP conversations while people are healthy, their choices may be different when they become patients experiencing the trauma of a serious illness. Therefore, we need to explore how to best share and engage patients in ACP conversations within different health circumstances. This may mean tailoring ACP processes for people living in crisis and actively coping with the realizations of death and dying. Cancer patients may represent one such population.

ACP Within Oncology Care

There are few studies describing cancer patients’ engagement in ACP. One notable study is by Michael, O’Callaghan, Clayton, Pollard, Stepanov et al. (2013). In this Australian study of 18 cancer patients a substantive grounded theory was proposed to explain how patients living with life-threatening cancer respond to ACP. For cancer patients, based

on this theory, ACP processes can be characterized by a dynamic and individualized process of actualizing, relinquishing and or rejecting various components in an intensive back-and-forth process over time. These authors identified the various components found within the process of ACP, such as: a medical enduring power of attorney; statement of choices; refusal of treatment certificate; and, advance directive. This repetitive process of evaluation and reflection allowed patients to re-confirm their wishes or choose to abandon or reject previously determined choices. Patients' values, memories, personalities, health perceptions, understanding of their prognoses, and trust in their substitute decision maker influenced this process. In some cases and based on these influences, offers to consider ACP could be rejected or considered offensive by the patient.

Oncology patients receiving treatment and coping with the culturally taboo concepts of death and dying are a vulnerable population, which may require a tailored introduction to ACP processes, in an effort to better meet their specific needs and orientations (Michael et al., 2013; Peppercorn, Smith, Helft, DeBono, Berry et al., 2011). There is a lack of pre-existing knowledge about how to best introduce ACP to oncology treatment populations who may be relatively early in the illness experience and unfamiliar with ACP processes. Based on the literature, competing perspectives from palliative care and standard disease-directed treatment options surround the introduction of ACP to curable and incurable cancer treatment patients. These dichotomized concerns around care are explained below.

Palliative care perspectives are supported by end-of-life research that identifies the benefits of early ACP discussions, including improved patient and substitute decision maker satisfaction and comfort with care, improved adherence to patient wishes, and increased completion of written advance directives (Canadian Hospice Palliative Care Association, 2012). However, oncologists often worry about causing distress and anxiety by introducing

ACP in the already stressful circumstance of cancer (Nissim, Freeman, Lo, Zimmermann, Gagliese et al., 2011), and some cancer patients may not consent to participate in ACP conversations (Michael et al., 2013) or may not be ready to discuss or envision end-of-life care scenarios (Barnes et al., 2007; Canadian Hospice Palliative Care Association, 2012; Dow, Matsuyama, Ramakrishnan, Kuhn, Lamont et al., 2010; Graneck, Krzyzanowska, Tozer & Mazzotta, 2013). Therefore, successfully engaging cancer patients in ACP is a challenging task that requires the identification of acceptable interventions. Interventions should be founded in evidence based options arising from multiple perspectives, including palliative care, acute care, disease-directed care, and be structured around the patient's preference in how we provide these interventions (Peppercorn et al., 2011). It has been recommended that interventions engage cancer patients in ACP conversations with their family and clinicians, and include identified substitute decision makers, thereby preparing oncology patients and their substitute decision makers for in-the-moment and future treatment decision making (Loberiza et al., 2011; Walling et al., 2008). Peppercorn et al. (2011) have advocated for research that focuses on determining strategies to overcome the barriers to engaging in ACP in order to increase the number of patients who have ACP conversations.

A targeted review of the literature was conducted to explore what we know about engagement in ACP by oncology patients receiving active treatment. This review was completed through UBC-Okanagan library, using CINAHL, Journals @ OVID, and MEDLINE (via EBSCOhost). Search terms included those associated with advance care planning and oncology or cancer treatment patients; chemotherapy or active treatment; curative culture or interventions within cancer or oncology. CINAHL search criteria included Boolean or phrase, English language, peer reviewed, research articles. OVID and

MEDLINE searches included original full text articles. Inclusion criteria included: published research articles, participants were active treatment cancer patients, and advance care planning interventions. Exclusion criteria included culturally focused studies, and research or articles that focused on care givers, rather than the perspective of patients receiving treatment. In this review findings related to active cancer treatment patients and their relationship with ACP are highlighted to provide support for the relevance of this study within the context of current ACP processes. This literature is reported in relation to the following themes: Timing of ACP Conversations; Barriers that Prevent Engagement in ACP; and Interventions Targeting Increased Engagement in ACP Conversations.

Timing of ACP Conversations

Early ACP conversations are now being officially recognised as a fundamental component in the provision of high-quality cancer care. However, there is evidence that these conversations remain poorly incorporated into the routine care of cancer patients and usually occur late in the patients' treatment trajectory (Mack, Cronin, Keating, Taback, Huskamp et al., 2012; Michael et al., 2013; Obel, Brockstein, Marschke, Robicsek, Konchak et al., 2014). For example, Mack and colleagues report that end-of-life discussions tend to be initiated about 33 days prior to a patient's death, most often in an acute hospital setting by a non-oncology physician. Based on these findings, these authors suggest that "physicians should consider moving ACP conversations closer to diagnosis and initiating conversations while the patient is doing comparatively well, so the patient has time to plan for more difficult times in the future" (p. 4392). In the following sections, the risks associated with delayed ACP and end-of-life discussions and the benefit of early patient engagement in these conversations will be discussed.

Risks of delayed ACP discussions. Delayed ACP and end-of-life discussions have been associated with acute hospital-based care and aggressive treatments for patients diagnosed with incurable cancer (Canadian Hospice Palliative Care Association, 2012). Mack, Cronin, Keating et al., (2012) found that patients who had late discussions about end of life were more likely to receive aggressive care, including chemotherapy. In the United States, 18% to 20% of patients with cancer are given toxic chemotherapy during their last two weeks of life (Earle, Landrum, Souza, Neville, Weeks et al., 2008). Chemotherapy treatments occurring at end of life continue to be an indicator of poor quality care and are associated with cardiopulmonary resuscitation, mechanical ventilation, and late hospice referrals in the last weeks of life (Buiting, Terpstra, Dalhuisen, Gunnink-Boonstra, Sonke et al, 2013; Bernacki et al., 2014; Matsuyama, Reddy & Smith, 2006; Mazanec, Daly, Pitorak, Kane, Wile et al, 2009; Wright et al., 2014). Chemotherapy occurring in the last weeks of life increases the likelihood that patients are dying with unmet needs and experiencing physical, psychological, emotional, social or spiritual pain (Buiting et al., 2013; Wright et al., 2014; Zhou et al., 2010).

Benefits of patient engagement in early ACP conversations. The benefits of patient engagement in early ACP have been identified in numerous studies. For example, Mack, Cronin and Keating et al. (2012) found that patients who engaged in earlier ACP and end-of-life discussions were less likely to received aggressive treatments before their death. These authors argue that early physician guided statistical and experiential-based estimates of prognosis, including the idea that life is nearing its end, give patients essential time to process and acknowledge some of this information, before having to make end-of-life plans. Based on a longitudinal study of 626 advanced cancer patients, Zhang, Wright, Huskamp, Nilsson, Maciejewski et al. (2009), reported that cancer patients who engaged in end-of-life

discussions with their physician, at least 6 months prior to their death, were more likely to want to know their life expectancy, to acknowledge they were terminally ill, and preferred comfort care over aggressive care that only extended their life for a few days. They were less likely to undergo mechanical ventilation, resuscitation or be admitted to or die in an intensive care unit in the final week of life. And, they were more likely to be referred to out-patient palliative care and received earlier hospice care, compared to patients who received late end-of-life discussions. As well, patients who reported having earlier ACP conversations with their physician did experience less physical distress compared to those who did not have those conversations.

With earlier ACP conversations, patients may be more likely to be open to considering a palliative approach to their care. There is some evidence to suggest that early integration of palliative care, including symptom management, psychosocial support, and assistance with decision making, has distinct advantages for cancer patients. A recent randomized controlled trial by Temel et al. (2010) demonstrated that when palliative care, including pain and symptom management and the promotion of self-determination, is given proactively alongside standard oncology care, it improves patient survival times and improves quality of life, compared to patients receiving standard care alone. The authors concluded that: “Early integration of palliative care with standard oncologic care in patients with metastatic non-small-cell lung cancer resulted in survival that was prolonged by approximately 2 months and clinically meaningful improvements in quality of life and mood” (p. 739). However, to enable ACP conversations as early as possible, barriers that prevent engagement in these discussions in the context of a cancer diagnosis need to be considered.

Barriers that Prevent Engagement in ACP

There are complex and interrelated professional and patient barriers that hinder engagement in ACP conversations in everyday clinical oncology practice. The most common barriers identified in the literature can be grouped into: a) patient barriers; b) oncologist barriers; and, c) nursing barriers.

Patient barriers that influence engagement in ACP. Canadian population studies indicate that people are willing to discuss issues related to end-of-life care if approached by clinicians, however these surveys also report that this population has a substantial lack of knowledge and understanding about ACP (Canadian Hospice Palliative Care Association, 2013; Canadian Hospice Palliative Care Association, 2013; 2015). This general lack of knowledge is complicated by barriers that are particular to oncology patients. This is supported by the results of a web-based survey of 300 oncology advanced practice nurses conducted in the United States. In this study, Zhou and colleagues (2010) found that patients and families were perceived by nurses to present the most common barriers to ACP. Others have also observed that as patients confront the physical, emotional, and spiritual insult of a cancer diagnosis, their distress becomes a significant barrier to the introduction of ACP information (Buiting et al., 2013; Cohen et al., 2011; Lynn, Arkes, Stevens, Cohn, Koenig et al., 2000). Patient-related barriers to engagement in ACP will be addressed in relation to 3 broad themes: coping by living life in the present and not looking ahead; lack of understanding of their health situation; and, the orientation to fighting cancer.

Barrier: coping by living life in the present and not looking ahead. Qualitative researchers investigating the experiences of 15 advanced cancer patients found that patients shifted their attention away from the last stage of life in alignment with whether or not they continued to receive palliative chemotherapy (Buiting et al., 2013). Those choosing to

receive ongoing palliative chemotherapy were less likely to acknowledge that their disease was terminal, were less likely to discuss their end-of-life wishes with a physician, and less likely to have completed a 'do not resuscitate order' (DNR), compared to palliative patients not receiving chemotherapy. As these patients became aware of the severity of their disease, they increasingly chose to live their lives in the present, on both a treatment level and a social/family level. The researchers suggest that living in the present can be understood as a common coping mechanism for long-term active treatment patients with advanced cancer, and a significant barrier to engagement in ACP conversations. This is because living in the present is supported by not looking forward. ACP challenges the coping strategy of 'not looking ahead' (Buiting et al., 2013; Walczak, Henselmans, Tattersall, Clayton, Davidson et al., 2015).

Advanced cancer patients' orientation to living in the present and reluctance to look ahead towards death is also supported by the work of Horne, Seymour and Payne (2012). In this study interviews with 25 patients with lung cancer and 19 family members were conducted to explore views regarding their wishes for end-of-life care and preferences related to discussing these wishes. The findings of this study are presented in a grounded theory on 'maintaining integrity in the face of death' which involved balancing living in the present with preparing for death. Horne and colleagues found that participants viewed ACP as containing both 'social' and 'medical' aspects of death. 'Social' content included topics such as what makes life worth living and what brings meaning to life (e.g., family, work, holidays and celebrations). 'Physical or medicalized' content included topics such as what makes life not worth living, prognosis and life expectancy, and goals of care. Findings indicate that participants were reluctant to bring forward medicalized end-of-life issues that bothered them, preferring to face death when it came rather than anticipating it. The authors

concluded: “Planning for one’s own dying and death was not something that people with lung cancer reported having discussed, except in relation to the practical arrangements that would be necessary following their death” (p. 721). Participants in this study preferred to focus on the positive social concerns of living in the present, choosing to delay awareness of their forthcoming death or postpone facing death until the time came. Horne and colleagues theorised that patients with advanced lung cancer and their families focus on acting and talking normal, rather than discussing their preferences for end-of-life care, in an effort to help them balance living in the present while facing death. These researchers recommend that nurses involved in ACP conversations should develop strategies to support cancer patients to plan for the social aspect of death, in addition to making inquiries about their medical end-of-life care. The importance of developing interventions to engage patient and family in ACP conversations was also noted.

Prommer (2010), based on a case report of a patient with advanced head and neck cancer, suggested one way to facilitate the discussion of ACP is to address the traditional language used in medicalized advance directive questions by using a values history approach. This approach aligns with other findings that patients prefer to focus on the social aspects of ACP (Horne et al., 2012). Rather than focusing on despairing medicalized treatment limitations by using questions such as, “Would you want to be put on a machine to help you with breathing?” or, “Do you want cardiopulmonary resuscitation?” the values-based language approach includes encouraging questions related to the patients’ overall health, personal relationships, independence, and symptoms. Prommer recommended asking values-based questions such as, “What makes life worth living” (p. 69) or, “If, in the future, you become severely ill and lose the ability to speak for yourself, would you want medical treatments used to prolong life or to keep you comfortable?” (p. 67). Hopeful values-based

language and questions help to focus on the patient's values and goals, help patients identify their preferences for treatment, and can indicate appropriate courses of action that may not be uncovered by medicalized questions alone.

Barrier: lack of understanding of their health situation. A key facet of ACP involves assisting patients to gain a clear understanding of their health situation, which is critical to decision-making. However, there is evidence that this is challenging in relation to cancer due to a number of interrelated factors. In a study of 1,193 cancer patients receiving chemotherapy by Weeks, Catalano, Cronin, Finkelman, Mack et al. (2012) 69% of lung cancer patients and 81% of colorectal cancer patients were found to lack understanding that their palliative chemotherapy was not likely to cure their cancers. These authors explain that even though oncologists generally tell patients when their disease is not curable, this disclosure alone may not lead to sustained understanding among cancer patients and their family. Factors contributing to patients' lack of understanding or acceptance of medical facts and engagement in the medicalized aspects of ACP may include denial, lack of trust in the oncologist, holding an alternative belief system, inability to interpret ambiguous medical jargon into normal language, and the unreliability of life expectancy estimates or treatment outcomes (Walczak et al., 2015; Weeks et al., 2012; Zhou et al., 2010). This lack of understanding may compromise patients' readiness to participate in discussions about ACP. For example, some patients may shy away from engaging in medically informative ACP discussions with their oncologist because they do not want their oncologist to give-up hoping or working towards a cure for their cancer, regardless of the prognosis (Back, Anderson, Bunch, Marr, Wallace et al., 2008; Michael et al., 2013). Robinson (2012) states that although hope may change over time, hope for a cure does not diminish as the disease progresses, and is significantly associated with patient coping. It can be seen that many

factors can contribute to a patient's lack of understanding of their health situation, which in turn can be a barrier to engagement in ACP.

Barrier: commitment to maintaining a positive attitude and fighting cancer. There is a pervasive societal orientation regarding the importance of enlisting a positive attitude as an ally in the fight against cancer that is reflected within the active cancer treatment paradigm and is taken up by patients. Sulmasy, Astrow, Kai He, Seils, Meropol et al. (2010) found in a study of 45 cancer patients participating in phase I and II cancer trials that they saw themselves as being engaged in a battle in which surrender was not an option, and believed that having an optimistic attitude would improve the likelihood that they would experience a therapeutic benefit. Nurses have been reported to observe that patients' desire to not give-up fighting cancer is a significant barrier to engagement in ACP (Zhou et al., 2010). This is also supported by Maciejewski, Phelps, Kacel, Balboni, Balboni et al. (2012) who found in their study of 345 cancer patients that positive religious coping or the perspective that 'God has called upon me to carry this burden,' was associated with lower rates of completing an advance directive, and predicted aggressive ineffective (not curative) treatment choices near death. Similarly, Sulmasy et al. (2010) reported that faith in religion, medicine, or God and medicine was an important factor influencing cancer patients' hope. Further, they found that hope can stem from trust, rather than a belief, in a person, group, or a human institution. Cultural expectations regarding the importance of maintaining faith, hope, and a positive attitude while fighting cancer are generated by physicians, nurses, medical scientists, families, friends, and religious connections. These cultural expectations may be strongly embedded in cancer centres, where optimism may serve as a defence mechanism for staff as well as patients.

A patient's will to live can override a logical decision to stop aggressive life prolonging treatment. In such instances, patients may choose to fight to the last day and may be willing to undergo burdensome treatment-related toxicities for small objective benefits (Matsuyama et al., 2006; Mazanec et al., 2009). In addition, some cancer patients may choose to receive therapies because they have different perspectives from that of their health care providers regarding what treatments should be considered aggressive. For example, in one study hospice patients, more often than not, were found to perceive transfusion, radiation, and even chemotherapy as usual and expected treatments (Matsuyama et al., 2006).

In summary, the cancer patient's orientation to living life in the present and avoiding looking ahead, lack of understanding of their health condition, and commitment to fighting cancer are factors that may impede engagement in the ACP process.

Oncologist Barriers that Influence Engagement in ACP. In contrast to guidelines that recommend that end-of-life care discussions occur during periods of medical stability, many oncologists continue to avoid lengthy and difficult ACP and goals-of-care discussions until the patient faces imminent death or no further options for standard care are available (Obel et al., 2014). This avoidance suggests that physicians are triggered to talk about end-of-life care and ACP after an acute medical deterioration, rather than around the time of an incurable cancer diagnosis (Bernacki et al., 2014; Mack, Cronin, Keating et al., 2012; Mack, Cronin, Taback, Huskamp, Keating et al., 2012; Mack et al., 2012). Experts in the field suggest that physicians are aware of the important role an accurately shared prognosis, including life expectancy, plays in ACP, patient goal setting and treatment decision making (Back et al., 2008). However, others explain that physicians also feel like they are offering some patients a looming death sentence, which may prove to be an inaccurate prediction of their treatment response and disease progression (Bernacki et al., 2014).

The oncologist's tendency to avoid ACP or goals-of-care discussions may lead to unrealistic patient expectations. Based on findings from a study of 1,193 advanced cancer patients' expectations related to chemotherapy, Weeks et al. (2012) suggested that cancer patients and their oncologists quickly collude and transition their initial conversation from one that focuses on prognosis, to in-depth discussions of promising treatment options, side effects and scheduling. This positive focus on chemotherapy, structured around the foundation of the oncologists' work, becomes the instrument that makes room for misunderstandings, false optimism, and draws the patient away from engaging in ACP conversations. These authors suggest that ongoing resources need to be allocated to help palliative patients remember and recognize that their treatment is not curative, thereby enhancing the need for self-determined choices, which are supported through ACP conversations (Weeks et al., 2012). Bruera and Hui (2010) suggest their 'integrated model' of ACP and palliative care delivery can overcome physician barriers, allowing oncologists to concentrate on oncological care, rather than palliative care.

Many research reports suggest that oncologists often censor unpleasant prognostic information in an effort to protect their own, and their patient's emotional well-being (Back et al., 2008; Helft, 2005; Mack et al., 2012; Mitchell, 2007; Panagopoulou, Mintziori, Montgomery, Kapoukranidou & Benos, 2008). However, Obel et al. (2014) found in their feasibility study, that early ACP discussions directed by the oncologist were feasible in the care of stage IV cancer patients although this required highly motivated providers and improvements in supportive workflow.

The time consuming nature of ACP conversations may also be a barrier for physicians. Bruera et al. (2010) point to the 'solo practice model,' where the oncologist is

the provider of both oncological care and palliative care to highlight the challenges of addressing all patient concerns during short clinic visits.

In summary, due to the difficult nature of ACP conversations, time limitations, and the availability of oncologists, it has been suggested that oncologists and their patients generally focus on conversations targeting ongoing cancer treatments, which is the intention and structure of follow-up treatment visits for both physician and patient. However, this single focus dissuades the patient from engaging in ACP conversations and goal setting, and encourages unrealistic patient expectations regarding treatment outcomes. Additional educational resources and integrated models for providing comprehensive cancer care have been recommended in order to ensure adequate provision of palliative/supportive services and address barriers faced by oncologists. (Bruera et al., 2010). More educational resources about cancer treatments for patients has also been recommended to help them understand when their treatments are not curative (Weeks et al., 2012).

Nursing barriers that influence engagement in ACP. In a review of research along with reports from US professional associations and agencies published during 2002-2011, Cohen et al. (2011) concluded that best practices in ACP include interdisciplinary involvement, but traditionally physicians have discussed advance directives and ACP with patients. Although nurses are well positioned to assist patients with ACP, barriers exist that prevent nurses from supporting patients and families in this way. One barrier identified is that nurses view their role in disease oriented treatment to be limited, indirect, and lacking authority. Other reasons nurses do not initiate patient ACP conversations have been reported and include: unwillingness of patients or families to engage in ACP conversations or to accept their prognosis; and, a belief that the oncologist may not have discussed prognosis, life expectancy or ACP with the patient prior to the nurse introducing the topic. Therefore,

the nurse hesitates, waiting for the oncologist to take the lead with their patient (Cohen et al., 2011; Zhou et al., 2010). Nurses have also reported discomfort with these conversations, limited time, lack of privacy, and a desire to maintain hope for patients and their families (Cohen et al., 2011; Samara et al., 2013; Zhou et al., 2010). Leung, Esplen, Peter, Howell, Rodin et al. (2011) claim that nurses working within cure-oriented facilities may experience an internal conflict related to their simultaneous need to help patients fight their disease, as well as prepare them for the possibility of letting go. These authors suggest that enhancing nurses' capacity to negotiate the contradictory clinical tasks of fighting disease and preparing patients for the end of life may be helpful. Cohen et al. (2011) recommend that nurses can become more confident and proactive in ACP conversations with patients, with education, as well as physician support.

This chapter has described the importance of early ACP for oncology patients with advanced disease, and described barriers to engaging in ACP. In the final section of this chapter, a discussion of applications or approaches within oncology is provided that addresses the problematic lack of engagement in ACP by cancer patients. In addition, the PREPARE resource will be introduced. This web-based resource was designed to increase engagement in ACP for American seniors by preparing patients to participate in these important conversations (Sudore et al., 2014).

Interventions Targeting Increased Engagement in ACP Conversations

Several approaches and interventions have been developed to improve access to and engagement in ACP conversations. To achieve desired treatments and outcomes Lynn et al. (2000) suggest improving clinical practice patterns directly, rather than relying only on the patient's own initiative to create change. Quality clinical improvements should first ensure that persons who were unable to engage in ACP and self-determination still receive routine

treatment that is close to what most persons would want. Secondly, clinical improvements should also include scheduled clinical time for supportive patient decision making, and continue to offer patients a variety of opportunities to engage in ACP at junctures where doing so serves the patients best interests, such as when the treatment options carry divergent outcomes. Based on research findings that tailoring ACP to patient coping styles may increase engagement in ACP, Loberiza et al. (2011) propose a two-pronged approach. They recommended that patients with a problem-focused coping style should be offered resources/tools to engage in ACP, whereas those with emotion-focused coping styles should be offered ACP as a routine part of their care as well as opportunities to learn to manage difficult feelings. Tools, such as PREPARE or other ACP engagement tools may, therefore, be particularly important in the context of problem-focused coping to enable patients to independently learn about the importance of ACP in directing personal care. This next section explores different supportive options for enhancing routine clinical practice and engaging patients in ACP, which include an electronic documentation and automated response system, a systematic algorithm, and a psychosocial intervention.

Clinically Initiated ACP Engagement Interventions

Several clinically initiated approaches have been reported in the literature to support engagement in ACP. In a United States centre, a program called “*My Choices, My Wishes*” was introduced to promote end-of-life conversations between clinicians and patients, and focused on documenting code status, progress, and outcomes within the electronic health record. The program was designed to enable a stepwise approach to ACP as well as the recoding of ACP progress and outcomes (Neubauer, Taniguchi & Hoverman, 2015). The documentation system identified patients at risk through an automated response to a diagnosis of metastatic disease. The system flags the physician to introduce ACP, order ACP

counseling services, plan a future transition into end-of-life care, and allow for appropriate documentation. Compared to nominal incidence of code status documentation prior to this initiative, this program demonstrated incremental improvements at all participating sites. For example, out of 369 outpatients at one study site, 134 had code status documented within the system at study outcome, of which 74.6% preferred full code status and 25.4% selected a do-not-resuscitate (DNR) status.

The quality improvement pilot study by Obel et al. (2014) explored whether incorporating ACP shortly after a stage IV cancer diagnosis for an outpatient population was feasible through the creation of a new workflow algorithm, development of ACP patient education, training seminars for oncology staff, and enhancement of the electronic health record to improve ACP documentation. Compared to nominal incidence of documentation in the electronic health record one year prior to the feasibility study, results indicate that with these strategies to support ACP that 33 of 48 participants had advance directive notes recorded in the electronic health record by their oncologist. Twenty-two of the participants had documented code status orders occurring during the 6 month trial period. Of the 22 code status orders, 16 were do-not-resuscitate (DNR) orders and 6 were a full code.

For patients unable to engage in ACP conversations due to anxiety, difficulty coping, and depression, the Princess Margaret Hospital, located in Toronto, Canada, offered patients a *Managing Cancer and Living Meaningfully* (CALM) semi-structured intervention designed to engage advanced cancer patients in ACP conversations. CALM consists of three to six individual interview sessions delivered by a trained mental health professional with experience in psychosocial oncology. The intervention had sessions of 45-60 minutes, was delivered over three months, and included the option of two booster sessions. Ten advanced cancer patients were able to complete the pilot study and results indicate that the CALM

intervention was associated with profound and unique patient-identified benefits and no patient-identified risks or concerns (Nissim et al., 2011).

Based on these examples, it appears that clinical interventions introduced into routine practice can increase cancer patients' engagement in ACP conversations, provide an opportunity for documentation, and supply the clinical infrastructure to support the utilization of patient self-directed independent tools associated with introducing and increasing engagement in ACP conversations.

Patient Self-directed ACP Engagement Interventions

Self-directed ACP engagement tools are for patients who prefer to independently explore resources to improve their health care experience. This is an emerging area of research and a small number of interventions have been designed and tested with cancer patients in relation to various aspects of the ACP process. This section explores patient directed interventions intended to engage cancer patients in ACP, and includes two targeted interventions, followed by a description of a broader multimedia computer-based decision aid, and the introduction of the PREPARE decision aid.

Yeh et al., (2014) piloted a Question Prompt List (QPL) with 30 new cancer patients. All patients were diagnosed with advanced or metastatic head and neck cancer. The one-page QPL targeted issues around cancer treatment, prognosis, quality of life, and end-of-life issues. The QPL was offered to patients before their initial oncology consult and patients were advised to use it as they wished. During their visit 90% of the participants used the QPL, and most participants felt the QPL was relevant, helpful, and recommended that more physicians use this sort of list. In addition to being favourably received by new cancer patients, the use of this tool did not result in increased patient anxiety or disruptions to physician workflow. In another example illustrating the usefulness of targeted interventions,

Epstein, Volandes, Chen, Gary, Li et al. (2013) offer evidence from a randomized controlled trial of a cardiopulmonary resuscitation video, which focused on ACP for patients with progressive pancreas and hepatobiliary cancers. These researchers found that compared to a traditional narrative description, this video intervention enhanced the completion of documented discussions about desired care.

A broader, more encompassing intervention is *Making Your Wishes Known: Planning Your Medical Future* (MYEK), which is a multimedia, computer-based decision aid for ACP, based on Multi-Attribute Utility Theory (MAUT). This computer program guides individuals through the process of ACP, and unlike standard advance directive documentation, provides tailored education, values clarification exercises, and a decision-making tool that translates an individual's values and preferences into a specific medical plan that can be saved, printed and distributed as a formal written advance directive for the health-care team to implement (Green et al., 2009; Schubart, Levi, Camacho, Whitehead, Farace et al., 2012). Based on a pilot test with 30 cancer patients, data indicated that satisfaction was high, there were no changes in hope or anxiety, and patients perceived that representation of their wishes was accurate (Green et al., 2009). In addition, Schubart et al. (2012) demonstrated that in the absence of major life changes the tool produces stable representations of users' wishes and preferences.

A New Paradigm Shift: PREPARE

PREPARE (www.prepareforyourcare.org) is a promising web-based resource designed to increase engagement in ACP by systematically preparing people to participate in the conversations that comprise the ACP process. Dr. Rebecca Sudore, Associate Professor in the Division of Geriatrics at the University of California, San Francisco (UCSF) School of Medicine and her research team developed this ACP web based communication and

decision-making tool for patients to view alone or with friends and family. PREPARE was designed for an American low income senior population over 65 years of age, is written at a fifth grade reading level, and contains many videos that model ACP behaviours and conversations. A unique aspect of this intervention is that ACP conversations are modeled, rather than discussed, and viewers can see how these conversations unfold in a variety of circumstances. This is an important feature of PREPARE because interactive computer educational programs for patients have been shown to result in improved patient outcomes, when compared to non-interactive tools, such as newsletters, media, or self-help booklets and manuals (El-Jawahri, Podgurski, Eichler, Plotkin, Temel et al., 2010; Prochaska & Velicer, 1997; Volandes, Barry, Chang & Paasche-Orlow, 2010; Volandes, Brandeis, Davis, Paasche-Orlow, Gillick et al., 2012).

PREPARE's multistep teaching program reflects a broadened definition of ACP, which focuses on preparing patients and substitute decision makers to participate with clinicians in making the best possible in-the-moment or real time medical decisions, as well as planning ahead for future decisions. This new focus on conceptualizing ACP as part of ongoing treatment decision making offers a paradigm shift from the traditional focus of ACP within end-of-life care (Romer et al., 2004; Sudore & Fried, 2010; Sudore et al., 2014).

PREPARE is based on a theoretical framework of behaviour change, as described by Prochaska et al. (1997), and contains five steps including (1) choosing a substitute decision maker, (2) deciding what matters most in life, (3) choosing flexibility for your decision maker, (4) telling others about your medical wishes, and (5) asking doctors the right questions.

Proactive health care behaviours, such as those modeled within PREPARE, support emergent conversations and partnerships between the patient, their family or friends, and

health care providers, aimed at identifying the patient's values, beliefs, and preferences for medical care. These foundational conversations strengthen relationships and prepare participants for in-the-moment medical decisions that reflect the patient's wishes during a time when they require assistance choosing a treatment option that is a fit for them (Briggs et al., 2004; Robinson, 2011; Robinson, 1996; Romer et al., 2004; Sudore et al., 2014).

The decision to participate in ACP conversations is increasingly being understood as a facet of behaviour change, similar to an individual's decision to stop smoking (Teno & Lynn, 1996; Fried, Redding, Robbins, Paiva, O'Leary et al., 2010; Sudore et al., 2014). Behaviour change models address several concepts that are relevant to ACP, including a person's perceived susceptibility to not receiving care, a lack of self-efficacy or belief one can attain their personalized health care goals, and an awareness of barriers to and benefits of engaging in ACP behaviours (Fried, Bullock, Iannone, & O'Leary, 2009).

The Transtheoretical Model (TTM) of behaviour change serves as a theoretical framework, guideline, and measurement tool for intervention programs such as PREPARE (Prochaska et al, 1997; Sudore et al., 2014). TTM describes behaviour change as a systematic and sequential trajectory through a series of stages, which include precontemplation, contemplation, preparation, action, maintenance, and termination. PREPARE helps participants to move out of precontemplation by providing interventions that build communication skills and self-efficacy through video dramatizations, role modeling, and media techniques. Envisioning ACP as a health behaviour occurring over a series of steps, allows clinicians to locate the patient within an ACP trajectory and introduce interventions that help move the patient along this path, and toward the completion of steps that are a fit for them. ACP processes within PREPARE avoid the unsuccessful traditional

requirement for documentation, and follow a series of steps, which do not have to be completed in a prescribed sequence (Sudore et al., 2008).

In a pilot study involving 43 racially and ethnically diverse older adults, (Sudore et al., 2014) participants were invited to review the PREPARE website on their own, at specific senior's center locations, where research staff were available to facilitate the viewing process and redirect participants as needed. Engagement in ACP was measured at baseline and retested after one week. The engagement survey, *Process Measures of ACP Behaviour Change*, was used to measure participants' behaviour related to ACP knowledge, contemplation, self-efficacy, and readiness to change using 5-point Likert scales. Participant's actions were measured by the *Completion of ACP Actions* questionnaire through yes/no responses, and included the domains of actively choosing a substitute decision maker, locating one's own values, and communicating these values with the substitute decision maker and physician. Action measures were also used to categorize participants into behaviour change stages (pre-contemplation, contemplation, preparation, action, and maintenance). Additional measures included 12 questions measuring decisional balance, 7 questions measuring ACP values and beliefs, and 15 questions measuring the processes of change using a strongly agree to strongly disagree response format. Immediately after viewing the website, participants completed one question asking them to rate their satisfaction with the website on a scale of 1 to 10.

All 43 participants enrolled in the study completed viewing PREPARE, and completed baseline and one week follow-up surveys. Correlations between baseline and follow-up survey data were estimated using Cronbach alpha. Scores on the *Completion of ACP Actions* were not significantly different between baseline and one week follow-ups. However, the number of individuals categorized as in the precontemplation decreased

significantly for most actions at follow-up. In addition, improvements were also evident in changes in decision balance and processes of change measures. These findings suggest that PREPARE may help individuals to independently move along an ACP behavioural change pathway, and may prompt ACP discussions. PREPARE was rated highly by participants in relation to ease of use and usefulness. The mean overall rating of satisfaction with the website was 9 out of 10. Overall PREPARE was found to be acceptable to older adults with diverse backgrounds, and limited health and computer literacy skills. However, an evaluation of the use of the PREPARE resource with cancer patients is needed before its use can be recommended in oncology.

Summary

Although there is a growing body of research focused on ACP, more research is needed to increase the number of oncology patients who are having ACP conversations by developing strategies and interventions to overcome identified barriers. The benefits of early patient engagement in ACP conversations have been identified and include patients making decisions that are right for them, spending less time in the hospital and intensive care, and spending more time with their families. Oncology patients' lack of preparedness and engagement in ACP is a problem that is being addressed via research into interventions that are delivered at both clinical systems and self-directed patient levels. PREPARE is a promising new web-based educational resource designed to increase engagement in ACP that may hold benefit for cancer patients. This innovative intervention is the focus of the reported study.

Chapter Three: Research Method

In this chapter, the systematic approach to inquiry used in this qualitative descriptive project is described. This chapter includes a description of the study design, sampling and recruitment strategies, data collection and analysis, and ethical considerations.

This qualitative descriptive study was designed to assess the acceptability, applicability, and understandability of PREPARE (www.prepareforyourcare.org), an online tool that prepares people to engage in ACP and treatment decision making, for use within oncology populations. When straight forward descriptions of a phenomenon are desired to enhance a limited evidence base foundation around a specific topic, a qualitative descriptive study is the method of choice (Sandelowski, 2000; 2010). The goal was to achieve a comprehensive summary of events, as described by the participants in this study. This requires a level of interpretation that is very close to the data, yet reveals new information. “Qualitative research, including qualitative descriptive research always requires moving somewhere: that researchers make something of their data” (Sandelowski, 2010, p. 79). The categorized findings and resulting discussion in this study should render a factual foundation and valued end-product, which can be applied to further research or offer clinical recommendations for practice.

Sample

The sampling strategy for a qualitative descriptive study supports the use of a smaller scale purposive selection of participants, with the intention of capturing latent data and response frequencies or patterns, from the subjective experiences of participants (Sandelowski, 2000). Inclusion criteria included: adults with a diagnosis of cancer, the ability to converse in and read English, adequate vision and hearing to see and listen to the PREPARE website, and absence of cognitive impairment as determined by a Short Portable

Mental Status Questionnaire (SPMSQ) and Mini-Cog (Appendix A). No restrictions were structured around tumour type, stage of disease, where the person was located in their treatment trajectory, or computer literacy.

Recruitment

Participants were recruited by the chemotherapy staff from the Cancer Centre who received an orientation to the study and the recruitment process. Staff introduced the study to patients, and interested people signed a Consent to Contact form (Appendix B). These forms were left in collection boxes located conveniently around the centre. Volunteers were made aware of the collection process so they could help patients drop off the Consent to Contact forms. I followed-up with interested people in-person or by phone to provide additional information and screening. A consent form (Appendix C) was sent to eligible participants who indicated they wanted to participate, by mail, email or was hand delivered during their next clinical appointment. Time was allocated for people to comfortably read the consent before an interview was scheduled. Informed consents were signed by the participant and the interviewer prior to the interview start, and participants retained a copy for themselves.

Other recruitment strategies included information posters, both paper (Appendix D) and electronic (Appendix E), designed for use within the Cancer Centre. The paper posters were placed on the collection boxes for easy identification by staff. Due to successful recruitment by nurses, the electronic poster was not used.

Data Collection

Interviews have become a primary source of data in qualitative clinical inquiry, which seeks to access language cues that help expose the participants' subjective experience (Thorne, 2008). Study interviews proceeded in a manner that was respectful of all participants, and in consideration of their ethical rights and comfort. Interviews were held

within the Cancer Centre meeting room (n=16), at participants' homes (n=4), and at the Canadian Cancer Society Rotary Lodge (n=1). The Canadian Cancer Society Rotary Lodge was used because 1 participant was a resident there. I ensured the participant's comfort during interviews at the cancer centre, by offering breaks, refreshments, warm blankets, and rescheduling as required. All participants were aware they could end the interview at any time if they wished.

Demographic information was collected from the participant (Appendix F) immediately prior to the scheduled interview, and additional demographic data was gathered at a later date from the participant's electronic chart (Appendix G). The goal of data collection within a qualitative description study is typically focused toward discovering the, "*who, what, and where* of events or experiences, or their basic nature and shape" (Sandelowski, 2000, p. 338). This inquiry used cognitive interviewing, followed by a brief semi-structured interview to gather a meaningful account of the participant's experience with the PREPARE website.

Cognitive interviewing is an approach to interviewing that enables the interviewee to accurately recount original events and the meanings surrounding those events. This approach shares a natural kinship with qualitative interviewing, enjoys an established reputation as a valid and reliable tool for social science investigations, and has been successfully validated both experimentally and practically (Waddington & Bull, 2007; Willis, 1999). Cognitive interviewing is theoretically rooted in cognitive psychology and rests on two concepts. First, memory of an event is stored in a network of associations and can be accessed via different roots. Second, retrieval of an event will achieve greater success if the original events can be reinstated at the time of retrieval. To facilitate an uninterrupted approach to interviewing, cognitive interviews are supported by two approaches, which include "think-aloud" and

“verbal probing.” Both of these approaches were used in this study. Each approach limits the input from the interviewer, and increases the recall from the interviewee. Interviewer attentiveness to the interviewee’s story and freedom from interruption seems to serve as an affirmation and encourages interviewees to provide extensive details.

In this study, and using cognitive interviewing, participants were asked to work their way through the PREPARE website and participate in a brief post interview (Willis, 1999). Both the “think-aloud” and the “verbal probing” approach to cognitive interviewing were used to gain an understanding of the participant’s response to the website (Appendix H). Prior to starting, participants received a short pre-interview training session that included an exercise question intended to help them perform the “think aloud” procedure. Participants were asked what they had for dinner the previous night. After they recalled and stated what they ate, participants were then asked what they liked about it and why? This was followed by the questions: what they disliked about it and why? And, what one thing they would change about their dinner to improve it if they could? Participants generally took their time recalling what they had for dinner last night, and some were hesitant to share their meal choice, particularly if they thought what they ate may not represent a typical Canada Food Guide type meal. Most participants were happy with their meal choice, and did not offer much in the way of improving it.

As participants worked their way through the PREPARE website on a slide-by-slide basis, I interjected by saying “tell me what you’re thinking as you see this page” when the subject paused. Interviewees received uninterrupted time to review and contemplate activities, as triggered by the website, and to “think aloud” without being pressed for a response. Participant responses were audio-recorded and I took notes on a print version of each slide on the website. As data collection proceeded, verbal probing was introduced in

response to data analysis. For example, if participants had difficulty with a particular part of the website, a verbal probe was added for subsequent interviews.

Upon completion of the website activity, the cognitive interviewing process transitioned to a semi-structured interview approach (Appendix H). This phase focused on participants' overall response to the website and included open-ended questions such as: What are your overall thoughts about this tool? What content in this website would need to be changed for cancer patients? What is the most important thing that you learned? When do you think it would be a good time to be introduced to this tool? How do we introduce it to patients and families? Field notes were completed by the interviewer immediately following the interview session (Appendix I). All data was retained in a permanent form, such as documentation notes and recorded conversations, which means the data can be verified, checked and rechecked for rigor (Richards & Morse, 2013).

Data Analysis

The data analysis was guided by content analysis strategies. Qualitative content analysis is focused toward summarizing the informational content of the data, and is the analysis strategy of choice in qualitative descriptive studies. Within content analysis, categories are generated from the data itself during the course of the study, and there is simultaneous collection and analysis of data, "whereby both mutually shape each other" (Sandelowski, 2000, p. 338).

The cognitive interview section of the study was not transcribed in its entirety or interpreted because of the limited analytical value of this process, due to the large volume of data that was produced by the repetitive characteristics and layering of the recall action. Data was extracted by careful reading of notes and listening to the audio-recordings. The data was reviewed with my supervisory committee and a coding framework was developed that

captured the patterned responses of participants in terms of what they liked, did not like and thought needed to be changed in the website. The research team reviewed and coded the data independently and, through consensus, reached agreement regarding the coding framework. Data was then coded and findings are reported in the following chapter in the categories of: content, language, videos, design/layout, and overall response.

Data and findings were safeguarded and valued, with biases being openly acknowledged from the initiation of the research project. The author was an employed treatment-focused chemotherapy nurse, who was curious about how active treatment oncology patients would respond to an ACP website such as PREPARE. As an active treatment nurse I tried to create a positive and safe environment for my patients to receive and respond to treatment, focused on keeping them safe and extending their lives. As a researcher, I was similarly concerned about creating a safe environment for the participants and about not causing them undue stress. I viewed the data as a patient advocate and through the eyes of my participants. Comparatively, the thesis committee for this research project included an influential group of palliative care leaders and researchers, focused on introducing ACP to patients during the treatment phase of their care. This research group worked together and across paradigms and philosophes of care to gain an understanding of the participants' responses to PREPARE.

Ethical Considerations

This study was approved by the Research Ethics Review Board of the University of British Columbia, Okanagan campus. Participation in this qualitative descriptive study was voluntary, and participant identities were kept confidential. Signed consents were stored securely and separately from demographic statistics, audio-recordings, field notes, and transcripts. All data collected was identified by a participant number.

Exposure to the PREPARE website was expected to be minimal risk for the oncology participants because they were not being asked to engage in ACP, merely to review the website. PREPARE was developed with the involvement of seniors experiencing various health situations and was not found to generate distress. However, I anticipated the possibility that some participants might feel uncomfortable reviewing ACP subject matter, including such topics as identifying someone to speak for you if you could not speak for yourself. Therefore, a referral mechanism to Patient and Family Counselling was put in place. In the event that participants experienced worry or concern, they were referred to the Patient and Family Counselling Department at the Cancer Centre, who were available for cancer patients experiencing distress, and would help participants deal with any adverse reactions to the interviews. There was one palliative participant who chose not to complete the interview because she considered its focus depressing, but agreed that the responses she gave could be used in this research. Patient and Family Counselling followed-up with this participant and resolved any outstanding issues. Also, I later met with this participant and her mother in-person at the clinic, thanked her for participating in the study and for sharing her thoughts about the PREPARE website, and assured her that her responses offered a valuable contribution to the study.

Chapter Four: Findings

The purpose of this qualitative descriptive inquiry was to assess the acceptability, applicability, and understandability of the PREPARE website (www.prepareforyourcare.org) as an online tool for oncology patients. The aim of the study was to determine whether revisions to PREPARE may be necessary before the site would be suitable for an oncology population, and if so, identify what changes may be required.

Study Sample

The participant sample included individuals who were actively receiving chemotherapy medications, with only one participant on a ‘watchful waiting’ care plan. This purposive sample included 21 participants (7 men, ages 52 to 67, with an average age of 61 years; 14 women ages 47 to 78, also with an average age of 61 years) with a variety of tumour types, disease stages, and computer literacy skills. In total, 9 out of 21 participants were under 60 years old. Seven participants were receiving treatment with curative intent and 14 participants were receiving treatment that was likely palliative. Out of the likely palliative group, 4 participants indicated they considered their treatment had a curative intent, and another 4 participants were unsure. No participants had a ‘do not resuscitate’ (DNR) order on their chart or other advance care planning documentation, and none of the participants accurately understood the meaning of ACP.

An additional 21 active chemotherapy patients circled ‘yes’ on their signed Consent to Contact form, but later declined to participate in the study after more information was provided for the following reasons: duration of the interview (8), sensitivity to the topic of ACP (2), struggling with health or not available (5), and not interested (6). An additional 2 active treatment patients returned their signed Consent to Contact forms, however they circled ‘no’ on the form, and were not contacted.

There was one palliative participant who chose not to complete the interview because she considered the focus depressing, but agreed that the responses she gave could be used to facilitate this research. The website included a ‘reader’ capability, where participants could choose to listen to the PREPARE program being read to them as they followed the written words. The ‘reader’ option was chosen by 10 participants, whereas 11 participants chose not to use the ‘reader’ due to its slow pacing. The framework for the following findings includes the categories of content, language, videos, design/layout, and overall response.

Participants responded more to some of PREPARE’s slides and less to others, all participants did not respond to every slide. In some cases, and according to cognitive interview theory, PREPARE became the trigger that allowed participants to retrieve their experiences around their cancer journey and lived experiences. Participants became engaged with the website, measuring their own real life experiences against PREPARE’s scenario examples, reflecting on how they felt then and now. Participants used their own experiences to gauge how other cancer patients would feel viewing the PREPARE website.

Content

Information within the website is organized into 5 steps or topics, including Choose a medical decision maker, Decide what matters most in life, Choose flexibility for your decision maker, Tell others about your medical wishes, and Ask doctors the right questions. These 5 steps are followed by an Action Plan, where viewers are expected to review their progress and consider future plans to complete any of the 5 step goals considered unmet.

This section on content describes how participants responded to the information presented by the PREPARE website, including the interwoven written and video scenarios. Participants’ responses and reflection with the content of PREPARE demonstrated their

significant engagement in the website, and their interest in improving the site and sharing it with other oncology patients. Their responses are detailed below.

Choose a Decision Maker

This section addresses the participant responses focused on the action of selecting a decision maker, someone to help them voice their wishes for health care, should a time come when they are unable to speak for themselves. Participants in this study acknowledged that choosing a decision maker is an important part of health care planning that is commonly left undone because patients assume others know what they would like. Participants understood that Canadians don't make decisions ahead of time, but think they should do so. Most believed that patients should be prompted to revisit previously made choices regularly, like a will. One participant explained, "You make the decisions now, which may be difficult, to avoid much more difficult decisions later" (218182). One suggested that preferred decision makers should be identified in your medical chart right from the start.

After viewing a video scenario about an unprepared family making decisions at a time of medical crisis, participants' emotional responses and reflections demonstrated that the website invited their engagement with the concept of having conversations with and about substitute decision makers. Their responses indicated the importance of this topic for participants and the relevance of this step of the process. "It really hits home...something we have never talked about, so it is really good to put it out front" (115152). This participant was emotional with quiet tears. Although aware we could stop the interview, this participant wanted to move forward. One participant stated, "It hits people over the head, if nothing else, with the fact that you could be in the same situation as they were, if you didn't have any discussion ahead of time" (221211). At a home interview, a participant had his spouse attend the interview session, which resulted in some back-and-forth prodding around PREPARE's

decision maker scenarios and this couple's ongoing journey through a terminal cancer diagnosis. Referring to the same video as above, regarding unprepared family decision making, the patient remarked: "That's a good one to show, especially people that,...like myself...you are terminal" (220201). His spouse then stated, "You're saying that now; for like 3 years I couldn't bring that up without you losing it." His response indicates the usefulness of the approach taken in the website:

Yah, yah, I think it would [pause] I think about seeing that [scenario] back then, I think it would have helped more. Not saying it would have solved everything. But I think it's a kind of reality check in one respect,...okay we have to talk about it and get certain things, you know, done (220201).

With tears in his eyes, another participant emphasized the importance of choosing a decision maker up-front. As he reflected on his current situation and his past experiences with his wife, who died at 28 years of age due to brain cancer, this was his thought: "Better get on it!" (219192). This patient had already chosen a medical decision maker for himself, and had a back-up decision maker. Other participants thought the idea of having one back-up decision maker was a good option, just in case.

"Tell wife or partner what is going on, and then...if I had family, I would tell the next person in the family so that they know, in case something ever happened to my partner...a second person like my son or daughter or whatever, just in case...somebody that you can trust" (20552).

Several participants' responses revealed concern regarding the option of appointing a group decision maker, because they did not consider this type of decision making to be a group process, and thought it would likely cause family issues. "The whole idea of having a group decision maker in my mind is not a good solution to a problem in at least some of the

cases” (221211). After watching a video scenario where an actor chose a group spokesperson, and opted to have his family make decisions as a group if he was unable to make his own decisions, a participant stated this concern:

I think that’s one thing you have to be careful of with family, love your family, but you know what, you don’t want too many people getting involved because they, my sister...[one sister] may recommend one thing, my sister...[other sister] might recommend another. So, if you’re going to choose family, choose one not two....When you get asked to do this [become a decision maker] you’re not just taking on the person that is sick, you’re also taking on their family (116162).

After considering a video scenario where a patient formally asked his wife to make decisions for him if he became too sick to do so, participants acknowledged they liked the prospect of having these formal discussions, rather than introducing these discussions in non-specific casual exchanges. Several participants noted that PREPARE’s formal discussion scenario did not elaborate on the actor’s statement, “you know me really well, you know what I want” (112122). Participants strongly agreed, we just assume others know what we want, and that is why we need those formal clarifying discussions. These discussions can also help clarify quality of life decisions for patients themselves.

What he [actor] really glossed over is what it’s like to be in the hospital, what sort of treatments you actually might get while you’re in there, which I think a lot of people have said to me “if they had any idea of what was going to happen, they never would have gone through the front door (112122).

After considering a video scenario where a patient chose to have his son make all his medical decisions, as the patient did not want to know about or make these decisions, many participants expressed concern about the father placing too much responsibility on this son.

One participant stated, “To me it is very naïve to tell the doctor you don’t want to know, I mean, how can you make decisions if you don’t know what you’re dealing with” (115152). Others also agreed with this saying, “He has put his child in a predicament, a real hard predicament” (219192), and “Really, this is how you treat your own son?” (221211).

In conclusion, participants liked the section on choosing a decision maker and found it strongly relevant to their situation in oncology. Participants thought it important to choose a decision maker up-front to help avoid confusion during a future health crisis, and thought it may be beneficial to choose a back-up decision maker as well. Participants reported liking the idea of having formal ongoing discussions with their chosen decision maker, offering clarification around what is important to them and how they want their care handled. A majority of participants did not like or understand the relevance of opting for a group of people or family to act as their medical decision makers, with one member appointed as a spokesperson, stating that their care was not a group decision. Most participants were also uncomfortable with situations where patients did not want to be involved in their own medical decision making, and placed those decision making responsibilities and burdens on their children.

Decide What Matters Most

Participant’s responses and reflection demonstrated their reflective engagement and challenges with the concept of deciding what matters most, a concept that also revealed participant preferences that will be reported in the language category of these findings. The concept of individual values and beliefs generated considerable participant feedback, and revealed their engagement in improving the appropriateness of the website for other cancer patients, based on their lived experiences as active treatment patients.

Some participants, in response to considering what matters most in life, mentioned that it is important to have little goals, like the video actors demonstrated, to help you plan for your future. One participant stated, “You know I’ve got goals, like next years the 25th [anniversary], I’ve got goals like that...those are helping me base my decisions...helping me keep a positive attitude at the same time” (220201).

In contrast, several participants stated that they did not consider themselves palliative and therefore were not thinking about what matters most in life. One participant stated deciding what matters most applies “too much emphasis on the fact that you are going to die because you know and I know that many cancers are curable if detected early enough....Something that was terminal last month is probably fully treatable today” (218182). Another stated,

I think a lot of people, when they first have cancer, they think ‘well I am going to be cured’ so they’re not thinking of that [what matters most in life]....Some people might think, well I’m not really at that stage yet, why do I have to make that kind of decision yet because I’m not palliative, my doctors haven’t told me I’m palliative (113132).

When PREPARE asked viewers to imagine a health situation that would make their lives not worth living, several participants started to reflect on what it was initially like to be diagnosed with cancer, and expressed their fear of being asked to imagine such a thing early in their treatment trajectory.

I sometimes think it is at the stage which you present this program to somebody because, you know, when I was first diagnosed at the end of June, I was just in shock and panicked, and didn’t want to talk to anybody for 2 or 3 weeks. Couldn’t believe

it, and if I talked about it, it was real. And, if I was given this program then, it would be absolute hell, it would be horrible (113132).

Another who at the time of diagnosis had 2 children below the age of 8, emphatically stated, “If I had to watch [read] that [imagining a health situation that would make your life not worth living] when I was first diagnosed....No!...I want to focus on my quality of life, absolutely, and being comfortable, hmm, but I still want to live as long as I can” (117171).

When PREPARE offered participants 4 distinct health care choices, 2 participants stated they could not answer or complete the step with these limited options. PREPARE’s 4 options included: 1) I want medical treatment to try to live as long as possible, 2) I want to try treatments for a period of time, but stop if they do not help or I am suffering, 3) I want to focus on my quality of life and being comfortable, even if it means a shorter life, and 4) I am not sure. Participants wanted to add alternative options between each of PREPARE’s choices, as one participant explained:

I am willing to put up with the suffering if there is a light at the end of the tunnel...I am willing to go on that short term treatment, and if it’s not improving my health, then let’s not carry-on, but if there is pain involved during that period of trial then that’s okay too, because that’s the price you have to pay (221211).

Another participant offered, “everybody is trying for a treatment...some people don’t consider...the naturopathic way as a treatment option...over conventional treatment....You know it would be nice if they could amalgamate and support alternative treatment,...but still don’t want to suffer” (10441).

In conclusion, most participants agreed it was important and relevant for oncology patients to have little goals when moving forward with treatment decisions, and it was important to be receiving some type of treatment. Having goals and receiving treatment was

a useful and acceptable aspect of this step in PREPARE. However, some participants thought that deciding what matters most in life was a question for palliative patients alone, and did not understand why they needed to consider it because no one had told them they were palliative. In addition, several participants became anxious when they reflected on the relevance of what it would have been like to consider a health situation that would make their lives not worth living immediately after receiving a diagnosis or early in their treatment trajectory.

Choose Flexibility for Your Decision Maker

Participants' reflective responses to this step demonstrated their engagement with the concept of choosing flexibility for their decision maker, a focus that most participants stated they had not considered previously and now considered a relevant topic. Some participants supported the concept of giving their decision maker total flexibility in decision making and others disliked the scenario that someone else could change their decisions. These participants did not want to give away their autonomy, expecting the chosen decision maker to support their wishes. A participant observed that the question of flexibility is a really good place for starting the "conversations between the substitute decision maker and the patient" (10112).

Contemplating the possibility of new and improved treatment options, one participant commented, "I would probably go for this [total flexibility] just because prior medical decisions were the best for you at that time,...who knows what's happening in the future" (113132).

In contrast, several participants disliked the scenario that suggested total flexibility as a way of supporting the decision maker and reducing guilt. They perceived that giving total flexibility added to the burden for their decision maker. Four participants identified that

family can feel a lot of guilt if they are given total flexibility in decision making for the patient because the burden of choice becomes theirs. Several participants expressed frustration with specific scenarios that supported total flexibility. They considered these scenarios to be extreme examples of flexibility, where the patient sacrifices their beliefs and values for those of their decision maker, in an effort to make their decision maker feel comfortable. Some participants believed these scenarios portrayed the decision maker as being selfish, thinking about choices that were best for themselves, and matched their beliefs and values, rather than those of the patient.

A participant commented that total flexibility or the sacrificing of one's autonomy or beliefs and values for your decision makers is wrong, when "you've laid down a plan of action that you want adhered to, now you're giving that person the decision to change this...and that's not your wishes at all!" (20771). Another stated, "I think the person...making the decision for you should at least appear...to adhere to your desires!" (221211). In a similar vein, another participant explained:

It's going to make it more difficult in the end....I think that because we've talked about this feeding tube...and...I don't want it done. To me if I say...[wife] you do whatever you think,...that's going to...leave the biggest guilt trip on her when finally the day happens. And say she decides to...put me on those feeding tubes and everything else, at the end of the day that persons going to...feel way more guilty...I guarantee it! (220201).

In conclusion, the concept of offering your decision maker flexibility engaged many participants in considering this option. Participants thought the discussion around flexibility was important, useful, and offered a new perspective. It was recognized by some participants that giving your decision maker total flexibility is a good option for an unknown future, and a

reasonable and relevant choice for oncology patients. However total flexibility, as depicted by the PREPARE video scenario, was met with opposition from many of the participants who did not feel sacrificing one's autonomy for that of their decision maker was a valid option for anyone. Several participants believed that giving total flexibility to their decision maker added to the decision maker's burden of choice and would increase their guilt, rather than diminishing it.

Tell Others About Your Medical Wishes

Participant's reflective responses demonstrated their engagement with the step of telling specific people about their medical wishes, and demonstrated the importance or applicability of this topic for oncology patients. Responses revisited participants' views on choosing a decision maker, offering concern around the burden of choosing one of their children as a decision maker rather than a spouse or other close family member. Participants considered written documentation on their chart as a way of confirming their choices for other family members and supporting their decision maker. Several participants disliked PREPARE's suggestion of telling extended family and friends about their medical wishes. As participants had previously indicated, their health care was not a group decision. As one participant stated: you, "[You] don't need to tell a whole bunch of people [friends], just close network of people, depending on situation" (10992). Rather than involving family, a participant said, the most important thing is to get the medical professionals involved. "If you get 10 different people [family] involved in making a decision, you're going to get 10 different answers....If you get too many people [family] involved someone may be pushing a personal agenda too" (218182).

Several participants considered that telling family about your wishes opens the door to existing family problems, revealing important issues that would not be resolved in one

little chat, as depicted by PREPARE's scenario. Participants noted that families may often be in a position where only 1 child has been chosen as the decision maker. To prevent family conflict with that decision maker, 3 participants stated the patient's wishes need to be written down and placed in their chart to clarify treatment related and end-of-life issues. One participant explained: "I am sure there is a lot of family conflict over what treatment you give to people, I'm sure that happens....So, it isn't just between the patient and decision maker, it's got to be written down, got to be available for people to see" (113132).

Several participants were curious about who starts medical conversations with the physician and who puts this information on their chart. "Who initiates this conversation?...Does the doctor say we're having a consultation, and hum, I want to know about this [your wishes]" (113132).

In conclusion, participants in this study supported the importance and relevance of having conversations with their decision maker to clarify their wishes. When considering telling others about their medical wishes participants tended to focus on immediate family first, preferring their spouse and then if necessary, and regardless of the pre-mentioned burden, opt for one of their children to act as their decision maker. Several participants disliked the idea of telling extended family about their wishes, believing that this opens the door to a variety of opinions and stirs up challenging family relations. To prevent family conflict with the decision maker, participants suggested writing their wishes down to protect the decision maker and facilitate family functioning.

Ask Doctors the Right Questions

Participant's reflective responses demonstrated their engagement with the step of asking doctors the right questions. The PREPARE website informs its viewers that it is okay to ask doctors questions, and it is the physician's job to answer those questions, so do not

hesitate to ask. Oncology participants in this study found the idea of asking doctors questions very relevant to their situation, and liked being reminded that they were free to do so. A participant explained that asking questions “gives you a little more power and that’s what you want when you’re going into treatment, to have some control because you may be losing a lot of grip of what you want” (10992).

One participant was particularly positive about the importance of the opportunity to ask questions, stating “that [in the] first month or so of decision making I think this stuff [asking questions] is crucial” (220201). This participant needed a secure space and time to adjust and come to terms with his terminal diagnosis. He originally wanted the oncologist to answer all his questions related to his prognosis upfront at his first consult, however he stated that “I’m glad of the way they did it...because I got into the routine....Once I got into the routine...you realize that, okay this isn’t...going to be the end tomorrow, or in a month” (220201).

Only one participant suggested that the idea of asking doctors questions was more like theory than real clinical practice, “I don’t think that this is actually practiced?”(20771). Another participant reflected on her life experience and suggested that unlike lengthy chronic diseases, cancer can sneak-up on you, and sometimes these back-and-forth conversations are initially missed in the urgency to start treatment.

Some participants took the blame for not asking doctors questions when they know they should, blindly taking their doctor’s advice when a new treatment is offered, rather than asking what this means. Another participant reflected that patients do not know what to ask until they have lived through the experience, stating: “Never occurred to me to ask how long I have to live or how sick I am” (10112). Several participants thought it would be helpful if a

list of questions could be provided to them because they did not know what to ask their oncologist.

When PREPARE asked the viewers to consider how they prefer to make medical decision with their doctors, it offered them 3 options to choose from, which included: 1) I prefer that I make all my medical decisions on my own, 2) I prefer that my doctors and I share decision making equally, and 3) I prefer that my doctors make all medical decisions for me. Participants offered various responses that indicated they wanted shared discussions or agreement occurring within an autonomous couples decision making process, an option not offered by the PREPARE program. Participants tended to prefer shared decisions over equal decision making, and some wanted to add their spouse or decision maker to the decision-making options offered by PREPARE as well.

In conclusion participants supported the relevance of asking questions to gather a greater understanding of their health situation. Asking questions was considered crucial to treatment decision making, patient and family understanding, and autonomy in health care planning. However, several participants noted that they did not know what questions to ask, and that a list of typical questions would be helpful in facilitating shared decision making.

Language

In general, participants found the language used within the website to be understandable, plain, and non-offensive. However, language associated with ‘Experiences of Serious Illness’ and ‘Life Not Worth Living,’ found in step 2, generated an unexpected response from some participants who expressed discomfort with the language and others who suggested a change in wording or phrases for oncology patients because they viewed the language to be unacceptable.

Experience of Serious Illness

The PREPARE website asks viewers what experiences they have had with serious illness and asks them to consider whether they have had their own experience with serious illness, whether they remember someone close to them who was very sick or dying, or whether they remember seeing someone on TV who was very sick or dying. Clearly, all cancer patients are in the midst of their own experience with serious illness. Five participants recognized this and suggested that asking an oncology population this question was somewhat redundant. One participant thought that remembering someone close to you who was very sick or dying could help you understand how you would like to be treated if you were dying.

The question about TV within this section of the website was greeted with numerous responses. Twelve participants commented that the reference to TV should be removed because it was associated with entertainment, as one participant explained: “This [TV piece] actually kind of threw me off a little bit. I don’t know if that’s a good idea to put that in there” (114141). Participants thought the reference to TV was superficial, minimized the seriousness of a cancer situation, and was not a good fit for oncology patients. They suggested that TV news or TV documentary information could be an appropriate alternative to the option given. Only one participant suggested that the example of TV may be good for younger people who do not have life experiences (211112).

Life Not Worth Living

The PREPARE website asks viewers if they can imagine health situations that would make their life not worth living. Examples offered to viewers included 5 scenarios such as: 1) never being able to wake up from a coma or get out of bed, 2) never being able to talk to

your family or friends, 3) never being able to live on your own, 4) having to be kept alive on machines, and 5) being in pain.

Four participants expressed their dislike of the word ‘coma,’ claiming that it would scare cancer patients. As a result, these participants wanted the word coma removed or replaced. For example, one participant stated:

I think this is too much information...for a person going through cancer...you’re going through your treatment and everything...I don’t think you really want to think about waking up in a coma...this could scare a lot of people....At night time, you think about things you shouldn’t, but I never thought about going into a coma (116162).

The suggestion that health situations could place a patient in a situation where life was not worth living generated concern for 5 participants, who voiced various comments to reinforce their belief that life was always worth living. One participant’s comment reflects this view:

I agree with parts of it...there may be some health situations that would make life not worth living, however I still don’t think that ‘life not worth living’ is the way I see it,...I think life is always worth living...part of it for me is my religious belief...that life is worth living...I’m not going to choose to end my life (117171).

The phrase ‘your life not worth living’ was associated with death and dying, suicide or assisted suicide and was deemed unacceptable to 4 of the participant respondents.

The first thing that stood out to me was ‘Can You Imagine a Health Situation That Would Make Your Life Not Worth Living,’...not everybody would take that the same way...other people may feel that, you know, life isn’t worth living (114141).

In response to the phrase, one participant reflected on their own experience, stating that when they received their diagnosis,

For about four or five days I had thoughts of suicide...didn't want to be a burden to anybody...I had thoughts that I never ever thought I would have, but then I kind a thought...I can either be down and depressed and not go through this in a positive way, or I can pick myself up and go forward and beat this. So, that's the root I chose, so I am in a totally different mind-set than the week I got told (10331).

Another participant associated the phrase 'your life not worth living' with assisted suicide, and stated,

It is a huge question right now in Canada for the federal government and provincial government...This is a serious topic that individuals have to make a decision on, regardless of whether the government legalises something, you need to have your own perspective and thoughts...and you need to communicate them to your family, given that they're the ones that may well have to make that decision for you (211112).

In addition to this interpretation, 2 other participants associated the term 'your life not worth living' with euthanasia. "Life not worth living alludes to something else...it alludes to euthanasia basically...so it would evoke different emotions to different people" (221211). "Euthanasia is a very, very difficult thing to talk about, and it's not something I would generally agree with, but I do believe in something called passive euthanasia, I think that's the term they use, isn't it?" (218182).

Two participants suggested changing the term 'not worth living,' as stated by the video character Dr. Thomas in one of the PREPARE video scenarios, to 'not worth suffering' or 'not worth extreme measures.' In addition, 6 participants asked that the phrase 'worse

than death' be changed, and 4 of those participants stated this phrase was too harsh. A participant explained, "I think death is worse than any health experience, that's my opinion" (117171).

In conclusion, some participants did not find the term 'life not worth living' acceptable and their responses indicated that they associated its meaning with death and dying, suicide and assisted suicide, and euthanasia. The term prodded several participants to reiterate that life was worth living. Several participants also disliked the term 'worse than death' and asked that it be changed to something softer and less scary.

Videos

Videos are an integral part of each step of PREPARE and are designed to work with the written material, becoming an exemplar that enacts the written word within the different perspectives of the 5 steps. This section reports on the acceptability, applicability and understandability of these exemplars for the participants in this study.

The option to view videos within the PREPARE website was offered to participants by a caption or written heading that represented the scenario or video. Participants accessed the videos by clicking on the caption. Those who participated in watching many of the videos found that these scenarios added to their understanding of PREPARE's material. Responses from 11 participants indicated an appreciation for the videos. For example, one participant stated, "It's nice having those scenarios...people can watch...I don't like reading...either give me pictures or give me a video" (220201). Even though most participants responded positively to the experience of watching the videos, 8 participants chose to view very few scenarios. These 8 participants also provided the fewest comments throughout the interview. Rather than viewing a video, some participants interpreted its meaning based on the scenario caption, and were not interested in clicking on the caption to

watch the scenario play out, even if they thought the video could be different than the message offered by the caption. One participant who did not view all of the videos explained, “I don’t see why you would have to have a skit [video]...Maybe some people might need it, but I think the screen [written caption] before it is good enough” (10661). Another stated, “From my perspective it’s very simplistic, the videos probably would not be necessary, there might be some sort of option...where the individual can ask for help or more information, thereby gaining access to the associated videos as desired” (118182).

Several participants who chose not to view the videos were time focused, and commented that viewing all the videos would extend the time it takes to complete the PREPARE website. Another participant stated that normally they would skip pages that offered too many choices and move forward. One participant stated they were not a film person, but would probably watch the videos if they were viewing the PREPARE website at home, taking extra time to get the gist of the information.

Participants who watched the videos did not take long to locate a favorite actor or actress because these characters played the same role and storyline throughout the website. One participant observed that “it’s pretty well seniors that are in there [videos], so what happens is, a 35 to 40 year old looks at it and says, ‘well, that’s not really pertaining to me’” (211112). It was also noted by some participants that the actors in the video scenarios shared similar ethnicity to each other, but offered a diverse ethnicity compared to the study population. A participant suggested that “multicultural diversity may bother older people, [but that] younger people should be okay with this” (113132). Participants observed that the PREPARE actors did not include ethnic populations that are considered common to British Columbia. After watching several of the videos, one participant stated,

[The actors were] not necessarily a good representation of Canadian society....A First Nation's person, I think, would be very valuable to have in that grouping as well....One Caucasian out of the five, then you know, I hate to say it but society is not to that point where they're that accepting (221211).

In response to the videos, this same participant also stated that PREPARE was obviously an American product, from a different culture and mind set, explaining: "It always bothers me when, we as Canadians, take something from another country, in particular the US, and substitute it into Canada without making appropriate changes" (221211). Although PREPARE may have carried an American flavour, its scenarios demonstrated their unique ability to help viewers observe, reflect, and engage.

Design/Layout of the Website

Participants appreciated the website's logical and sequential delivery of information, which included the following 5 steps or topics: 1) choose a medical decision maker, 2) decide what matters most in life, 3) choose flexibility for your decision maker, 4) tell others about your medical wishes, and 5) ask doctors the right questions. Each of the 5 steps included a menu or index slide at the start to orient the viewer to their location in the website. These steps were followed by an Action Plan, a section of the website where viewers were expected to review their progress and consider future plans to complete any of the 5 steps considered unfinished.

Although participants commented on PREPARE's repetitive design, which presented similar information in both written and video formats including detailed summations at the end of each step, few participants identified this as problematic. One participant said that PREPARE offered too much information, and compared it to the Mayo Clinic site that does not load you down with information. Two participants suggested that the website colours

appeared to be a bit faded, wanting something bright and sunny. Two others wanted to reduce the number of pictures or character photos at the top of each page.

Learn How to Make it Easier

Each of the 5 steps offered a section or option where it asked the viewer if they would like to learn how to make their decisions around the given topic easier. This ‘Learn How to Make it Easier’ section of the PREPARE website was not well utilized by the participants, with most choosing to skip it. The few that did view it reported little value or benefit in doing so, and noted that this section was not relevant for them.

If the viewer chose to access the ‘Learn How to Make it Easier’ section of the website, PREPARE offered those viewers various options or examples to help them identify what was making it hard for them to decide before returning them to the main program. These options, offered once in each of the 5 steps, generally included examples such as: being afraid, God and prayer, becoming a burden, or something else. One participant commented that some of these examples were presented simplistically, suggesting that simplistic answers can be worse than no answer at all. For example, options that focused on ‘God and Prayer’ attracted several responses. One participant suggested that the information presented about God and prayer was almost dismissive. “Should pay homage a little more, for lack of a better term...then go into however God would want you to...take as best care as possible” (221211). Five of the 10 participants who viewed these examples felt this section was not relevant for them.

Generally, participants found the ‘Learn How to Make it Easier’ section of the PREPARE website to be unhelpful in building their knowledge and understanding about ACP, and was not considered to be applicable to their situation.

Navigation Within the Website

Like all websites, PREPARE is piloted by the viewer, who independently maneuvers their way through the program. After completing some preliminary access questions, PREPARE uses its menu or index slide as a starting point for each of its 5 steps. Most participants reported that the PREPARE menu or index slide was like a Global Positioning System (GPS) and relatively easy to use. And, if the viewer did not understand how to move forward from the menu slide, the PREPARE ‘reader’ gave verbal direction around advancing to the next slide. Three participants suggested having one button to move viewers from the menu slide into the program, rather than 3 options, which included the Menu Steps, Stickman Steps, or the Next button. However, after navigating and completing the first step, 2 participants reported that the graphics around the menu slide made better sense. Overall participants were happy with the ease of navigating the PREPARE website and expressed few concerns.

Action Plan

After working their way through the 5 steps, participants were then invited to create a personalized action plan, which focuses on completing any steps in the PREPARE website they feel remain undone. The PREPARE program is able to print out a summary of participant’s answers within the 5 steps, and include their Action Plan, should they decide to complete one. Nine participants reported that they did not understand the directions within the Action Plan section, and were unsure what to do. “I don’t have a clue what they want” (112122). However, 7 participants thought they had received enough direction to move forward in the program. A participant who was familiar with online tutorials stated this section was, “fairly self-explanatory” (221211).

Participants liked the ability to have a summary of their work within the tutorial, and 2 participants commented that having the ability to print this summary and Action Plan was helpful. Four participants were concerned that the summation of their answers within PREPARE represented a legal form.

Overall Evaluation of the Website

The summative findings were similar across both the cognitive interviews and the semi-structured interviews that immediately followed, where participants were asked for their overall thoughts about the PREPARE website and what they had learned.

One participant commented that there are two things missing from the PREPARE website, and they include a direct discussion of cardiopulmonary resuscitation and mechanical ventilation, and the experience of end-of-life care.

One thing that is really missing from all of this [PREPARE] is a discussion about what it means to stay at home and die at home and what a burden that is... for the family. I mean it is not nice if you're incontinent... and you have someone you know come and clean you up... heck of a lot better to have someone you don't know, don't have to share memories with...so humiliating anyway, you'd rather do it with someone who is not that close to you (112122).

Responses from 10 participants indicated the PREPARE website makes you think about what you do and consider what you should do, and it presents things in a different way, compared to current ACP practices. One participant explained, "Generally I liked it because it does prepare you for thought, and you really need to think it through, and take some action" (115152). Four participants commented that the website was too long, 3 participants complimented PREPARE on its logical and sequential organization, and 3 participants

mentioned that the program moved too slowly. One participant, who was concerned about the American flavour embedded within the tutorial stated:

If something is taken from the States, and just put a Canadian flag on it, it doesn't sit well...cause we're a separate country...and what is important in the States is not necessarily important here. Certainly different values...in the medical systems in our culture (221211).

After completing the PREPARE website, responses from 9 participants indicated a new understanding around the importance of completing their action plan, and 3 responses focused on the importance of having conversations. For example, one participant stated, "I re-learned that doctors are okay with questions....I thought that was valuable...even for me, who thinks that I have done everything right,...to have a formal conversation with my husband...to have it really clear in our minds what we want (113132).

Advice About its Use

Participants had strong opinions around when and how the PREPARE website should be introduced to oncology patients. Responses from 18 participants indicated that patients should not receive an invitation to view PREPARE on their first visit to the oncologist.

Well, I don't think you should direct them to this on their very first visit, when they're finding out what their treatment is going to be. I would think maybe two or four weeks in, but early, fairly early on...There is too much to take-in that first week or two....I think it would be hard at the very beginning, almost too much (10992).

Six of these 18 respondents indicated that PREPARE should be offered while individuals are still healthy, and another 6 indicated that PREPARE be offered 2-4 weeks into treatment by the family physician or oncologist. One participant stated, "[It] should be

introduced in the doctor's office really...it should be an initiative for family practitioners" (10441).

Responses from 7 participants suggest that the PREPARE website be introduced to patients and families by a written pamphlet inserted into their new patient information binder at the cancer centre, 6 participants indicated the pamphlet should be offered in the family doctor's office, 2 participants suggested a link on the BC Cancer Agency website, and 2 others suggested working through the website in small group sessions.

That is actually a really good place to introduce it [new patient binder], cause you've got so much going on that eventually you get through it in your own time....The GP's office is always a good place to do any ACP or any decision making....People look at pamphlets all the time, I think a pamphlet would be really good (10441).

Summary

PREPARE included the following 5 steps or topics: 1) choose a medical decision maker, 2) decide what matters most in life, 3) choose flexibility for your decision maker, 4) tell others about your medical wishes, and 5) ask doctors the right questions. These steps were followed by an Action Plan, a section of the website where viewers were expected to review their progress through the site and consider future plans to complete any of the 5 steps considered unfinished. Participant responses indicated the PREPARE website made them think about what they did and consider what they should do, and it presented things in a different way compared to current ACP practices. Responses indicated participants gained a new understanding around the importance of engaging in care planning conversations. Participants appreciated PREPARE's logical and sequential delivery of information, and found it to be acceptable, applicable, and understandable for oncology populations, with an exception found in step 2. This exception focused on the use of language and hypothetical

scenarios associated with 'Experiences of Serious Illness' and 'Life Not Worth Living,' where some participants found these phrases unacceptable and difficult to understand. The following chapter will integrate and explain the findings from this research project and place them in the context of clinical practice, offering discussion and recommendations for practice and research.

Chapter Five: Discussion and Recommendations for Practice and Research

This thesis reports on a qualitative descriptive study designed to explore the acceptability, applicability, and understandability of PREPARE, a promising advance care planning (ACP) resource. The web-based resource prepares patients to engage in ACP conversations but had not been tested for use within cancer care. In this chapter the role of ACP is defined, the goal and method of the study is described, findings are briefly summarized and key findings are discussed in relation to the existing literature and our current understandings of ACP within an active treatment oncology practice. Limitations of this study will be noted, then recommendations for practice and future research will be offered, followed by a conclusion.

ACP conversations play an important role in achieving patient-centred care that is consistent with the care and treatment the patient wants at end of life, which ultimately facilitates a ‘good death,’ as seen through the eyes of the patient (Canadian Hospice Palliative Care Association, 2012). Rather than focusing on end-of-life decisions alone, ACP has recently been broadly re-defined as a facet of good health care that also involves in-the-moment patient and family treatment decision making (Loberiza et al., 2011; Sudore et al., 2014; Walling et al., 2008). Despite acknowledging ACP is important, the majority of Canadians do not benefit from ACP because they do not want to engage in ACP discussions or documentation (Canadian Hospice Palliative Care Association, 2012; 2013; 2015). This study addressed the need to find an acceptable and relevant way to engage cancer patients in ACP.

PREPARE is a web-based ACP intervention that introduces viewers to behaviours associated with ACP, and actively engages them in key aspects of the ACP process including: choosing a medical decision maker, reflecting on their beliefs and values, making

decisions and sharing those choices through conversations with key individuals, and having the freedom to ask physicians questions (Sudore et al., 2014). The purpose of this qualitative descriptive study was to evaluate the acceptability, applicability, and understandability of PREPARE for cancer patients. Data was collected via cognitive interviewing, followed by a brief semi-structured interview to gather a meaningful account of the participants' experience with the PREPARE website. Responses were analyzed and reported in the following categories: content, language, videos, design/layout, and overall evaluation of the website. The PREPARE website helped participants think about what they wanted and consider what they should do; it presented things in a different way compared to current ACP practices. Findings indicate that participants engaged in a significant reflection process while reviewing the website, and simultaneously increased their knowledge around ACP practices. The importance of having purposive conversations about ones' wishes with both close family and physicians was acknowledged by participants. These responses indicate that participants gained a new understanding of ACP and the importance of engaging in ACP conversations. Overall, the active cancer treatment patients enrolled in this study indicated that the PREPARE website was acceptable, applicable, and understandable for an oncology population. Importantly, this was the case for both older and middle aged participants in this study. These findings extend previous research by Sudore et al. (2014) where PREPARE was developed and tested with seniors ≥ 65 years of age. The following discussion is organized around key findings from this oncology study in relation to the following topics: overcoming barriers to engagement in ACP; language of living or dying; and, PREPARE and the Canadian oncology population.

Overcoming Barriers to Engagement in ACP

PREPARE was successful in engaging the participants in the ACP process. Not only did participants respond to what they liked and did not like about the website, they actively debated the options offered by the website and passionately suggested alternative options to the ones given. This occurred despite the many clinical and social barriers that prevent engagement in ACP conversations. The top three reasons Canadians use to avoid ACP conversations include being afraid of death, not wanting to upset family, and being ‘creeped out’ by the conversation (Canadian Hospice Palliative Care Association, 2013). When diagnosed with cancer, Canadians bring their avoidance behaviours and misconceptions surrounding ACP, death and dying into treatment with them. These behaviours and misconceptions become barriers which compete with the patient’s readiness to engage in ACP conversations and exercise self-determined care options. The most common barriers that hinder ACP discussions originate from patients and families, followed by their physicians (Zhou et al., 2010). Weeks et al. (2012) found that cancer patients and their oncologists quickly collude and transition their initial conversation from one that focuses on medical prognosis, to in-depth ongoing discussions of treatment options and possible trials, side effects and scheduling. This mutually acceptable positive focus on living, structured around the foundation of the oncologists’ work in cancer treatment, draws the patient away from engaging in ACP conversations.

Viewing PREPARE is a first step in bridging many barriers and inherent cultural behaviours that prevent patient engagement in ACP conversations with family and health care professionals. PREPARE directly addresses the barrier of lack of knowledge and understanding of what ACP means (Canadian Hospice Palliative Care Association, 2013; 2015; Zhou et al., 2010) and presents necessary knowledge in a systematic and logical

progression of steps. Further, the website demonstrates how to have potentially difficult conversations in a straightforward way that strengthens rather than disrupts relationships. The importance of attention to relationships is supported by research, which found that patients do not engage in ACP for its potential medical outcomes, but rather for its social function in strengthening family communication, function, and relationships (Robinson, 2011; Singer et al., 1998; Tilden et al., 2001).

Viewing PREPARE helped the oncology patients in this study to engage in ACP by offering them opportunities, through PREPARE's scenarios, to reflect on, compare, and re-evaluate or re-envision their story in a positive and functional way. PREPARE became the trigger that guided and caused the viewer to reflect on their cancer story, and thereby engaged them in the process of ACP. Increasing engagement in ACP depends on raising public awareness and enabling people to think about its applicability or relevance in their own life situation (Seymour, Almack, Kennedy & Froggatt, 2011). A study by McMahan, Knight, Fried, and Sudore (2013) found that the process of personal reflection through probing questions and the use of vignettes helped to prepare participants for decision making and clarified their values and interpretation of 'quality of life.' These researchers recommended that future ACP interventions should incorporate these reflective activities. The importance of reflection is further supported by Michael et al. (2013) who theorized that ACP is characterized by continually reconsidering ones' previous choices regarding wishes for current and future treatment options. This repetitive process of evaluation allows the patient to re-confirm their wishes or choose to abandon or reject a previously determined choice. PREPARE's scenarios and web-based format appears to be well suited for supporting the kind of personal reflection that is important in ACP.

Language of Living or Dying

Some participants found it easier to engage in the steps of choosing a decision maker and having purposeful conversations about ACP, compared to the step involving values clarification around what makes life worth living. In particular, concerns were expressed over the terms “life not worth living” and “worse than death,” and the word “coma.” Participants associated this language with medical limitations and dying. Some participants described this language as harsh and scary, and it generated an unexpected response. They suggested a change in wording for oncology patients is necessary because they viewed the language to be unacceptable. In addition, some participants associated these terms with suicide or euthanasia. This association may have been due to a recent Canadian Supreme Court decision that people have a right to assisted dying. This Supreme Court decision was in the news during the time of this study. However, Seymour et al., (2011) state that some older people associate a problematic link between ACP and euthanasia.

These findings, regarding the language of medical limitations, may be unique to oncology because they trigger unwelcome thoughts around life expectancy. Research indicates that many active treatment cancer patients do not want to talk about their medical life expectancy estimates, preferring to use a coping strategy of ‘not looking ahead’ and focus on fighting their disease (Buiting et al., 2013; Walczak et al., 2015). Research by Horne et al. (2012) indicates that patients are reluctant to bring forward medical language that bothers them, preferring to face death when it comes. Rather than focusing on language and questions that emphasise medicalized treatment limitations, such as ‘Would you want to be put on a machine to help you with breathing?’ or ‘Do you want cardiopulmonary resuscitation?’ To address this problem, Prommer (2010) suggests using a values-based language that asks encouraging questions. These questions include: “What makes life worth

living” (p. 69), and “If, in the future, you become severely ill and lose the ability to speak for yourself, would you want medical treatments used to prolong life or to keep you comfortable?” (p. 67). Hopeful values-based language and questions help to validate the patient’s preference around treatment and fighting their cancer, and can indicate appropriate courses of action that could not be uncovered by medicalized questions alone.

Enhancing PREPARE for a Canadian Oncology Population

Video scenarios are an integral part of each step of PREPARE and are designed to complement and demonstrate the content in the written material. Participants did not take long to locate a favorite actor or actress because these characters played the same role and storyline throughout the website. Participants observed that the scenarios included a cast of actors with similar characteristics, most were seniors and included an overexpression of one ethnic population not common to British Columbia. Some thought that younger actors and cultures found across Canada, such as First Nations and others, could be added to the video scenarios to offer a fair representation of Canadian society and Canadian health care services. Several participants suggested that adding Canadian content to PREPARE could support engagement and increase the likelihood that the Canadian viewers would relate to each of the scenarios.

Limitations of This Study

This thesis reported on a study with a small sample size that used a qualitative descriptive design. Participants in the study were receiving active chemotherapy treatment, with one participant on watchful waiting post chemotherapy. All participants in the study were culturally homogeneous, belonging to a social group with common traditions and living in a small city or rural community.

Implications for Practice

PREPARE was found to be appropriate, applicable, and understandable for cancer patients. The resource shows promise as one way to engage patients in ACP and prepare them for conversations with their family, family physician, and oncologist. Participants had strong opinions around when and how the PREPARE website should be introduced to oncology patients. Responses from a majority of participants indicated that patients should not receive an invitation to view PREPARE on their first visit to the oncologist. Some of these participants indicated that PREPARE should be offered while you are still healthy, and others indicated that PREPARE should be offered 2-4 weeks into treatment, at a time of stability and treatment, by the family physician or oncologist. Responses from participants suggest that the PREPARE website be introduced to patients and families by a written pamphlet inserted into their new patient information binder at the cancer centre, others thought the pamphlet should be offered in the family doctor's office, and a few suggested a link on the BC Cancer Agency website or working through the website together in small group sessions.

Implications for Research

Given the lack of diversity in the sample for this study, further research is warranted to better inform the use of PREPARE with patients from diverse cultural backgrounds and receiving various kinds of cancer treatment. Specific attention needs to be paid to the language and terms that some participants experienced difficulty with, given the potential of causing distress and disengagement from ACP. Enhanced understanding of these concerns about language will better support decisions about whether to change the language and how best to do it. Prior to the clinical implementation of PREPARE in oncology, evaluation research is required to determine whether the website is effective in bringing about behavior

change and to insure it is not associated with harm. This should be followed by implementation research to identify when and how to most effectively introduce PREPARE, determine how best to sustain viewers'/patients' new interest in ACP conversations, and support their inquiries and decisions within clinical practice.

Conclusion

PREPARE was found to be appropriate, applicable, and understandable for cancer patients. The website invited reflection, which supports the patient's role in decision making and prepares them for conversations about current, future and emergency treatment decisions with their family, family physician, and oncologist. Findings from this study indicate that patients want and support the social aspects of ACP, content that supports family function, brings meaning and makes life worth living. Engagement in ACP depends on raising awareness and enabling people to think about its applicability or relevance in their own life situation (Seymour et al., 2011). The process of personal reflection that was generated through the use of video scenarios within PREPARE helped to share new knowledge around ACP processes, prepare participants for decision making and clarify their values and preferences. McMahan et al., (2013) recommended that future ACP interventions should incorporate these reflective activities, and that limited medical documentation, goals of care or advance directives alone are not sufficient to fully prepare patients and their decision makers for in-the-moment complex decision making along the treatment trajectory or at end of life.

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Appendices

Appendix A: Screening Tool for Recruitment



a place of mind

THE UNIVERSITY OF BRITISH COLUMBIA



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority



BC CANCER

FOUNDATION

partners in discovery

Screening Tool for Recruitment

Dialogue: “Thank you for your interest in our study.”

Date: _____

ID #: _____

Dialogue: “Do you have any questions about the study... or are you interested in additional information around what the study will look like?”

Explain study:

- The study is being done to explore cancer patients’ perspectives, about a unique web-based resource designed to prepare people for engaging in conversations about treatment decision making and advance care planning.
- The purpose of this study is to assess the acceptability and understandability of the PREPARE web site for cancer patients.
- The study interview will be scheduled for a time, date and location that works for you.
- If you choose to participate in this study you will be asked to answer some general questions, intended to describe yourself and your health situation.
- The interview will take 2-3 hours to complete. You will receive simple pre-interview training for the session, and with the help of a research team member, comfortably view and talk about what you think of the PREPARE website, at you own pace. The viewing session will be followed by a brief post interview.
- The interviews will be audio recorded for accuracy, and a research team member will offer direction, take notes, and assist you as required.

- Taking part in this study is your choice, you can stop the study at any time.
- The care you receive from the cancer centre will not be affected by your decision to participate, not participate, or stop the study.

Dialogue: “If you are interested in participating in the study, I have a few questions to make sure you are eligible for the study... is this okay?”

Dialogue: “These are just some questions to check your memory.

Don’t worry if you miss a few.”

| <u>SPMSQ</u> | | |
|--|---|---------------------------|
| Question | Answer Key | Mark if Incorrect |
| What are the date, month, and year? (PAT_SPMSQ1) | Must be fully correct for point. | |
| What is the day of the week? (PAT_SPMSQ2) | | |
| What is the name of this place? (PAT_SPMSQ3) | Any descriptions of location is correct (home, SF, hospital, Fort Miley, VA, etc.) | |
| What is your phone number? (PAT_SPMSQ4) | Please remind me of your phone number? | |
| How old are you? (PAT_SPMSQ5) | And, how old are you? | |
| When were you born? (PAT_SPMSQ6) | So, what year were you born? | |
| Who is the current prime minister? (PAT_SPMSQ7) | OK if last name only (Stephen Harper) If just first name, prompt for full name (Paul Martin) (Jean Chretien) | |
| Who was the prime minister before him? (PAT_SPMSQ8) | | |
| What was your mother’s maiden name? (PAT_SPMSQ9) | Correct if any last name other than own. If same, confirm “mother’s maiden name is the same as your own?” | |
| Can you count backward from 20 by 3’s? (PAT_SPMSQ10) | If refuse or mess up, incorrect. 20 17 14 11 8 5 2 | |
| SCORING *1 more error is allowed if grade school education or less (-) *1 less error is allowed if education beyond high school (+) | | |
| | | Total Errors _____ |

Total Adjusted Score(PAT_SPMSQ_SCORE): _____(+/- 1 for education)

☐ **0-2 errors:** normal mental functioning

→ ✓ Eligible

☐ **3-4 errors:** mild cognitive impairment → ADMINISTER

MINI-COG

☐ **5-7 errors:** moderate cognitive impairment → ADMINISTER

MINI-COG

☐ **8+ errors:** severe cognitive impairment → 

INELIGIBLE

What is your highest level of education?

☐ Less than high school

☐ High school

☐ Technical and non-university education (college/technical school)

☐ University (undergraduate/bachelor's degree)

☐ University (post-graduate degree, master's degree, doctorate degree)

☐ Other (please specify):

MINI-COG (if needed)

“The last part of the memory check is to please listen to the following three words and repeat them after I say them. Ready?”

Apple. Penny. Table.

Can you repeat those words?” [Prompt until successful repeat] “Please try to remember these three words because I will ask you about them again in a few minutes.”

[Mini-Cog continues on page 5]

Are you able to read English? ☐ yes ☐ no

How is your vision during activities of daily living? _____

☐ eye glasses

☐ no eye glasses

How is your hearing during activities of daily living? _____

☐ hearing aid

☐ no aids


Do you have access to the internet in your home? ☐ yes ☐ no ☐ unsure

MINI-COG (continued)

“Can you remember the three words I told you a few minutes ago?”

[Do not prompt for missing words: Answers: **Apple, Penny, Table**]

SCORE: ____/ 3
(3ITEMRECALL)

☐ 3/3 or 2/3 → ✓ [Eligible]
☐ 1/3 or 0/3 →  INELIGIBLE

Dialogue: “Thank you for answering all my questions. I am sorry, but it looks like you are not eligible for our study, but thank you so much for your time.”

or

Dialogue: “Thank you for answering all my questions, and yes you are eligible to join this study.”

➤ Can I schedule a time for you to view the Consent form? _____

Next scheduled appointment at SAHCSI: _____

or

Mailing address: _____

➤ Can I schedule a time for your interview? _____

Appendix B: Consent to Contact



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Consent to Contact

Title of Study: Evaluation of a Web-Based Tool for Preparing

People to Engage in Conversations and Medical Decisions:

Applicability for Oncology Patients



This is to inform you of a study about oncology patients' perspectives around a unique web-based tool called PREPARE.

The resource helps prepare people for engaging in conversations about future treatment. We call these conversations 'advance care planning (ACP).'

The purpose of this study is to learn what cancer patients think about the new resource. You will review the web-based resource and tell us your thoughts. The interview will happen at a time and place that is convenient for you. This study will help researchers understand whether changes to PREPARE may be necessary before the resource is suitable for people with cancer, and if so, identify what essential changes may be required.

At this time, we are asking only for your permission to be contacted to hear more about the study. We ask that you sign and return this form to any staff member, volunteer, or the main front desk of the cancer centre and we will respond according to your wishes. If you indicate you would like to be contacted, we will provide you with more details about the study and you can decide if you would like to participate. Your participation in the study is entirely voluntary. Your decision about whether or not to participate in this study will have no effect on the care you receive from the BC Cancer Agency.

If you have any questions about your rights as a research subject, please call the Research Subject Information Line in the UBC Office of Research Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832.

I would like to receive more information about the study,

please circle **YES** or **NO**

print name

date

contact phone number

signature

Return this form to any staff member or the main front desk,

located the lobby/reception area of the cancer centre.

You will be contacted by Martha Cresswell, a Master of Science in

Nursing student, who will answer your questions.

ID #: _____

Appendix C: Informed Consent to Be in a Research Study



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Consent to Be in a Research Study

Title of Study: Evaluation of a Web-Based Tool for Preparing People to Engage in
Conversations and Medical Decisions: Applicability for Oncology Patients

Principal Investigator:

Dr. Carole Robinson, School of Nursing, University of British Columbia Okanagan

Research Team Members:

Dr. Joan Bottorff, School of Nursing, University of British Columbia Okanagan

Dr. Gillian Fyles, Sindi Ahluwalia Hawkins Centre for the Southern Interior

Martha Cresswell, BSN, RN, CON, Master of Science in Nursing student, University of
British Columbia Okanagan

Why is this study being done?

To explore oncology patients' perspectives, about a unique web-based tool (PREPARE) designed to prepare people to engage in medical or treatment decision making conversations. The purpose of this study is to assess how acceptable and understandable the PREPARE website (www.prepareforyourcare.org) is for oncology patients. This study will help researchers understand whether revisions to PREPARE may be necessary before the site is suitable for people with cancer, and if so, identify what essential changes may be required.

Why am I being asked to be in this study?

You are an oncology patient receiving care at the Sindi Ahluwalia Hawkins Centre for the Southern Interior (SAHCSI).

How many people will take part in this study?

20 participants will be recruited from Chemotherapy and/or Radiation programs, including 10 men and 10 women. Half of the participants will be under 60 years of age.

What will happen if I take part in this research study?

If you choose to participate in this study, and sign this Consent to Be in the Research Study, you will be asked to answer some general questions, intended to describe yourself and your health situation. A mutually agreed upon date, time, and location will be scheduled for the study interviews, which will be audio recorded for accuracy. A research team member will offer direction, take notes, and assist you as required.

How long will I be in the study?

You will be in the study for 2-3 hours. You will receive simple pre-interview training for the session, and with the help of a research team member, comfortably view and reflect on the PREPARE website, at your own pace. The viewing session will be followed by a brief post interview. You may receive a follow-up phone call, if researchers require additional clarification around your responses.

Are there any costs of taking part in this study?

There is not cost to you, except for some additional parking at SAHCSI, if you choose to come to the Cancer Centre for your interview.

Will I be paid for taking part in this study?

Participants will be offered a 'day pass' for the Impark BC Cancer Agency parking lot in Kelowna, should participants decide to be interviewed at the Cancer Centre. All participants will receive a \$20.00 gift card as a token of appreciation for their time.

Who is paying for this study?

This study is part of a master's thesis, facilitated by the School of Nursing, University of British Columbia Okanagan campus. The study has received funding for the Impark 'day pass' and gift cared from the BC Cancer Foundation. This study has not received any other funding.

Are there benefits to taking part in this study?

This study can help you define your values and beliefs around health care, and show you how to share these preferences with your family and health care providers. Benefits may include the satisfaction of knowing you helped to consider and evaluate upcoming trends in the delivery of better health solutions for people with cancer.

What are the risks or side effects of being in this study?

You may feel uneasy while considering and evaluating the appropriateness of a website that presents new understandings of how to participate in Advance Care Planning. The Patient and Family Counselling Department at the Cancer Centre are available for cancer patients and their families experiencing worry or concern.

How will you keep my information private?

This research study is part of a Master's Thesis. A Master's Thesis is a public document. General findings from this research will be published.

However, your identity and discussion will be kept strictly confidential by the research team. Consent to Contact and this Consent to Be in a Research Study will be locked away and kept separate from your interview information. All personal identifiers (such as names and places) will be removed from your interview information (data). All data records will be stored in a locked filing cabinet in Dr. Robinson's research office and electronic files (e.g., audio-recordings and transcripts) will be kept on a password-

protected computer and/or site on the P: drive at the UBC Okanagan Campus. After the study is completed, audio-recordings will be erased and paper copies shredded. Participant information (data) will be stored in accordance with the UBC Okanagan policies and procedures, data that has had all personal identifiers removed will be stored electronically for a minimum of 5 years after publication, at UBC Okanagan Campus in Dr. Robinson's research site and will be password protected. Access to your data will be restricted to the research team. All those who have access to the data are trained in the appropriate methods of handling and storage of confidential data. If necessary, an experienced research assistant will transcribe the audio-recordings and will be educated on confidentiality issues and will be required to sign a confidentiality form.

What are my rights if I take part in this study?

Taking part in this study is your choice, you can stop the study at any time, just tell the researcher team member assisting you. The care you receive from the cancer centre will not be affected by your decision to participate or stop the study.

What are my rights if do not participate in the study?

Your decision not to participate in this study, will not affect the care or services you receive from the cancer centre, and its health care providers.

Who can answer my questions about the study?

- You can contact Dr. Carole Robinson, who is in charge of the study, at phone # 250-807-9882.
- If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, you may contact the Research Participant Information Line in the UBC Office of Research Services at 1-877-822-8598

or the UBC Okanagan Research Services Office at 250-807-8832. It is also possible to contact the Research Participant Complaint Line by email (RSIL@ors.ubc.ca).

CONSENT: You have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY

Signing this consent means that being in this study is your choice. You can stop being in this study at any time without any risks or loss of benefits or medical care.

If you wish to be in this study, please print your name, date, and sign below.

| | | |
|------------|------|-----------------------|
| print name | date | signature for consent |
|------------|------|-----------------------|

| | |
|------|---------------------------------------|
| date | signature of person obtaining consent |
|------|---------------------------------------|

Would you like to receive a brief summary of feedback at the conclusion of this study?

Please initial either yes or no: Yes No

Is it OK for us to call you in the future about other studies?

Please initial either yes or no: Yes NO

If Yes, please give contact information below:

| | |
|--------------|---------------|
| phone number | email address |
|--------------|---------------|

ID #:



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New Kelowna research Study Open for Participation

The study will explore patients' ideas about
a web-based resource designed to
PREPARE* families to
participate in treatment decision making conversations!

- ☒ **If you would like to contribute to the development of a new resource for cancer patients...**

Please ask a nurse about the PREPARE* study!

Interviews involve...

- One-to-one assistance from a research team member.
- Relaxed interactive tour of the PREPARE* website.
- Exploration of your valued perspective
- Approximately 2-3 hours of your time



PREPARE FOR YOUR CARE

Appendix E: Study information power point slides

**We need your help
to review an
online educational tool.**



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May 17, 2014



1

**We would like your feedback about
an online resource that prepares
patients to participate in
treatment decision making
Conversations!**



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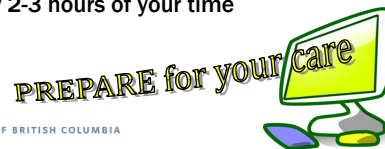
2

Interviews involve...

- ✓ One-to-one assistance from a research team member
- ✓ Relaxed interactive tour of the PREPARE* website
- ✓ Exploration of your valued perspective
- ✓ Approximately 2-3 hours of your time
- ✓ You



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3

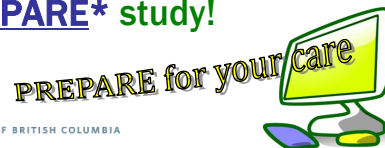
If you would like to...

- ✓ Assist in the development of a resource for cancer patients

**Please ask a nurse about the
PREPARE* study!**



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4

Appendix F: Participant Demographic Sheet



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Date: _____

ID #: _____

Participant Demographic Sheet

Title of Study: **Evaluation of a web-Based Tool for Preparing People to Engage in**

Conversations and Medical Decisions: Applicability for Oncology

1. Marital Status: ☐ Single ☐ Married/Common-law/Living with Partner

☐ Divorced/Separated ☐ Widowed

2. What was your household income in the last year, before taxes?

☐ Less than \$ 11,000

☐ \$ 11,000 – 25,000

☐ \$ 25,000 – 50,000

☐ More than \$ 50,000

☐ Prefer not to answer

3. Compared to other people your age, would you say your health is:

☐ excellent

☐ very good

☐ good

☐ fair

☐ poor

4. Intent of treatment / care: ☐ curative ☐ palliative ☐ unsure

5. Are you familiar with the term **Advance Care Planning**?

☐ yes

☐ no

If yes please explain:

6. Have you completed any **Advance Care Planning documentation/ forms?**

☐ yes ☐ no ☐ unsure

If yes, what type of documentation?

☐ Will ☐ Power of Attorney ☐ Enduring Power of Attorney

☐ Standard Representation Agreement

☐ Enhanced Representation Agreement

☐ Advance Directive or Living Will

☐ Goals of Care

☐ Do Not Resuscitate (DNR)

☐ if other, please explain:

7. Have you talked about your beliefs, values, and wishes for health care with your close family/friend(s)?

☐ yes ☐ no ☐ unsure

8. Have you talked about your beliefs, values, and wishes for health care with your health care providers?

☐ yes ☐ no ☐ unsure

9. Have you asked anyone to be your Substitute Decision Maker if there comes a time when you cannot speak for yourself?

☐ yes ☐ no ☐ unsure ☐ do not have anyone to ask

10. What role do you prefer when making your health care treatment decisions? Please choose one of the following:

☐ I prefer to share the decision with _____

☐ I prefer to decide myself after hearing the view of _____

☐ I prefer that someone else decides. Who? _____

11. Do you normally have access to a computer?

☐ yes ☐ no ☐ sometimes

12. Are you comfortable navigating the internet?

☐ yes ☐ no ☐ sometimes

Thank you for your responses!

Appendix G: E-Chart Demographic Sheet



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Date: _____

ID #: _____

E-Chart Demographic Sheet

Title of Study: Evaluation of a Web-Based Tool for Preparing People to Engage in
Conversations and Medical Decisions: Applicability for Oncology

1. Date of Diagnosis: _____

2. Diagnosis: _____

3. Current Treatment:
- ☐ Chemotherapy
 - ☐ Radiation
 - ☐ Watchful waiting / surveillance
 - ☐ Follow-up before discharge
 - ☐ Pain & Symptom Management

4. Intent of treatment / care: ☐ curative ☐ palliative ☐ unclear

5. History of Cancer Treatments: _____

6. Current Age: _____ 7. Gender: ☐ female ☐ male

8. Advance Care Planning documentation/ forms scanned into E-Chart: ☐ yes ☐ no

If yes, what type of documentation? ☐ Goals of Care ☐ Do Not Resuscitate (DNR)

☐ Enhanced Representation Agreement

☐ Advance Directive or Living Will

☐ Other:

Appendix H: Interview Guide



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Cognitive Interview Guide

Note to the interviewer: The interviewer is to collect notes, including comments, responses, and observations from the participant, as they work their way through each web page. Ask the participant to comment or think-aloud, so their perspective can be documented.

Dialogue: “Thank you for agreeing to look over the website and give us your feedback. The website focuses on how to prepare patients and their families to engage medical decision making conversations.”

Dialogue: “As you work your way through the website, we need you to think-aloud, commenting on anything that comes to your mind, regardless of whether you think I agree with it or not.”

Pre-Interview Training Session

Dialogue: “Let’s start with an exercise to help you think-aloud:

- Can you tell me what you had for dinner last night? Great!
 - What did you like about the dinner? Why?
 - What did you dislike about the dinner? Why?
 - And, if you could change one thing to improve your dinner last night, what would it have been?
 - Perfect, that is exactly the kind of thinking-aloud and opinions we are interested in.”
-

Website Interview

Dialogue: “Our goal is to have this website be useful for cancer patients. While you review the website, please think about whether there is anything you think cancer patients would like or not like.”

Dialogue: “The things we would like you to focus on are

- whether the website is easy to understand and work through,
- and whether there are any words, phrases, or stories in the videos that you like or do not like, and why?”

Dialogue: “You can say anything ranging from

- I don’t understand these instructions
- I do or don’t like the colours on a webpage
- or I do or don’t like the story someone is telling.”

Dialogue: “There is no right or wrong answers, and no test at the end, so please be as honest as possible, and think-aloud as you view the website, let’s begin.”

Note to the interviewer: The participant is to think aloud... then asked the verbal probes as required.

Instruction probes:

(ask these questions as appropriate during the website interview and post interview)

- Were there any instructions (buttons) that you liked? Why?
- Were there any instructions that were hard to understand or that you think other people will have a hard time understanding? Why?

Verbal probes: (for each web page):

- Tell me what you are thinking as you see this page?
- What thoughts are going through your mind right now?
- What do you like about this webpage? Why?
- Were there any pictures, actors, or **videos** that you liked? Why?
- What do you dislike about this webpage? Why?
- Were there any pictures, actors, or videos that you didn't like? Why?
- Is there material that is hard to understand?

Brief Post Semi-structure Interview

(Open-ended questions, with a focus on participants overall response to the website)

1. What are your overall thoughts about this website tool?
 - What did you like? Why?
 - What did you dislike? Why?
 - Were there any instructions that were hard to understand or that you think other people will have a hard time understanding? Why?
2. What content in this website would need to be changed for cancer patients?
 - What would you like to see changed? (pictures, actors, videos)
 - What is essential to change for the website to be useful for cancer patients?
4. When do you think would be a good time to introduce this website to cancer patients?

Closing

Dialogue: “Thank you for taking the time to talk with me about the website. Do you have any questions?”

Dialogue: “If the research team requires clarification around your responses, can we contact you?”

Appendix I: Field Notes



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Title: Evaluation of a Web-Based Tool for Preparing People to Engage in Conversations and

Medical Decisions: Applicability for Oncology Patients

Field Notes

Participant Identification Code #: _____

Interviewer: Martha Cresswell

Date of Interview _____ Start time _____ End time _____

Locale of Interview (where the interview took place): _____

Location of Interview (physical room): _____

Non-verbal behaviour (tone of voice, posture, facial expressions, eye movements):

Researcher's Impressions (discomfort of participant with certain topics, emotional

responses):

Content of Interview: (key words, topics, phrases): _____

Analysis (tentative hunches, trends in data, emerging patterns): _____

Technological Problems: _____
