Advance Care Planning: A Qualitative Study with Families of Deceased Cognitively Impaired Older Adults

by

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M.Sc., University of Victoria, 2012
B.Sc., University of Alberta, 2009

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Supervisory Committee

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Older adults with dementia are at increased risk of becoming incapable of making their own decisions and may therefore benefit from planning for care at the end-of-life. Advance care planning (ACP) is a complex, multifaceted process by which people can express their wishes about care at the end-of-life in case they become incompetent to make decisions for themselves. However, we have little understanding of the ACP process among people with dementia and their families. This study addressed three questions: 1) when and how to cognitively impaired older adults and their families receive information about ACP; 2) in which aspects of the ACP process do families of cognitively impaired older adults engage, and why (and does this fit within the framework of the transtheoretical model of behaviour change [TTM]); and 3) how ACP relates to the way in which family members perceive the quality of death of their loved one. 22 family members of deceased older adults with dementia were interviewed and data was analyzed using interpretive description qualitative methods. Participants reported that information about ACP is provided in a haphazard and often incomplete manner, leading to difficulty engaging in the ACP process. Older adults were in various stages of readiness to engage in ACP behaviours, with most only engaging in a subset of ACP behaviours. Although ACP was viewed as beneficial by participants, several barriers were identified that prevented people with dementia from dying in a way that was aligned with previously-expressed wishes. Implications for the practice of clinical neuropsychology and implications for policy on ACP are discussed.

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Acknowledgments

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Dedication

For Eryk - my husband, my partner, my occasional research assistant.

Your patience, your support, and your willingness to singlehandedly take on all household responsibilities allowed me to focus on this project. I am proud to have you by my side.

Introduction

Rationale for study

Discussing wishes regarding care at the end-of-life commonly conjures feeling of discomfort, anxiety or even fear. It is a topic fraught with stigma and may even be taboo for many people. However, it is an issue that we all must face at some point and is becoming more openly discussed in the media, as evidenced by several recent articles in widely-read newspapers such as *The New York Times* (Lamas, 2018; Khullar, 2017) and *The Globe and Mail* (Martin, 2018). There is increasing awareness and discussion of issues at the end-of-life, including the concept of advance care planning (ACP). The National Advance Care Planning Task Group has defined ACP as:

> A process of reflection and communication in which a person with decision-making capacity expresses his or her wishes regarding his or her future health and/or personal care in the event that he or she becomes incapable of consenting to or refusing treatment or other care. (Canadian Hospice Palliative Care Association, 2012, p. 3)

The concept of ACP applies to all people but has been most extensively discussed with respect to older adults. In recent years, there has been a strong push from provincial governments and healthcare authorities across Canada to encourage older adults to begin thinking about their preferences for care at the end-of-life before they become seriously ill or incapable of making decisions for themselves. There has even been movement in Canada toward further autonomy over the quality of one’s death with the introduction of medical assistance in dying (MAiD), also known as physician-assisted death. Planning for care at the end-of-life is a burgeoning area of research with a dramatic increase in the number of peer-reviewed articles addressing this topic.

One promising avenue of research has been investigating the applicability of the transtheoretical model of behaviour change (TTM; Prochaska & Velicer, 1997) as it relates to ACP (Fried, Bullock, Iannone, & O'Leary, 2009; Sudore et al., 2008). The TTM posits that people have variable readiness to engage in behaviour change and go through a series of stages in the process of behaviour change (Prochaska & Velicer, 1997). Despite this rising interest in ACP, we are still in the infancy of understanding this process, particularly in populations of underserved older adults, such as those with illnesses resulting in cognitive deficits.

Older adults with cognitive impairment are a particularly vulnerable group who often experience multiple comorbidities, increased risk of hospitalization, and medical complications (Griffith et al., 2016; Mitchell et al., 2009; Mondor et al., 2017). Currently, there is no cure for dementia; therefore, people with dementia are at high risk of losing capacity to make their own decisions as the disease progress. Early engagement of older adults with dementia in the ACP process allows people an opportunity to provide input on their future care and identify beliefs about quality of life, thereby increasing autonomy (Hirakawa, Chiang, & Aoyama, 2017). Benefits of engaging in the ACP process have been identified, both for people with dementia and for their caregivers (Moore et al., 2017; Vendervoort et al., 2014). However, studies suggest that there may be low engagement in ACP among people with dementia (Garand et al., 2011; Ho et al., 2017) and that people may only engage in a subset of the components of ACP (Jeznach, Tuokko, Garcia-Barerra, & Stajduhar, 2015). Barriers to engagement in ACP unique to this population have been identified (de Vleminck et al., 2014; Schonfeld et al., 2012) with lack of education about ACP and limited communication with healthcare providers about ACP being some of the most-commonly reported barriers (Davies et al., 2014; Schonfeld et al., 2012).

Currently, we are only beginning to comprehend the intricacies of ACP in this population. Although ACP is considered a complex, multifaceted process, much of the previous research has conceptualized ACP as a single event or has only focused on a single aspect of the process (i.e., creating legal documents). Further, the great majority of previous studies have not addressed a fundamental aspect of the ACP process. The question remains: why cognitively impaired older adults engage in certain aspects of ACP but not in others. This question is being addressed for cognitively intact older adults using the framework of the TTM by examining readiness to engage in a range of ACP behaviours (Fried et al., 2009; Sudore et al., 2008). However, this framework has not yet been applied to people with dementia.

There is great clinical utility in exploring how engagement in different aspects of this complex process relates to family perceptions of the quality of death. A good death can be conceptualized as one where the person died in a way that aligned with their preferences for dying while considering unavoidable circumstances related to the death (Patrick, Engelberg, & Curtis, 2001). There is a dearth of studies exploring the reasons behind the ACP-related decisions that are made within the family of an older adult with cognitive impairment. It is of the utmost importance to understand why these decisions are made if we hope to improve the strategies currently used in the healthcare system to encourage adults to engage in ACP.

Statement of the problem

Currently, we have little understanding of the decision-making process involved in ACP for cognitively impaired older adults and their families. As the ACP process is extremely complex, it is not enough to know whether cognitively impaired older adults engage in ACP or not, but rather which aspects of this process are undertaken, and why. Identification of reasons for engagement in aspects of ACP and, even more so, the reasons why people don't engage in certain aspects, can provide a starting point for the development of more effective strategies to enhance the ACP process. A main goal of ACP is to increase autonomy and help people die in a way consistent with their beliefs and values in the hopes that individuals and their families will experience a good death. It is therefore important to investigate family members' perceptions of the role of ACP in the dying process of a loved one, particularly as it relates to the perceived quality of death. This increased understanding of ACP in this population will be of great relevance for clinicians who work with older adults in understanding ways in which the ACP process works well in this group as well as areas in which there could be further improvement. Further, these are research areas that have been identified as priorities in a Canadian call to action (Johnson, Hanvey, Baxter, & Heyland, 2013).

Research objectives

The current study aims to provide the first step in understanding the reasons cognitively impaired older adults choose to engage in aspects of ACP. I will explore ACP as a complex process encompassing multiple aspects and disentangle reasons for engagement in each aspect. The purpose of the current study is then to explore not only which aspects of ACP occur in families of cognitively impaired older adults, but also the reasons why older adults and their families make these decisions. Additionally, this study will provide valuable information regarding ACP and its outcomes among families of people residing in British Columbia.

The research questions addressed in this study are:

1) When and how do cognitively impaired older adults and their families receive information about ACP?

2) In which aspects of the ACP process do families of cognitively impaired older adults engage, and why? Aspects of ACP examined include discussion of beliefs, values, and goals with a family member, deciding on a substitute decision-maker, and creating legal documents regarding healthcare and/or financial wishes.
    a. Does engagement in ACP behaviours fit within the conceptual framework of the TTM?
3) What role does ACP play for family members? How does this relate to the way in which they perceive the quality of death of their loved one?
    a. How does this relate to beliefs about MAiD, including beliefs about its possible future use for people with dementia?

Literature Review

In this section, I will provide a review of the current research on ACP among older adults. I will begin by providing a definition of ACP and discussing the components of this complex process. The relevant legal policies related to ACP in British Columbia will then be reviewed to provide a context for the experiences of the participants in this study. I will also briefly review the recent changes to Canadian law that has led to the legalization of physician-assisted death as there has been advocacy for extending this right to people with dementia, though this is not currently available. My focus will then move to providing a brief overview of the research on ACP among cognitive intact older adults, with a focus on the use of the TTM as a framework for research. I will conclude this section with a discussion of the concept of dementia, challenges faced by this population, and the role of ACP in this group.

Advance care planning

One of the most prominent difficulties in investigating the process of ACP is the plethora of ways in which this process has been described in the literature (Kermel-Schiffman & Werner, 2017). Upon even a cursory examination of the literature, the idea of making choices regarding one’s end-of-life care has been described as advance care planning, creating an advance care plan, and making an Advance Directive (AD). Often, these terms have been used interchangeably even though they refer to very different aspects of planning for care at the end-of-life, leading to difficulties comparing results across studies. For example, studies examining barriers to completion of a legal document, such as an AD, have a very different focus than those investigating barriers to discussing one’s beliefs and values as they relate to preferences for care at the end-of-life. However, both types of studies may use the term “advance care planning” to define the phenomenon under investigation, resulting in discrepancies among results and confusion for readers. This issue is further complicated by the fact that ACP is inexorably connected with legal considerations in the country in which the research is completed, leading to further differences in nomenclature (Flo et al., 2016). However, an international group of experts recently came to a consensus on a definition of ACP:

> Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions. (Rietjens et al., 2017, p. e546)

The process of advance care planning (ACP) will be discussed in accordance with the broad definition above as it highlights the complexities of this multifaceted process. Several key aspects of this construct are discussed below.

First, ACP is a voluntary process through which an individual can choose to reflect upon his/her own values to make decisions as to the care he/she would like to receive at the end-of-life. Although this commonly refers to medical care, it also includes personal decisions such as preferences for type of residential care. ACP is a process through which capable adults can plan for their care if there comes a time when they are incapable of making such decisions for themselves. It is important to note that capacity to make decisions is not equivalent to the presence of illness, including diseases that impact cognitive functioning, and is assumed to be present for all adults unless proven otherwise. The greatest benefit of ACP is in providing people the opportunity to retain autonomy and a sense of self-determination for as long as possible by providing information about a person's wishes to their families, caregivers, and their healthcare providers. However, it has been argued that autonomy should not be the only ethical principle considered when it comes to decision-making about end-of-life as this may not be of highest priority for all people and some may prefer not to bear the responsibility for choices at end-of-life (Winzelberg, Hanson, & Tulsky, 2005). The authors suggest that exploration of an individual's beliefs and values about autonomy should be included in the ACP process.

ACP is commonly considered a multi-component process as opposed to a single event such as having a conversation with a physician or signing a legal document. In a systematic review, ACP interventions including multiple components have been associated with fewer hospital admissions and greater adherence to a person's wishes when compared to interventions only including completion of legal documents (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). One qualitative study revealed that family members placed a high value on comprehensive ACP compared to only completing legal documents (Saini et al., 2016). Robins-Browne, Palmer, and Komersaroff (2014) note that although ACP is often promoted as an "unequivocal good" (p. 957), there is a risk that completing legal documents can become routine and "another box to be ticked" (p. 958) thereby obscuring the complexities of this process.

ACP is often defined as comprising three main components: learning about key conditions and situations necessitating care, weighing the options regarding care, and documenting wishes either through discussions or, preferably, in writing (Gillick, 1995; Hammes, 2001). Bomba (2005), has further broken down the ACP process to include 5 components: 1) becoming educated about ACP; 2) exploring your values, goals, and beliefs, particularly as they relate to healthcare and quality of life; 3) understanding the role of and choosing a substitute decision-maker (including discussing this choice with family); 4) becoming educated about situations commonly encountered at end-of-life (e.g., CPR, use of a feeding tube); and 5) making practical arrangements to document your wishes. Importantly, this process should be revisited periodically as goals of care often change based on our situations in life, including development of chronic and life-limiting illness (Bomba, 2005). These five components often occur simultaneously, though in many situations people engage in only a subset of these elements.

A qualitative study by McMahan, Knight, Fried, and Sudore (2013) further highlighted key components of a multifaceted ACP process through focus groups with individuals needing to make complex medical decisions and with substitute decision-makers. Participants identified the following components of the decision-making process: clarifying a person’s values and beliefs, based on their individual history and their views on quality of life, engaging a substitute decision-maker in the ACP process to ensure they understand their role and responsibilities, exploring the role of substitute decision-makers’ decisional power in unexpected situations, and relaying their wishes to other family members or friends. It has been further suggested that ACP should include exploration of both general goals for end-of-life as well as exploration of preferences for specific treatments as these may not always align (i.e., artificial nutrition, mechanical respiration, etc.) (Evans, Pasman, Deeg, & Onwuteaka-Philipsen, 2014). The need for education about the realities of specific treatments was highlighted by Adams and Snedden (2006) in a study of older adults’ expectations of survival rates following cardiopulmonary resuscitation. In their study, most participants believed their chance of survival was at least 50%, which is significantly higher than survival rates from clinical studies. The authors concluded that many older adults have an inaccurate understanding about CPR and improved education is needed to bridge this gap during the process of ACP. Malpas (2011) cautions that ageist attitudes and stereotypes of older adults as overusing healthcare resources must be kept in mind when engaging in ACP as older adults could be encouraged to forgo medical procedures in their ADs as a means of reducing healthcare costs.

Although ACP is garnering more attention, an online survey of Canadian attitudes towards ACP revealed that only a minority of the sample (16%) were aware of the term ‘advance care planning’, though a much larger proportion were actively engaged in some component of ACP (Teixeira et al., 2015). Further, participants tended to discuss ACP issues more with friends and family rather than with healthcare professionals. A study of older adults in acute care hospitals across Canada revealed that although a large proportion of older adults had had discussion about their preferences for end-of-life care with another person, only a small number had had such conversations with a healthcare provider (Heyland et al., 2013). Among the entire sample, almost half had created an AD or a written advance care plan and 72.1% had identified a substitute decision-maker. However, there was a high level of discordance between patients’ stated care goals and those that were documented in the medical record. Importantly, only a quarter of the patients in the sample reported that the hospital medical team asked about ACP on admission. A large-scale national study of Canadian older adults revealed that most of the sample (83%) had considered who would be a substitute decision-maker and over half the sample had discussed preferences for care with another person (Garrett, Tuokko, Stajduhar, Lindsay, & Buehler, 2008). However, only a third of the overall sample had created an AD. The authors found a positive association between thinking about end-of-life preferences or discussing these preferences with someone and completing an AD, suggestive of a stepwise approach to ACP.

Advance care planning in British Columbia

One of the most commonly researched aspects of the ACP process is the completion of legal documents, which is intrinsically tied to the legal system of the area in which an individual resides. In British Columbia, several legal acts, the Health Care (Consent) and Care Facility (Admission) Act, the Power of Attorney Act, the Representation Agreement Act, and the Adult Guardianship Act, were amended in 2013 to reflect changes in legal aspects of ACP, as described below. Several choices of legal documents regarding healthcare and personal decisions are available in British Columbia and in all cases, adults are asked to document their beliefs and values to be used to guide future decisions. These changes to the legal aspects of planning for care at the end-of-life, particularly the creation of relatively easy-to-complete legal documents, address many of the problems that faced British Columbians prior to their revision. However, it is important to note that creation of legal documents is but one aspect of the complex ACP process.

Two types of Representation Agreements exist in British Columbia (British Columbia Ministry of Health, 2013). In the first, the Standard Agreement (Section 7), adults can name a representative to make common healthcare, personal, and financial decisions on their behalf (Representation Agreement Act, 1996). However, this representative is not sanctioned to make decisions regarding refusal of treatments to preserve life unilaterally and there must be consensus from the adult’s family members and healthcare providers to make these types of decisions. People with lower levels of capacity can complete a Standard Agreement and are thereby able to engage in planning for their future healthcare decisions. There also exists an Enhanced Agreement (Section 9) in which the named representative can make all decisions regarding medical treatment, up to and including decisions regarding life support, but cannot make financial decisions on someone's behalf (Representation Agreement Act, 1996). Adults with compromised cognitive abilities who are deemed not capable of understanding the consequences of such an agreement may not complete an Enhanced Agreement. People who complete an Enhanced Agreement can also complete an Enduring Power of Attorney (EPoA) which allows for the selection of a representative to make financial decisions but not medical decisions.

If adults choose to not name a representative to make decisions on their behalf, a temporary substitute decision-maker (TSDM) will be selected in a standard prescribed order. The order of substitute decision-makers has been determined by law in British Columbia and is as follows: spouse, adult child (birth order not taken into consideration), parent (biological or adoptive), sibling (birth order not taken into consideration), grandparent, grandchild (birth order not considered), other family members, a close friend, and a person immediately related by marriage. A healthcare provider will select the highest person on that list who is at least 19 years old, is capable of making decisions, does not have conflict with the person who requires a TSDM, and has been in contact with the person requiring a TSDM in the past year.

Adults can also choose to complete an AD in which specific preferences regarding healthcare treatments, including refusal for life support, are laid forth for healthcare providers. In these situations, if the decision needing to be made is not covered in the AD, a TDSM will be appointed if a Representation Agreement is not also in place.

Following legislative changes effective September 1, 2011, The Public Guardian and Trustee released a guide for personal planning should a person become incapable of making decisions for themselves titled *Its Your Choice – Personal Planning Tools* (Public Guardian and Trustee of British Columbia, 2011). In 2013, the BC Ministry of Health also published a guide for advance care planning titled *My Voice – Expressing My Wishes for Future Health Care Treatment* (British Columbia Ministry of Health, 2013). This workbook provides an overview of the ACP process, information about legal documents that can be created as part of the ACP process, and templates for the various legal documents.

Medical assistance in dying (MAiD)

During the course of the present study, major legal changes arose regarding Canadians' rights to medical assistance in dying (MAiD) with the introduction of Bill C-14 (2016). The legalization of physician-assisted death is in line with policies in several other countries including Belgium, the Netherlands, and Luxembourg, as well as several states in the United States (Oregon, Washington, Montana, New Mexico, and Vermont) (Attaran, 2015). The most recent data indicates that between December 10, 2015 and December 31, 2017, 3714 people received MAiD in the Canadian provinces (data from the Yukon, Northwest Territories, and Nunavut are not available; Health Canada, 2018). Considering the relationship between MAiD and issues at the end-of-life, I will briefly discuss the history of MAiD, key tenets of Bill C-14, and recent research since its implementation.

Notable legal cases leading up to the introduction of Bill C-14 include *Rodriguez v. British Columbia* (1993) and *Carter v. Canada* (2015). In *Rodriguez vs. British Columbia* (1993) the plaintiff, a woman with amyotrophic lateral sclerosis (ALS), challenged the Canadian constitutional ban on assisted suicide due to fears that she would be unable to commit suicide in the future when her disease progressed to a point where she was physically unable to do so. Ms. Rodriguez's petition was denied by a judge in British Columbia and this ruling was later upheld by the Supreme Court of Canada in a 5-4 ruling. Milton (1995), an attorney who worked on this case, opined that this case brought to light the issue of appropriate medical treatment for people with terminal illness experiencing significant suffering and that further discussion on this matter was warranted.

In *Carter v. Canada* (2015), a woman with spinal stenosis that she considered intolerable received physician-assisted death in Switzerland with the help of her family, who were then concerned about being prosecuted in Canada for their role in this issue. Therefore, they challenged the provisions on physician-assisted suicide in the Canadian Criminal Code. The judge found for the plaintiff and noted that complete prohibition of assisted suicide infringed on people's rights to autonomy. This led to the development of Bill C-14 (2016), which was assented to on June 17, 2016 by the Parliament of Canada. In this bill, MAiD is defined as follows:

> The administration by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death (p. 5).

Several criteria are outlined in terms of eligibility for MAiD: the person is eligible or will soon be eligible for health services in Canada, the person is at least 18 years old and is capable of making his/her own healthcare decisions, the person has a "grievous and irremediable medical condition”, he/she has voluntarily made a request for MAiD without any external pressure, and he/she provides informed consent for MAiD. In terms of assessing whether a condition is grievous and irremediable, Bill C-14 stipulates that the disease/disability must be serious and uncurable, that the person has experienced severe, irreversible decline in capability, that the disease/disability is causing intolerable physical or psychological suffering, and that their death is now reasonably foreseeable (a specific length of time prior to death does not need to be identified). The MAiD process involves the person providing a written request for MAiD (co-signed by two independent witnesses) and confirmation by independent healthcare providers that the person meets all criteria listed above. There is then a ten-day waiting period from the date the request was signed until MAiD can be provided, though this can be shortened dependent on the circumstances and imminence of death.

Given this framework, people with mental disorders who do not also have a grievous and irremediable physical disorder are excluded from participating in MAiD. Additionally, ADs may not include requests for MAiD. Therefore, people with cognitive impairment resulting from dementia are precluded from participating on the basis that they are not capable of providing consent. It has been argued, however, that people should have the right to request assisted death in their ADs, particularly for people with severe dementia who may experience significant suffering (Menzel & Steinbock, 2013).

Supporters of MAiD have argued that allowing people to choose the timing of their death is not an act of suicide, but rather an expression of autonomy and self-determination (Karsoho, Wright, Macdonald, & Fishman, 2017). Trachtenberg and Manns (2017) modeled the cost savings of implementing MAiD in Ontario based on data available from the Netherlands and Belgium, where this type of legislation has been in place for quite some time. The authors stated that if Canada were to have similar rates of uptake as those found in the Netherlands and in Belgium, there could be significant healthcare cost savings, even considering expenditures needed to offer MAiD. However, they caution that their models are limited until there is sufficient Canadian data on MAiD to more accurately assess the financial impacts of MAiD and they strongly note that MAiD should not be used as a cost-cutting initiative.

Recent studies have explored healthcare providers' views on MAiD. Karesa and McBride (2016) completed an online survey of Canadian psychologists' opinions on MAiD shortly after the *Carter v. Canada* (2015) ruling which revealed that a clear majority of psychologists supported MAiD. Although just over half the sample (52.5%) was willing to professionally support a request for MAiD for a client with a terminal illness, only 10.8% were willing to support such a request from a client with a mental illness. A more recent survey of psychologists completed by the Canadian Psychological Association's Task Force on End-of-Life examined psychologists' views on the current MAiD legislation as well as their views on extension of MAiD to include people with other medical and/or mental health conditions (Canadian Psychological Association, 2018). A majority of psychologists (72.3%) supported the existing MAiD legislation and a similar proportion supported extension of MAiD to people with dementia (68.3%). Support for extending MAiD to people with dementia was significantly higher than support for extending MAiD to other circumstances including permanent physical disability, chronic mental disorder or mature minors. Similar responses were gleaned from a survey of Canadian psychiatrists, with 72% of the sample supportive of MAiD and only 24.9% supportive of MAiD for people with a mental illness (Rousseau, Turner, Chochinov, Enns, & Sareen, 2017). Most Canadian medical students were supportive of MAiD following the passing of Bill C-14 (Bator, Philpott, & Costa, 2017). The primary reason for supporting MAiD was to assist patients in maintaining autonomy. The students highlighted the need for training in several areas related to MAiD, including medical-legal aspects, technical aspects, and communication.

However, the introduction of this legislation has not been without controversy, with one critic stating that "Canada went from a nation in which assisted suicide was a federal crime to a nation enacting one of the most radical euthanasia legalization regimes in the world" (Smith, 2016, p.44). Opponents have argued that MAiD may begin a slippery slope toward inappropriate and unethical killing of vulnerable people, though debate on this matter is ongoing (Downie, 2016; Downie & Bern, 2008; Schafer, 2013). Tanuseputro (2017) argued that we should focus on strategies to minimize suffering and highlighted the importance of increased access to palliative care to reduce requests for MAiD. Palliative care has been defined by the World Health Organization (2002) as follows:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (p. 84)

Although MAiD and palliative care are both approaches to respecting wishes at end-of-life for people with terminal illness, a key difference is that palliative care does not aim to hasten death, while MAiD is specifically designed to end one's life. However, it has been claimed that the principles underlying MAiD do not contradict the principles underlying palliative care as they both claim to support patient autonomy and the avoidance of unnecessary suffering (Morrison, 2017). It is further speculated that these two approaches may be used concurrently with certain patients.

Advance care planning among cognitively intact older adults

There are many well-noted benefits of engaging in ACP for older adults. In large-scale studies, ACP has been shown to be associated with fewer in-hospital deaths and improved quality of care received at the end-of-life (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013) as well as healthcare system cost savings (O'Sullivan et al., 2016). It has been suggested that engagement in ACP can mitigate the overuse of medical interventions such as use of feeding tubes (Monturo & Strumpf, 2007). Retrospective chart reviews indicate that there is a high consistency between patients' documented wishes for end-of-life care and the treatment that occurred at end-of-life (Hickman et al., 2011). This suggests that documenting wishes for end-of-life treatment, a component of ACP, is a valuable method of ensuring that a person receives the type of care they prefer.

Older adults have emphasized the importance of ACP in providing guidance for family members to make decisions on their behalf and in decreasing the decision-making burden on families (Seymour, Gott, Bellamy, Ahmedazi, & Clark, 2004). In a randomised controlled study of cognitively intact older adults in a university hospital in Melbourne, Australia patients in the intervention group received usual care plus facilitated ACP from a trained facilitator using a well-established program (Detering, Hancock, Reade, & Silvester, 2010). Among the intervention group, most people for whom preferences for end-of-life were known (92%) were considered to have had their wishes respected based on review of their medical charts. Further, the family members of patients in the intervention were said to have reduced "emotional trauma"

(Detering et al., 2010, p. 6), with a significant reduction in symptoms of post-traumatic stress, anxiety, and depression. Given the inherent difficulties in coping with the death of a loved one, this reduction in risk of developing serious symptoms of several mental health problems is important.

In a metasynthesis investigating quality of end-of-life care for cognitively intact older adults, as perceived by their family members, several themes emerged (Jackson et al., 2012). Quality of death was frequently viewed as high when families believed that their loved one died comfortably and when they believed that high-quality and compassionate care was provided. More negative evaluations of the quality of the death occurred in response to poor transitions in care (e.g., admissions to acute care viewed as inappropriate by family members) and especially poor communication with healthcare providers, both regarding prognosis and regarding end-of-life care. Of interest, families noted a strong need for open communication with healthcare providers when making decisions for loved ones to feel well informed and ensure that pain and suffering was minimized. Sudore, Casarett, Smith, Richardson, and Ersek (2014) reported that older veterans whose family members were involved at the end-of-life were more likely to receive palliative care consultations and have DNR orders compared to older veterans whose families were not involved. However, a recent meta-synthesis of studies evaluating factors that impact family members' perception of the quality of death of a loved one, that is, whether the death was considered 'good', noted that there was little focus on the role of ACP (Tenzek & Depner, 2017).

A systematic review of studies of ACP with frail or older adults without major medical diagnoses revealed that although most older adults were interested in having conversations about end-of-life care with health professionals, only a small minority were given this opportunity

(Sharp, Moran, Kuhn, & Barclay, 2013). Additionally, a large-scale survey of older adults in the East Midlands (UK) revealed that although a third of the sample was interested in exploring ACP with their family physician, only 17% had created some form of advance care plan (Musa, Seymour, Narayanasmy, Wada, & Conroy, 2015). The best predictor of having created a plan was having an opportunity to discuss ACP with a medical professional but less than 5% of the entire sample had had such an opportunity. This is unfortunate given evidence that suggests that older adults were more likely to have completed ADs if these were requested by healthcare providers and if they were explained by the healthcare provider (Alano et al., 2010).

Despite significant benefits to engagement in ACP, it has been suggested that healthcare practitioners, particularly physicians, may be hesitant in initiating ACP-related discussions with their patients. A survey of family physicians in Ontario revealed that although a clear majority (86%) supported the use of ADs, only a minority regularly completed these forms with their patients (Hughes & Singer, 1992). A systematic review by de Vleminck et al. (2013) identified several barriers to engagement in ACP including physician characteristics, such as perceived deficit in skillset regarding ACP and beliefs that it is not the role of the physician to discuss ACP. A study of older adults with serious chronic health conditions (not including dementia) revealed increased satisfaction with their primary care physician following discussion of ADs (Tierney et al., 2001). Further, the older adults reported even greater satisfaction with the appointment with their primary care physicians, suggesting that although some physicians may hesitate to bring up the topic of ACP, this may strengthen the patient-physician relationship.

The issue of which healthcare provider is best suited to engage patients in ACP is one that has not been resolved. Studies suggest that although clinicians consider ACP to be of great value, it is often not occurring in a systematic manner with great uncertainty about division of responsibility among members of multidisciplinary teams (Arnett et al., 2017). Most of the survey respondents agreed that non-physicians could be involved in the ACP process but that additional training was needed for this to occur. Canadian healthcare providers in a variety of disciplines similarly reported uncertainty if ACP was within the scope of practice for their discipline (Ho, Jameson, & Pavlish, 2016). The authors argue that these issues are further affected by the traditionally hierarchical structure in medical settings and suggest that collaboration between different disciplines, which can draw on the unique expertise of each discipline, may be key in providing a better approach to engaging patients in ACP.

Physicians have also noted perceived patient characteristics as a barrier to engaging in ACP, including fear of causing a patient to lose hope, patient denial of the severity of their own illness (de Vleminck et al., 2013), and physician discomfort discussing death and dying (Ho et al., 2016). Physicians also noted difficulties ascertaining the right moment to introduce the topic of end-of-life care as well as beliefs that patients themselves should have the onus to initiate ACP. A study of family physicians in Australia revealed that physicians were less likely to engage in ACP with patients with whom they had poor relationships (Sinclair, Gates, Evans, & Auret, 2016). They were more likely to initiate ACP with patients with limited social supports, suggesting that a wide range of psychosocial variables affect physician likelihood of engaging in ACP with their patients.

Several other patient characteristics affecting likelihood of engaging in ACP have been explored through studies of patients themselves. Dispositional factors have been suggested as a facilitator of ACP, including a lifelong preference for planning (Samsi & Manthorpe, 2011). In a study of decisional control, Chiu, Feuz, McMahan, Miao, and Sudore (2016) found that a fifth of their sample of older adults preferred for their physicians to make medical decisions on their behalf. However, this group did not differ in likelihood of previously engaging in ACP compared to older adults who preferred to share decision-making control with their physician or those who preferred to make all their decisions independently. A significant minority of participants in one study reported that they absolutely would not want to have these conversations, due to family members being unwilling to discuss end-of-life care, fears of negative emotions that could arise during conversations, or expectations that family members, physicians, or God would take care of them (Sharp et al., 2013). Other factors impacting likelihood of engaging in ACP include attitudes towards death (death seen as negative, positive, or neutral) and a person's religious beliefs (Lynn, Curtis, & Lagerwey, 2016).

Finally, healthcare system characteristics, including limited resources in primary care, have been identified as barriers to ACP (de Vleminck et al., 2013). However, in a survey of primary care nurses in New South Wales, most participants indicated that ACP discussions are more suited to a community environment (Fan & Rhee, 2017). A large study of hospitalized unwell Canadian older adults assessed the congruence between patients and family members' wishes for life-sustaining treatment and documented orders in the patients' charts (Heyland, Ilan, Jiang, You, & Dodek, 2016). Alarmingly, over a third of the sample had a medical error, with more patients potentially being overtreated (patient does not want CPR, but their chart indicates that they should receive it) than being undertreated (patient wants CPR but their chart indicates that they should not receive it). Patients without family members involved in their care were more likely to be potentially overtreated. The authors argue that there is significant risk of harm due to overtreatment as this contradicts the patient's autonomy and goes against the principles of patient-centred care.

Transtheoretical model of behaviour change. The goal of understanding why people choose to engage in ACP has been investigated among healthy older adults under the framework of the Transtheoretical Model (TTM) of behaviour change. The TTM was originally proposed by Prochaska and Velicer (1997) to describe changes in health behaviours and was initially used with smoking cessation and latter applied to substance abuse, eating disorders, prevention of HIV/AIDS, medication compliance, and many other areas. The crux of the TTM is that change in health behaviours occurs over time and that people move through stages in a specified order in the journey towards behaviour change. Aspects of the TTM that are relevant to the process of ACP are described below.

In the first stage, precontemplation, people are not planning on making any change in the next six months, possibly because they do not understand the consequences of their current behaviour. They may be viewed as resistant or unmotivated for change by healthcare professionals. In the second stage, contemplation, people are still not planning on making any change in the next six months but have become more aware of the benefits of change. However, the negative aspects associated with the change remain very strong and outweigh the benefits of change. Prochaska and Velicer (1997) described people in this stage as being in a state of “behavioral procrastination” (p. 39). The third stage, preparation, describes people who are planning to make change soon (loosely defined as the next month). People in this stage have thought about their behaviour and likely have a plan for how they will make changes. The fourth stage, action, describes the point at which people have made overt changes in their behaviour in the past six months. The threshold for moving into this stage is variable depending on the type of health behaviour that is being explored, which is often determined by experts in the field. The fifth stage, maintenance, can be thought of as the relapse-prevention phase. It is believed that the longer that a person is in the stage, the less likely they are to relapse. The final stage of the TTM, termination, describes the point at which people are not at all tempted to resume their problematic behaviour. This stage is not used in studies of ACP as this does not apply in this type of behavior change. Of note, it is not expected that people move in a linear manner through the stages, but rather that they move forward and back through stages, thus the stages are often visualized as a spiral (Redding, Rossi, Rossi, Velicer, & Prochaska, 2000).

Another set of important concepts in the TTM are the processes of change (Prochaska, DiClemente, & Norcross, 1992), that is, the “covert and overt activities that people use to progress through the stages” (Prochaska & Velicer, 1997 p.39). Ten processes of change were defined in their work; however, only five will be described here as these have been found to be applicable to the behaviour change seen in ACP (Fried et al., 2012). Consciousness raising refers to increased awareness of the consequences of a problematic behaviour and includes interventions such as education campaigns and receiving feedback from healthcare professionals. Self-reevaluation refers to a person’s self-assessment of themselves with and without the problem behaviour and includes value clarification. Helping relationships refers to receiving support and acceptance from others in the process of behaviour change and can be found in the therapeutic alliance and other forms of social support. Stimulus control refers to the removal of cues for the problem behaviour and introduction of prompts for the target behaviour. Finally, self-liberation refers to the belief in one’s own ability to change and the commitment to making that change.

A key component of the TTM is decisional balance, which refers to a person’s weighing of the pros and cons of continuing the problem behaviour versus changing their behaviour. Prochaska and Velicer (1997) argue that for a person to move through the stages, the relative weights of the pros and cons must change. For example, the pros of changing the behaviour must increase for people to move from the precontemplation stage to the contemplation stage. Additionally, the cons of changing the behaviour must decrease for a person to move from the contemplation phase to the action phase. The concepts of self-efficacy (confidence that a person can continue with their healthy behaviour in a high risk situation) and temptation (intensity of the urge to revert back to the problem behaviour when in difficult situation or to keep changing one's mind) will not be explored in detail here as they are not as relevant to the application of the TTM to ACP.

Pearlman, Cole, Patrick, Starks, and Cain (1995) were the first to suggest that use of the TTM may increase effectiveness of ACP and found preliminary evidence for their thesis in a subsequent study (Pearlman, Starks, Cain, & Cole, 2005). Two studies assessed the applicability of the TTM to a single ACP behaviour – completion of an AD – and found support for its applicability (Finnell et al., 2011; Medvene, Base, Patrick, & Wescott, 2007). However, Medvene and colleagues (2007) noted difficulty distinguishing between the action and maintenance phases as completion of legal documents does not involve ongoing change after the documents are signed, therefore these phases are often combined when this model is applied to ACP.

In other studies, the TTM was applied to a more comprehensive set of ACP behaviours. Sudore and colleagues (2008) suggested that people may engage in ACP through a set of discrete steps, moving from contemplation (considering engaging in ACP) to action (discussing wishes with family, friends, or healthcare providers and/or creating legal documents). Given the nature of the data collected in this study, Sudore and colleagues (2008) were unable to gain insight into the pre-contemplation, preparation, and maintenance stages, as well as the underlying reasons why participants chose to engage in certain aspects of the ACP process and not others. A later study revealed that participants exhibited a wide range of readiness to engage in ACP indicative of the different stages of behaviour change in the model (e.g., precontemplation to action), providing support for the importance of assessing readiness to engage in each aspect of ACP, rather than looking at readiness for ACP as a single construct (Fried et al., 2009).

Factors that positively influenced a person's choice to engage in ACP included decreasing the burden on family, wanting to make sure that wishes are met, and attempting to decrease the likelihood of family discord (Fried et al., 2009). In a follow-up study, the authors found that people in later stages of the TTM (i.e., ready to engage in ACP or already engaged in ACP) had greater knowledge and understanding of legal documents related to end-of-life, that is, ADs (Fried et al., 2010). Of great interest, studies of community-dwelling older adults found that those who had had experiences with end-of-life care or substitute decision-making for others were readier to themselves engage in aspects of ACP (Amjad, Towle, & Fried, 2014; Fried et al., 2009; Fried et al., 2010). Participants who believed a loved one experienced a "bad" death due to insufficient medical care were in a higher state of readiness for engaging in ACP (Amjad et al., 2014). Perhaps surprisingly, having personal experience with serious illness was not associated with increased likelihood of engaging in ACP. The authors suggest that factors such as well-publicized media cases regarding ACP (e.g., Terri Schiavo) and experiencing a "bad" death of a loved one may be particularly salient in influencing a person's decision to engage in ACP, though further evidence is needed to confirm this postulation.

Schickedanz and colleagues (2009) explored barriers to engagement in four components of ACP (contemplating wishes for end-of-life care, discussing ACP with family and friends, discussing ACP with their family physician, and creating an AD) after an intervention that included reviewing ADs. The most prevalent barrier to engagement in each step of the ACP process was belief that ACP was not relevant to the person's situation. Additional barriers that were common across steps in the ACP included personal barriers (becoming upset by the process, not having time to address ACP, etc.) and lack of information about ACP. Participants who did not discuss their wishes with family or friends also noted relational barriers, including difficult family dynamics and worries about becoming a burden. Those who did not discuss ACP with their physician identified time constraint in the patient-physician relationship as a major barrier. Participants reported difficulty with the AD form as a barrier to completion of legal documents outlining ACP.

Cognitively impaired older adults

While it is widely believed that ACP is of importance to all adults, irrespective of age or health status, it can be argued that it is of particular salience for those with diagnosed cognitive impairment or dementia given their likelihood of requiring substitute decision-making in later phases of the disease. People with dementia often have multiple comorbidities and increased risk of hospitalization, including admissions to the emergency department (Griffith et al., 2016; Mondor et al., 2017). Older adults with advanced dementia also often face medical complications such as infections and eating problems (Mitchell et al., 2009). Below I discuss the definition of dementia, issues providing quality care at the end-of-life in this population, the impact of dementia on caregivers, and the current state of the research on ACP with people with dementia.

Dementia. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) overhauled the labeling and diagnostic criteria for dementia, instead including it as Major Neurocognitive Disorder (MND). The term

MND is broad and encompasses several disorders that are not presumed to lead to progressive cognitive decline, such as traumatic brain injury. However, the focus in the current study is on neurodegenerative disorders causing progressive cognitive and functional decline subsumed under the term ‘dementia’. The diagnostic criteria include evidence of significant cognitive decline in one or more cognitive domains (i.e., learning and memory, language, executive functioning, complex attention, perceptual-motor, or social cognition) based on self- or informant-report as well as clinical assessment, preferably completed by a neuropsychologist (American Psychiatric Association, 2013; Ngo & Holroyd-Leduc, 2015; Salmon & Bondi, 2009). People with MND typically score at least two standard deviations below the age- and education-adjusted norms on cognitive tests in the affected domains. Functional impairment related to the cognitive decline, particularly with instrumental activities of daily living such as paying bills or managing medications, is the next diagnostic criterion. The DSM-5 further notes that these deficits should not occur solely in the context of a delirium and should not be better explained by another mental disorder. Murray, Kendall, Boyd, and Sheikh (2005) identified the trajectory of decline among people with dementia as “prolonged dwindling” (p. 1008) with gradual cognitive and physical decline with a variable timeframe prior to death.

The MND is then assigned a subtype based on known or assumed etiology. For example, the most common subtype is MND due to Alzheimer’s disease. Probable Alzheimer’s disease is diagnosed if there is evidence of genetic mutation causing Alzheimer’s from family history or from genetic testing or if there is clear evidence of decline in memory and learning as well as at least one other cognitive domain, the decline is steady and gradual, and there is no evidence of mixed etiology. If these criteria are not met, people are diagnosed with possible Alzheimer’s disease. Other types of MND include Major Frontotemporal Neurocognitive Disorder (gradual onset of behavioural and personality change and/or language impairment with relatively little impairment in learning and memory), MND with Lewy Bodies (fluctuating cognitive impairment, particularly in complex attention and executive functioning, visual hallucinations, and parkinsonian features beginning after the onset of cognitive decline), Major Vascular Neurocognitive Disorder (presence of cardiovascular disease and decline in complex attention and executive functioning), and MND due to Multiple Etiologies (evidence for multiple etiologies resulting in cognitive and functional decline). Despite this new nomenclature, the term 'dementia' is still in common usage both among laypeople and in the medical community and will therefore be used in this study.

Estimates of the prevalence of dementia in Canada vary, but one study reported that 45% of people over the age of 45 residing in long-term care facilities were diagnosed with dementia, with prevalence increasing with age (Wong, Gilmour, & Ramage-Morin, 2016). A report by the Public Health Agency of Canada (2014) estimated that the prevalence of dementia among older adults (age 65 an older) living in the community and in long-term care facilities in British Columbia between 2010 and 2011 was 7594.6 per 100 000 population. This report also highlighted that healthcare costs for people with dementia were three times as high as healthcare costs for age-matched peers who did not have dementia. Further, it was noted that this is likely an underestimate of the financial impact of dementia due to difficulty capturing indirect costs such long-term disability payments and income lost due to not being at work (Public Health Agency of Canada, 2014). A simulation of dementia prevalence in Canada estimated that, compared to data from 2011, the number of people with dementia will double to approximately 674 000 (Manuel et al., 2016) while an estimate based on data from the Canadian Study on Health and Aging suggest that the number may be even higher – 937 000 (Alzheimer Society of

Canada, 2016). Further, the model estimated that the healthcare costs associated with dementia are also expected to double by the year 2031. This may be an underestimate of the true extent of the disease given that many people with cognitive impairment may not be diagnosed with dementia, possibly because they don't meet diagnostic criteria or because they have not been fully assessed and diagnosed (Bartfay, Bartfay, & Gorey, 2013).

Care at the end-of-life. Several unique challenges in providing end-of-life care in this population have been identified. Among the most clinically challenging issues is uncertainty regarding the classification of dementia as a terminal illness and its complex death trajectory, which differs greatly from those of other life-limiting illnesses such as cancer or congestive heart failure (Ryan, Amen, & McKeown, 2017; Sachs, Shega, & Cox-Hayley, 2004; Sarabia-Cobo, Pérez, de Lorena, Nuñez, & Domínguez, 2016; Thuné-Boyle et al., 2010). Given the lack of cure for people with dementia, it has been suggested that a palliative approach with an emphasis on quality of life, identifying the patient's goals, and working collaboratively with the family should be employed (Arcand, 2015; Merel, DeMers, & Vig, 2014; Oliver & Silber, 2013; Pinzon et al., 2013; van der Steen et al., 2014a;). A secondary benefit of employing a palliative approach in dementia is the potential healthcare cost savings associated with increased palliative care in this population (Araw et al., 2015).

A knowledge synthesis of key components of the palliative approach was undertaken by Sawatzky and colleagues (2016), who identified three key characteristics of a palliative approach. First, the needs of patients and families should be addressed early in the illness trajectory, perhaps even beginning at time of diagnosis of a chronic life-limiting illness. Sawatzky and colleagues (2016) noted that due to the uncertain prognosis and variable illness trajectory for people with dementia, it is of great importance to address end-of-life needs early in the disease process and continue to review these needs throughout the illness trajectory while emphasizing quality of life as a main goal. The authors argue that early identification of end-of-life care needs for people with life-limiting illness can facilitate ACP among patients and their families. This is consistent with previous work suggesting that ACP is a key component of a palliative approach for people with dementia and should commence within the first two years following diagnosis (Lawrence, Samsi, Murray, Harari, & Banerjee, 2011; Merel et al., 2014). The second characteristic of a palliative approach is that knowledge and expertise from palliative care should be adapted to meet the needs of different patient groups (Sawatzky et al., 2016). For example, older adults with dementia and their family members may not be aware that dementia is a life-limiting illness and therefore discussions related to ACP may need to be adapted to be sensitive to this misunderstanding. Finally, Sawatzy and colleagues (2016) highlight that the palliative approach requires integration within a healthcare system and among a variety of healthcare providers.

A qualitative study examining factors impacting family and healthcare providers' perspectives on good deaths for people with dementia suggested that "there is a need to 'dementia-proof' end-of-life care for people with dementia" (Lawrence et al., 2011, p. 420) by taking into account the unique needs of older adults with dementia in order to provide high-quality care at the end-of-life. Several crucial components to providing care that led to a good death have been identified, including providing care to meet the physical needs of people in the context of challenges due to decreased cognitive functioning and communication barriers, providing holistic care including addressing psychosocial aspects of functioning, and communication with family members (Davies, Rait, Maio, & Iliffe, 2017; Lawrence et al., 2011). A recent exploration of expert views on factors essential in delivering high-quality end-of-life care to people with dementia in England identified continuity and coordination of care as well as integration of palliative care services into other care settings as being of the utmost importance (Lee, Bamford, Exley, & Robinson, 2015).

Goodman, Froggat, Amador, Mathie, and Mayrhofer (2015) suggested three areas of uncertainty in providing effective end-of-life care for people with dementia who are dying in care facilities: treatment uncertainty (managing differing dying trajectories, making treatment decisions, etc.), relational uncertainty (identifying roles and responsibilities of healthcare providers, both within and outside of the care facility, and family members), and service uncertainty (organization-level factors, including availability of care facilities and palliative care). A survey of family physicians in Northern Ireland identified several additional barriers to provision of palliative care in dementia, the most frequent of which was a lack of knowledge about dementia among the healthcare providers, the family members, and the public (Carter, van der Steen, Galway, & Brazil, 2017; Robinson et al., 2014). Another potential barrier to quality care is conflict between family members' wishes and standardized approaches to care within an organization, particularly in acute care (Davies et al., 2017).

Although palliative approaches have been heavily emphasized as being valuable in this population, evidence suggests that people with dementia are less frequently referred for formalized palliative care services (Sampson, Gould, Lee, & Blanchard, 2006). Epstein-Lubow, Fulton, Marino, and Teno (2015) completed a large American study of discharge location for older adults with dementia in the last 90 days of life following inpatient psychiatric treatment who were previously residing in nursing homes. The authors found that only a very small minority (8.7%) were referred to hospice services, suggesting that hospice services may be underutilized in this population. Of note, in many states, hospice admission requires determination by a healthcare provider that a person’s life expectancy is six months or less, which is extremely challenging to determine for people with dementia (Brickner, Scannell, Marquet, & Ackerson, 2004; McCarty & Volicer, 2009). Additionally, a population-level study of decedents in Ontario supported the notion that people with dementia are less likely to receive palliative care across all health sectors (Tanuseputro, Budhwani, Bai, & Wodchis, 2017). A study of critical decisions for people with advanced dementia in Italy suggested that decisions were often made to prolong life and were contrary to general principles of palliative care (Toscani et al., 2015). The authors argued that this may reflect the fact that some healthcare providers do not view dementia as a terminal illness.

Aside from palliative care services, people with dementia may have less access to other healthcare resources. A study of British Columbians newly diagnosed with dementia revealed that people diagnosed at an older age were less likely to receive a brief counselling session primarily consisting of psychoeducation and were also less likely to be referred to specialists such as geriatricians and neurologists (Sivananthan, Laverge, & McGrail, 2015). The authors also found that older adults with higher incomes were more likely to receive counselling sessions and specialist referrals compared to their lower income peers, suggestive of inequality in resource distribution.

People with dementia often experience multiple transitions in care in the year following diagnosis (Sivananthan & McGrail, 2016) and even among those with moderate-to-severe dementia (Callahan et al., 2015). This is of great importance given recent studies reporting that older adults who die in care facilities or at home tend to have more comfortable deaths compared to those who die in hospital, irrespective of cognitive status (Fleming et al., 2017). A recent qualitative study examining challenges in decision-making among family members and healthcare providers of cognitively impaired older adults suggested that frequent changes in residence at the end-of-life may limit the ability of healthcare providers to fully understand the older adult's biopsychosocial history, which can increase the difficulty of decision-making (Lamahewa et al., 2018).

Impact on caregivers. Although dementia and the dying process most directly impacts the person with the diagnosis, there are also significant impacts on their families and caregivers. Most people with dementia (85%) received some form of support, either formally (through organizations) or informally (through friends or family). Among informal caregivers of older adults with dementia, most were either spouses or adult children (Wong et al., 2016). A British Columbia study of the well-being of caregivers of family members of people with dementia identified wives as the most vulnerable group of caregivers, with negative impacts on self-esteem and an experience of greater burden (Chappell, Dujela, & Smith, 2015).

Canadians with dementia tend to receive significantly more informal assistance, particularly with medical care, managing care (making appointments, managing finances, etc.), and transportation, than Canadians with other types of neurological conditions (Obembe, Goldsmith, Simpson, Sakakibara, & Eng, 2018). In comparison to caregivers of people that do not have dementia, those who provide caregiving for people with dementia spend more time providing support, experience more physical and emotional strain, and have greater family conflict (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Caregivers appear to be particularly negatively affected by neuropsychiatric symptoms, especially disruptive behaviours such as aggression and disinhibition (Cheng, 2017; Zhu et al., 2015).

Providing care for a person with dementia can increase risk of both physical (Richardson, Lee, Berg-Weger, & Grossberg, 2013; Roepke et al., 2012) and mental health problems, including depression and anxiety (Joling et al., 2010; Joling et al., 2015; Sallim, Sayampanthan, Cuttilan, & Ho, 2015). A population-based study of Canadian caregivers of people with various physical and/or mental health issues, revealed that a significant portion of the sample described experiencing at least one of the following negative consequences due to caregiving: less time spent on social activities, cancelling holiday plans, postponing educational or vocational training, moving in with the person receiving care, rejecting a job offer or promotion, or negative impact on the caregiver's health (Shooshtari, Duncan, Roger, Fast, & Han, 2017). Further, a longitudinal study of care recipient-caregiver dyads found that caregivers of people with dementia with more comorbidities and higher dependency had greater use of healthcare services themselves (Zhu et al., 2015). Additionally, caregivers with out-of-pocket expenses were significantly more likely to have experienced multiple negative consequences, which is of great concern given that most caregivers incur costs associated with this role.

Family members required to make decisions on behalf of an older adult who is no longer able to make decision for themselves may be unprepared to do so (Dening, Jones, & Sampson, 2013). Family members of people with moderate to advanced dementia expressed significant guilt and distress when making decisions regarding end-of-life for their family member, particularly regarding relocation to a care facility (Moore et al., 2017; Sarabia-Cobo et al., 2016). A prospective study exploring the experiences of caregivers of people with advanced dementia near end-of-life and post-death revealed that although caregiver burden was relatively low after their family member was placed into care, caregivers still reported a high degree of emotional distress, including depression, anxiety, and grief both prior and after the death of their loved one

(Moore et al., 2017). The authors suggested that ACP is a key component to managing caregiver burden as it can provide family members with insights on their loved one’s wishes.

Advance care planning. The British Columbia Ministry of Health (2012) identified promotion of ACP for older adults with cognitive impairment as a key component of early intervention for people with dementia. Authors of a study examining barriers to high quality care for people with dementia in the community also identified ACP as a key component to improve care by enabling people with dementia to have a voice in their care, even when they are deemed incapable of making decisions independently (Hirakawa et al., 2017). Due to the specific challenges faced by this population, including but not limited to, declining cognitive and functional abilities, one cannot assume that ACP among this group occurs as it does among cognitively intact older adults. A recent systematic review of the effectiveness of ACP on end-of-life care for people with dementia and their caregivers suggested that ACP may improve care and outcomes at end-of-life. However, strong conclusions are not possible at this time due to variability in components of ACP examined in studies, high variability of outcome measures, and an absence of evaluation of causal pathways (Dixon, Karagiannidou, & Knapp, 2018). The authors stressed the importance of further high-quality research in this area, noting the importance of examining process factors in ACP.

A prospective study of the decisions faced by people with dementia over the course of the illness identified four key areas in which decisions need to be made: daily activities (taking medications, driving, managing money, etc.), healthcare needs, role in the community (social engagement, living situation, etc.), and representation (choosing a substitute decision-maker, end-of-life decisions) (Groen-van de Ven et al., 2017). The authors further identified key events in the illness trajectory, including, among others, diagnosis, caregiver burnout, and admission to long-term care. They suggested that an understanding of the timing and types of decisions commonly encountered in this population can lend insight into issues that should be addressed in ACP. They further argue that knowledge about issues likely encountered by people with dementia can increase their sense of control and may help prepare for transitions in advance.

In a prospective study of people newly diagnosed with Mild Cognitive Impairment (cognitive decline without functional deficits) or Alzheimer's Disease attending a memory disorders clinic who had not yet engaged in ACP, only 39% went on to engage in ACP within the next five years (Garand et al., 2011). This suggests that receiving a diagnosis in and of itself may not be a sufficient motivator to engage in ACP. Similarly, Ho and colleagues (2017) reported a low rate of ACP engagement (11%) one year following psychoeducation sessions about ACP in a memory clinic in Singapore due to patient factors (poor understanding of ACP, reliance on family members to make decisions, etc.), process factors (little or no follow-up from healthcare providers), and/or family factors (family members not supportive of ACP).

In a previous study, we explored differences in engagement in aspects of ACP between cognitively impaired and cognitively intact older adults in the Canadian Study of Health and Aging (CSHA; Jeznach et al., 2015). While most of the participants in the CSHA had engaged in some aspects of ACP prior to death, differences between the two groups emerged in the likelihood of engagement in aspects of this process. Specifically, cognitively impaired older adults, relative to controls, were more likely to have arranged for a substitute decision-maker but were less likely to have discussed their preference for end-of-life care with others. We postulated that this discrepancy may be related to people's unease with discussing specific aspects of end-of-life care with others as opposed to simply naming someone to make decisions on their behalf.

Due to constraints of the quantitative data collected in the CSHA, we were unable to explore this hypothesis.

Among older adults with recently diagnosed MCI or mild dementia, those with more intact executive functioning abilities and those with higher education levels were more likely to engage in ACP (Tay, Davison, Jin, & Yap, 2015). This is not surprisingly given the complexities of the ACP process that requires learning and understanding new information about a diagnosis, weighing the benefits of different end-of-life options, and planning and organizing for later decisions. Ho and colleagues (2017) found that unmarried people with cognitive impairment were more likely to engage in ACP than their married peers possibly because they do not have as many family members who can take on decision-making roles in the future.

A study investigating the impact of an ACP intervention shortly after diagnosis of dementia suggested that the intervention was perceived as positive by people with dementia and their family members (Poppe, Burleigh, & Banerjee, 2013). A systematic review of the effectiveness of ACP interventions for cognitively impaired older adults provided some evidence of reduced inappropriate hospital admissions and overall healthcare costs in nursing homes that implemented ACP interventions (Robinson et al., 2012). Schonfeld, Stevens, Lampan, and Lyons' (2012) study indicated that patients and family members often view a dementia diagnosis as leading to a poor quality of life, which tended to make them more receptive to discussions regarding end-of-life care. However, a survey of physicians in the Netherlands and in the UK revealed high variability in physician belief that ACP should begin at the time of diagnosis, which was independent of country (van der Steen, Galway, Carter, & Brazil, 2016). Notably, physicians who believed their role included initiation of ACP also tended to agree that ACP should begin at the time of dementia diagnosis.

Gilissen and colleagues (2017) completed a systematic review of conditions necessary for effective implementation of ACP in nursing homes. The authors identified several key features of facilities that supported effective ACP: easy accessibility of written components of ACP (including ADs), availability of resources for ACP (e.g., staff have time and resources to engage in ACP), and ACP is a part of standard care. In one study of caregiver satisfaction with end-of-life care for people with advanced dementia, the strongest predictor of satisfaction was having conversations about ADs lasting more than fifteen minutes (Engel, Kiely, & Mitchell, 2006). This suggests that engaging in ACP is of great importance for family members.

Several benefits to engaging people with dementia in ACP have been identified. A nationally representative study of older American adults with cognitive impairment revealed an association between having an AD and receiving less aggressive care at the end-of-life for those with advanced dementia but not for people with milder cognitive impairment (Nicholas, Bynum, Iwashyna, Weir, & Langa, 2014). Completion of an AD was associated with higher ratings of wellbeing and decreased fear and anxiety during the dying process (Vendervoort et al., 2014). Unexpectedly, communication between a nurse and a relative was associated with increased physical distress and dying symptoms. The results of this study, particularly regarding the neutral or negative impact of communication with healthcare providers, appears to contradict previous work, both with cognitively impaired and cognitively intact participants. Previous work strongly encourages communication with healthcare providers to improve care at the end-of-life. The authors suggest that this negative association may reflect the ad-hoc or reactive nature of end-of-life conversations between nurses and family members that occur too late in the dying process. They suggest that communication regarding ACP is needed in earlier stages of the disease process to have benefits at the end-of-life, a critical area for future research.

An additional source of support for increased ACP in this population comes from a recent modeling study of ACP for people at risk of dementia in Australia (Nguyen et al., 2017). This study provided preliminary evidence for the cost-effectiveness of a national ACP intervention in primary care if at least half of this population engages in ACP and there is high compliance with the person's wishes (Nguyen et al., 2017). It appeared that most of the cost savings were related to people dying outside of hospital and declining heroic measures at end-of-life. The authors found that the cost-effectiveness was greatest when ACP was introduced before the person developed dementia.

While it can be argued that the topic of end-of-life care is one that can be difficult and uncomfortable to discuss with any individual, it appears that this may be particularly difficult for physicians to address with patients with dementia, and especially in those with multiple comorbidities (de Vleminck et al., 2014; Schonfeld et al., 2012). Physicians noted that it was easier to discuss end-of-life planning with patients with a diagnosis of cancer as compared to those with a dementia diagnosis, often due to the wide inter-individual variability of the course of dementia and the lack of certainty for prognosis (Schonfeld et al., 2012). Additional barriers for general practitioners to initiate ACP-related discussions with patients with dementia included lack of familiarity with the progression of the disease (particularly regarding its terminal phase) and the inability to identify key moments in the trajectory of dementia that trigger the need for ACP-related discussions (as opposed to many moments identified with cancer patients) (Davies et al., 2014; de Vleminck et al., 2014; Lee et al., 2017; Lamahewa et al., 2018). Physicians also noted a strong fear of causing depression and anxiety in people with dementia by discussing future declines in mental capacity, especially in cases where patients were unaware of their prognosis. These issues were further compounded by differences in practitioner skill-sets and expertise in this area (Lamahewa et al., 2018; Lee et al., 2017).

Others have noted that dementia itself may be perceived as a barrier to engaging in ACP (Stewart, Goddard, Schiff, & Hall, 2011). To plan for care at the end-of-life, the cognitive abilities of attention, executive functions, and memory are heavily relied upon. These are also among the most commonly compromised abilities in older adults with impaired cognitive functioning resulting from strokes and neurodegenerative disorders (e.g., Alzheimer's disease, frontotemporal dementia), or a non-dementia cognitive decline that may be indicative of a prodromal phase of a neurodegenerative disease (Buckner, 2004; Byrne, et al., 2011). Many physicians indicated discomfort discussing ACP with people with already-deteriorating cognitive abilities (de Vleminck et al., 2014; Mignani, Ingravallo, Mariani, & Chattat, 2017). Many healthcare providers have concerns about engaging in ACP with cognitively impaired older adults due to uncertainty as to the validity of this process in the face of cognitive deterioration or lack of information about legal aspects of ACP leading to moral and ethical concerns (Beck, McIlfatrick, Hasson, & Leavey, 2017; Robinson et al., 2013).

Several studies have attempted to quantify level of cognitive impairment at which a person is no longer able to engage in ACP, often using a cut score on the MMSE as a measure of cognitive function (Gregory, Roked, Jones, & Patel, 2007; Hirschman, Xie, Feudtner, & Karlawish, 2004). However, the use of a threshold on the MMSE as a decision tool regarding decision-making capacity is widely contested as being inappropriate (see Dening, Jones, & Sampson, 2011 for a review of this issue). This difficulty in ascertaining whether a person with cognitive impairment is able to engage thoughtfully in ACP likely contributes to the issues surrounding ACP engagement in this population and may have trickle-down effects on families' perceptions about ACP and its benefits for care at the end-of-life for their loved ones. However, many studies indicate that people with mild or even moderate levels of cognitive impairment can continue to be engaged in ACP and provide consistent, valid information regarding the preferences for care (Hirschman, Kapo, & Karlawish, 2008; Karel, Moye, Bank, & Azar, 2007). A recent study of older adults with relatively mild cognitive impairment (MMSE score of 24 or above) revealed that just over half of the sample did not have capacity to engage in ACP (Kiriaev et al., 2018). The authors noted that participants primarily had difficulty understanding the complexities of ACP, suggesting that that this process needs to be explained in a more simple and straightforward manner to maximize the likelihood that a person can engage in this process.

A potential ethical dilemma related to advance care planning could occur if a cognitively impaired person's current wishes conflict with their previously-stated or -written preferences (Lemmens, 2012). Lemmens (2012) argues that a person's current wishes must be considered, regardless of their current cognitive status or previously-identified preferences and described this scenario as a conflict between the right to self-determination of the previously competent person versus the right of the currently incompetent person to be involved in decision-making as much as possible. Lemmens (2012) recommends approaching such situations on a case-by-case basis by weighing the risks of benefits of both views, preferably done within the contact of a multidisciplinary team. He strongly cautions against automatically upholding the ADs in these situations without careful consideration.

Smith, Lo, and Sudore (2013) discuss the ethical and moral burden that can occur when the previously-stated wishes of a person with dementia conflict with the healthcare provider or family member's current beliefs about what is in the person's best interest. They suggest that the healthcare provider and family member discuss the person's previously-stated wishes and their applicability to the current situation and consider the person's overall values and beliefs, not just the specifics noted in an AD. They also recommend that amount of leeway for decisional autonomy by the substitute decision-maker must be considered. All of this should be considered within the context of exploring if a substitute decision-maker is acting in the best interests of the person.

While several studies have investigated the reasons for healthcare practitioners' decision to engage in ACP with their patient, fewer studies have examined the reasons why people with neurological conditions engage in ACP. In terms of qualitative research in this area, one study of stroke patients used grounded theory methods to explore the ACP-related conversations between patients and healthcare providers (Green et al., 2014). Stroke survivors in the study indicated that they did not feel that engaging in ACP was pressing as most assumed that their family members and physicians would know what treatment they would want. However, it has been shown in previous research there is often little agreement in end-of-life treatment between cognitively impaired people and their caregivers, particularly regarding scenarios based on possible future events (Ayalon, Backner, Dwolatzky, & Heinik, 2012; Harrison Dening, King, Jones, Vickestaff, & Sampson, 2016). Patients in Green and colleagues' (2014) study also noted that the lack of information regarding prognosis and likely outcomes of their medical condition contributed to lack of awareness of the importance of ACP. This was further exacerbated by a lack of communication with healthcare practitioners regarding ACP, often due to provider discomfort, lack of knowledge about ACP, and poor skill-set in discussing issues regarding end-of-life. It must be noted that participants in the study ranged in age from 37 to 87 years (mean age not indicated), thus these results may be limited in their applicability to an older population. A study of older adults with early cognitive impairment in Singapore noted that a significant portion of their sample declined engaging in ACP, with many noting that they had taken informal steps to plan for end-of-life, such as creating joint bank accounts with family members or writing a will (Cheong et al., 2015). The authors interpreted this data as reflective of a lack of understanding of the role and implications of ACP among the population and highlighted the importance of increased education and awareness of ACP.

A second study of ACP among older adults with dementia aimed to explore the experiences and attitudes of participants regarding ACP, though reasons for engaging in ACP were not explored *per se* (Dickinson et al., 2013). In their study, Dickinson and colleagues (2013) used thematic analysis to understand their data. Participants indicated that they were motivated to engage in ACP to decrease burden on families and to gain some control over their future care. However, participants noted that they greatly preferred having information discussions with family members as compared to creating legal documents due the inherent uncertainty about the future. They believed that having informal discussions allowed for a more flexible approach to caregiving. While these results provide some insight into the decision-making process of cognitively impaired older adults regarding ACP, many questions remain unanswered, including, critically, an examination of the reasons for engaging in aspects of ACP beyond completion of legal documents and discussions with family members. A systematic review of factors impacting engagement in ACP by van der Steen and colleagues (2014b) suggested that family factors, including family initiative to begin the process of ACP and willingness to engage in the process, were of utmost importance in initiating ACP.

In summary, people with dementia often experience a complex illness trajectory, with negative impacts not only on their quality of life, but also on the quality of life of their caregivers. A palliative approach focusing on quality of life has been recommended for people with dementia, which includes ACP as an early intervention. However, previous research exploring ACP among older adults with dementia suggests that there may be low engagement in this process, despite noted benefits of ACP. Considering the cognitive and functional changes that occur for people with dementia, several unique barriers to engaging in ACP in this population have been identified. Most of the research to date has focused on healthcare providers' perspectives on these barriers and there remains limited understanding of the decision-making process of people with dementia and their families regarding ACP.

Limitations of previous research

Although research exploring ACP among older adults with dementia has been increasing, several gaps and limitations exist. There has been a wide variety of methodologies used across studies, with differences in definitions of ACP, type of participant involved in the study (healthcare provider, patient, family members, etc.), and setting of study (hospital-based, nursing homes, community, etc.). However, more important than the methodological differences is the lack of in-depth exploration of which aspects of the ACP process are helpful for people with dementia, and which may be less so. There is little clarity at this time regarding the reasons older adults with cognitive impairment and their families engage in aspects of ACP, which limits the utility of ACP interventions that can be designed to improve care at the end-of-life. Although the TTM appears to be a promising theoretical model for understanding engagement in ACP, it has not yet been investigated among people with dementia. To address these limitations, I will explore engagement in multiple aspects of ACP among older adults with dementia, with an emphasis on understanding why people engage in the various behaviours involved in ACP. Further, I will evaluate the utility of the TTM as a theoretical framework for understanding ACP in this population which could have impact on future development of policy on ACP among people with dementia.

Methods

Interpretive description

Interpretive description (ID) was the research methodology used to guide this study. The method was developed by Sally Thorne to address the limitations in traditional schools of qualitative research (see below for further discussion of this issue) and includes two main aspects: description and interpretation (Thorne, Kirkham, & MacDonald-Emes, 1997). Research conducted under the rubric of ID initially aims to describe a particular phenomenon, that is, what did we observe? This description, which is created through inductive reasoning (creating generalizations based on specific observations), can in itself have great clinical utility in bringing increased awareness of phenomena that have not been the focus of previous research. As indicated by the "interpretive" aspect of its name, ID goes beyond description of a phenomenon to try to understand the relevance of the phenomenon by considering the cultural and social context within which individuals function. While ID questions aim to understand patterns within a phenomenon, they do not attempt to understand causality within this relationship. Central to this method is the philosophical belief that there are multiple constructed realities therefore reality is subjective, that is, is understood through the perception of an individual (Thorne, Kirkham, & O-Flynn-Magee, 2004). Based on these underlying principles in ID, this research methodology is aligned with constructivist and naturalistic orientations to inquiry (Hunt, 2008; Thorne et al., 2004).

In the field of nursing, as in the field of psychology, understanding of phenomena is often learned through experience in working with patients/clients, leading to subjective perceptions about a topic that are learned "on-the-job." In most qualitative approaches, this practical knowledge about a phenomenon is underutilized, potentially leading to a loss of important insights into the phenomenon resulting from the researcher's own experiences. A key tenet of the ID approach involves grounding the research in both the previous literature in a particular area, as well as the practical knowledge gained from experience (Hunt, 2009). This allows for minimization of repetitive research studies (e.g., reproducing similar results because the researcher is not utilizing the information from previous research) and can help researchers develop increasingly complex understandings of phenomena. Therefore, an important aspect of the ID method is the focus on practical application of the understanding of phenomena, particularly the clinical utility of this information to guide best practice. This focus is very attractive for researchers in disciplines other than nursing who also have a focus on pragmatic research with clinical utility (Hunt, 2009) and has been used in a wide variety of social science disciplines including social work (e.g., Craig, Betancourt, & Muskat, 2015; Oliver & Charles, 2016) and psychology (e.g., Weisenbach & McDonough, 2014; Williams & Haverkamp, 2015). Recently, this method has been applied to a study of bereavement among caregivers of older adults with dementia (Peacock et al., 2018).

In the development of ID, aspects of three common schools of qualitative analysis have been incorporated (i.e., ethnography, grounded theory, and phenomenology), though Thorne (2008) argues that strict adherence to these methods is not in the best interest of qualitative inquiry in the fields of health and illness. Instead, there is an openness to borrowing from different research designs to best fit the question being asked by applied research (Thorne, 2016). The methods of participant observation and interviews common in ethnographic work have been adopted into ID. However, Thorne (2008) notes that pure ethnographic approaches are limited in their applicability to clinical research as it is often either impossible to situate the research within the context of a culture, or, more to the point, this is often not a key objective of the research. Aspects of grounded theory, including its use of the constant comparative method, were also included in the conceptualization of ID as a structured method of data analysis used to investigate relationships among themes in the data. However, the main purpose of grounded theory, as evidence by its very name, is the building of theories to explain the relationship between social processes and individual perceptions, commonly used in sociology. A somewhat different approach is taken in ID as described by Thorne and colleagues (2004) whereby "researchers seek understandings of clinical phenomena that illuminate their characteristics, patterns, and structure in some theoretically useful manner" (p. 3). Thorne (2016) notes that the ID is different from other traditional qualitative methodologies in that its primary objective is not theorizing. Instead, she highlights the importance of theoretical scaffolding a study, which includes reflecting on and clarifying the researcher's theoretical forestructure (Thorne, 2016). Through this process, the researcher reflects and identifies his/her theoretical allegiances and disciplinary orientation to "ensure that the research products you generate are true to your purpose and become meaningful empirical contributions" (Thorne, 2016, p. 70). Finally, ID is also related to the school of phenomenology, which seeks to understand "the essential nature of the thing" (Thorne, 2008, p. 29), primarily through introspection. This method is closely aligned with the purpose of ID in its emphasis of undertaking research to more deeply understand the experience of an individual. However, ID departs from traditional phenomenology in its consideration of the context of the individual, and the role this context plays in a person's experience (compared to the bracketing of context common in phenomenology). Overall, Thorne (2016) noted that none of these traditional approaches were in line with the pragmatic and inherently messy nature of clinical research.

ID was selected as the qualitative approach for the current study for several reasons. First, considering my clinical work as a trainee in clinical neuropsychology, I am particularly interested in the clinical applicability of my research. A main goal of this study is to inform clinical practice in working with older adults with dementia and to inform policy on ACP in this group. ID was borne out of the desire to find practical and useable knowledge in an applied health discipline, which is in alignment with my goals. Further, ID encourages the consideration of clinical experiences in research, which allows me to consider the experiences I have had with ACP in my clinical work. Finally, ID emphasizes the importance of considering participants' social and cultural context, which aligns with my beliefs in the bio-psycho-social model of functioning (see details in Personal Theoretical Orientation section below).

Participants

Family members (e.g., spouses, children, nieces/nephews) of deceased older adults who were cognitively impaired prior to death were recruited for this study. Considering interprovincial differences in legislation related to ACP, participation was limited to people residing in British Columbia as ACP behaviour may relate to the legislative context in which people function. Purposive sampling, a non-random approach to sampling, was used for recruitment to ensure that participants with a unique perspective on ACP among people with dementia were included in the sample (Robinson, 2014). This unique perspective comes from having experienced the loss of a cognitively impaired family member, being involved in their care prior to death, and having some experience with ACP as a part of the caring process. These were expected to be key informants who had experience with the process of ACP among this population and who could provide information to help understand the challenges specific to this group. Data were collected in two waves to allow for analysis of preliminary themes between waves and to further refine interview probes based on preliminary themes. The timing of data collection was also impacted by my involvement in the Predoctoral Residency in Clinical Psychology (Neuropsychology) through Vancouver Coastal Health, a requirement of my doctoral program at the University of Victoria. I collected data for wave 1 of the study prior to starting my residency and continued with data collection following completion of the residency program.

Participants were screened either through telephone interview or via email to ensure that they met inclusion criteria: 1) at least 19 years of age; 2) the decedent experienced cognitive impairment prior to death; 3) at least six months, but no longer than ten years, have elapsed since the decedent's death; and 4) the participant was involved in the decedent's care at end-of-life and had experience with ACP in this context. Recruitment specifically targeted family members who had a close relationship with the deceased or were involved in their care at the end-of-life. These participants were more likely to be able to provide information about the end-of-life care received by the deceased, as well as their involvement in the ACP process. Participants whose family member died within six months of the time of interview were given the choice to participate later, once the six-month criterion had been met. This was used as an exclusionary criterion as people who recently experienced a loss are likely to be experiencing aspects of acute grief and may not be ready to discuss the death of their loved one (Zisook & Shear, 2009). While the length of grief varies from person to person, it has been suggested that within a few months of the death, the bereaved person transitions into the abiding grief phase, at which point the loss becomes integrated into the person's life and thinking about and discussing the deceased is not debilitating. People in this phase of grief may continue to experience sadness while thinking about their loved lost one but are unlikely to experience intense grief reactions (e.g., intense sadness and crying, disinterest in pleasurable activities). In case any participant became too distressed during the interview, the researcher prepared a list of bereavement support services available in different geographical areas of British Columbia.

I experienced challenges with recruitment of participants for this study, likely due to several factors. Initially, inclusion criteria was restricted to people living on Vancouver Island, which significantly limited the population from which the sample was drawn. Due to difficulty with recruitment, this criterion was later modified prior to recruitment for wave 2 to also include people living in the Lower Mainland area of BC and then again modified to include people living throughout BC. A second issue that arose during recruitment was the restriction regarding time since the decedent's death. Several potential participants were turned away because their family member had died more than ten years ago. Finally, several seniors' organizations responded to the recruitment email noting that they were uncomfortable advertising for this study due to the sensitive nature of the topic under study (i.e., death).

Study design

The current study received approval from the Human Ethics Research Board at the University of Victoria (see Appendix A for ethics certificates). Family members were recruited through various non-profit agencies in British Columbia, as well as through assisted- and long-term care facilities and hospice centres (see Appendix B for recruitment poster and Appendix C for recruitment email sent to local agencies relevant to older adults).

People meeting eligibility were invited to participate in an individual interview, either in person or by telephone. Initially, participants were asked if they would be interested in participating in a focus group, but the first five participants were strongly against discussing this issue in a group setting and therefore subsequent participants were offered individual interviews only. Interviews were typically 45-90 minutes in length. For participants communicating via email, a copy of the consent form was sent electronically for review. At the beginning of the interview, information in the consent form was discussed and participants either provided consent in writing (for in-person interviews) or verbally (for phone interviews). Participants were given a brief demographic questionnaire about themselves and about the decedent (see Appendix D) to collect basic information used to describe the sample. Responses were provided either verbally (for phone interviews) or in writing (for in-person interviews). All participants were then informed that the purpose of the interview was to get a sense of the decedent's story from onset of symptoms of dementia to their death, with a focus on ACP. Semi-structured interviews with open-ended questions and additional probes were used to guide discussion in the interviews to answer the research questions described above (see Appendix E for questions from wave 1 and Appendix F for questions from wave 2). At the end of the interview, participants were asked if they would like to receive a summary of study results following study completion. All participants requested receipt of this summary either by mail or by email.

The interviews were audiotaped and I transcribed the content of the audiotapes verbatim. I then re-listened to the recordings while reading the transcripts to ensure accuracy. Summaries of each interview were created to keep track of the overall sense of each interview as more data were collected. Data were collected until there was significant redundancy in information from the interviews and I had confidence that rich and diverse experiences had been collected. However, it is important to be mindful that new and different experiences could be found in further studies of this topic (Thorne, 2016).

Analysis

Analysis procedures. Data collection and analysis occurred concurrently as an iterative process. Thorne (2016) indicated that ID “shamelessly encourages borrowing from the full universe of available design technique as appropriate to the nature of the research question at hand” (p.39). However, she also noted that methodical modifications can be made as rigid adherence to design logic may not fit well with applied research. To that end, techniques from the framework method (Ritchie & Spencer, 1994), which falls within the broader family of thematic analysis methods, were utilized as the goal of the framework method is to “identify commonalities and differences in qualitive data, before focusing on relationships between different parts of the data” (Gale et al., 2013, p.2). The framework method is considered a flexible tool that can be adapted to be used with various qualitive approaches when the goal is to elicit themes (Gale et al., 2013). Although it is often used in studies with an inductive approach, it can also incorporate deductive aspects when pre-existing theory is used within analysis, such as the use of the TTM in aspects of analysis in this study (Braun & Clarke, 2006; Gale et al., 2013). Therefore, although I began with the TTM as the theoretical scaffolding for a small portion of the data, that is, the information about engagement in ACP behaviours, I moved beyond this theoretical framework using an inductive approach to more holistically understand participant experiences, a key component of ID (Thorne et al., 2004).

Considering Thorne and colleagues’ (1997) warning against “premature coding” (p. 174), which could impede the ability to deeply and meaningfully interpret the data, analysis began with focusing on the “big picture” prior to coding the data. Following completion of data collection from wave 1 and prior to any coding, I immersed myself fully in the data through transcription of interviews from wave 1. I then re-read the transcripts and looked for broad themes as a first step in the analysis. I also kept detailed notes of my own reactions to the data, as well as my understanding of how participant responses relate to the already-established literature on ACP among cognitively impaired older adults. As part of immersion experience, I used different colour highlighters to sort portions of text suggestive of possible thematic relationships (Thorne, 2016) to allow for an evolving and active process of finding meaning in the study. Portions of text with common elements (i.e., reasons the decedent created legal documents relevant to ACP) were then grouped together to help further refine patterns and themes.

I then applied an analytical framework of the TTM to code ACP behaviours. Considering the extant literature on the applicability of the TTM to ACP behaviours, coding was pre-selected based on stages within the TTM. I re-read each transcript and sections pertaining to the three ACP behaviours of interest were highlighted and were then assigned a stage within the TTM. Classification of participant responses into the TTM was done by adapting previous guidelines from quantitative studies into a format that would fit data arising from qualitative research (Ernecoff, Keane, & Albert, 2016; Fried et al., 2010; Lum, Sudore, & Bekelman, 2015). Stages of change were determined independently for three ACP behaviours: discussion of beliefs, values, and goals with a family member, deciding on a substitute decision-maker, and creating legal documents regarding healthcare or financial wishes. Given the nature of the data collected, I was able to ascertain movement through stages for some decedents but not for others. Of note, this information was based on retrospective collateral report, thus it is possible that family members were not fully aware of the decedent's stage of change. However, I attempted to mitigate this limitation by only selecting participants who were heavily involved with the decedents' care and would have had a good understanding of their engagement in the three ACP behaviours examined in this study.

For each of the three ACP behaviours, responses were categorized into the various stages of the TTM according to the following guidelines:

Precontemplation: The decedent did not engage in the behaviour, evidenced by the decedent either explicitly stating that they did not want to engage in the behaviour or by not knowing about this behaviour.

Contemplation: The decedent did not engage in the behaviour but informed their family member that they were thinking about the behaviour and/or knew about its relevance to their situation.

Preparation: The decedent did not engage in the behaviour but informed their family member that they were planning on engaging in the behaviour.

Action/Maintenance: The decedent engaged in the behaviour.

I then moved to a broader analysis of themes among all the data. This process of data analysis is inherently extremely flexible, allowing for shifting of data construction and the relationships among the data and allowing for an openness to changing clusters of codes or themes as new understandings of relationships are elicited. Careful note taking of this process was used to provide readers with an understanding of the decision-making process in analyses. For example, although it initially appeared that participants with a healthcare background were more easily able to navigate the healthcare system and engage in ACP, upon further consideration, this relationship was not as simple as it initially appeared. Therefore, my understanding of the relationship between having a healthcare background and engaging in ACP needed further refinement to be more nuanced and capture the range of participant experiences. Under the rubric of ID, the goal is not to just create a list of themes, but rather to further professional knowledge, makes sense of an issue in healthcare, and provide a coherent description of the data collected (Hunt, 2009). Although a main goal of this study is to identify themes and commonalities among participant experiences, I captured a wide variety of experiences and was mindful of exploring and understanding experiences that could be described as outliers and did not fit cleanly with the overarching themes (McPherson & Thorne, 2006).

Following completion of data collection in wave 1, preliminary themes interpreted from the data were identified and discussed with my supervisor as a method of peer debriefing and were also compared against findings from previous research on ACP. Based on issues identified in these discussions and in the comparison with the literature, additional questions were incorporated into the questions and probes for data collection in wave 2. Participants in wave 2 were also asked to reflect on preliminary findings from wave 1. Further, as Bill C-14 came into effect between data collection in waves 1 and 2, questions about MAiD were incorporated into probes for wave 2 given the relevance of MAiD for people at the end-of-life. Participants were asked to consider not only their general views on MAiD, but also their thoughts about allowing people with dementia to request MAiD, which is not currently legal. They were further asked to consider if the decedent would have requested MAiD had it been available in a hypothetical scenario to encourage consideration of this issue in the context of their experiences with the death of a family member.

As interviews from participants in wave 2 were transcribed and summarized in a similar fashion as those from wave 1 of data collection, initial themes were further refined and evaluated in the process of creating a cohesive understanding of the subject. For example, in terms of receiving education about ACP, a preliminary theme was that participants were not given information about the impact of cognitive impairment/dementia in the ACP process. However, upon further reflection, I began to question if other factors were playing a role in participants not receiving this type of information. I then went back to the transcripts and reviewed sections pertaining to education and realized that participants were describing a lack of education about dementia itself, not just about the relationship between dementia and ACP, leading to changes in my interpretation of the data.

Credibility indicators. Trustworthiness, or credibility, in qualitative research can be thought of in a similar manner as validity in quantitative research and is of great importance when creating high-quality qualitative research (Morrow, 2005). ID studies often make use of techniques from other epistemologies in building in measures of credibility. Four criteria of trustworthiness in postpositivist qualitative research have been identified by Lincoln and Guba (1986) and are discussed below in relation to methods used in the current study.

Credibility, akin to internal validity in quantitative research, refers to the rigor with which the study is undertaken to understand the truth and reality. The procedure of disconfirming evidence was employed to look for data that does not fit with or challenges themes that have been identified in the study (Creswell & Miller, 2000). Although Creswell and Miller (2000) noted that this process is inherently difficult due to the tendency to prefer evidence that supports the conclusions rather than the evidence that challenges the conclusions, this process must be undertaken considering the underlying assumptions of ID that reality is complex and multifaceted. For example, I was initially struck by the number of participants noting the lack of education about ACP following diagnosis and created a broad theme that education is not provided. However, through the iterative analysis process and through re-reading the transcripts, I noticed that a small number of participants described receiving comprehensive and ongoing education about ACP from the decedent’s family physician. Although their experiences did not fit with the majority of the participants, their experiences were still important to document, and I began a process of trying to understand why their experiences differed so much from those of other participants.

Reflexivity is a term used to describe self-reflection throughout the research process (Creswell & Miller, 2000). The authors highlight the importance of clearly defining one's assumptions, beliefs, and biases that could affect the research findings. To this end, the final part of the Methods sections describes my views on ACP prior to beginning the study. Other strategies used included keeping a reflexive journal throughout the course of the study and peer debriefing, that is, discussing my thoughts and experiences with another person (my supervisor) to explore my interpretations of the data and to allow for challenges to my interpretation. The term "thick descriptions" has been used to describe the richness of descriptions gleaned from participants which includes not only their personal experiences but also the context in which these experiences occurred (Geertz, 1973). During the interviews, I prompted participants to provide a longitudinal description of the decedent's journey from before diagnosis of dementia to death, providing a rich context for their experiences. In many interviews, participants began telling a narrative of the decedent's experiences after the first interview question. I encouraged participants to tell me the story in a detailed fashion, which then provided context for later questions.

Transferability, akin to the notion of external validity in quantitative research, refers to the generalizing of the study findings. To address this issue, detailed information about participants, the research, and methods is included in this document. Given the nature of qualitative research, and studies such as this which are a first step in exploring a phenomenon in a specific group, sample sizes are generally small, limiting generalizability. Thick descriptions are again of importance to transferability as this provides a means by which readers can assess the similarity between the context of this study and other contexts to determine if the results may fit in other contexts (Lincoln & Guba, 1986). To that end, descriptions of the legal framework regarding ACP is included in the literature review to situate the participant experiences in this specific social context. Further, participant experiences described in the Results section include descriptions of the context in which they occurred.

Dependability, akin to reliability, refers to the extent to which the study can be replicated. This is again bolstered by thorough and explicit documentation of methods and through use of an audit trail. In this study, I kept notes on my reactions during and after interviews as well as following transcription of each interview. I created an anonymized spreadsheet outlining the dates of interviews, noting whether they were completed in-person or by phone. I also continued to journal throughout the analysis process, including making notes of questions that arose during peer debriefing.

The final criterion, confirmability, is similar to the notion of objectivity and refers to minimizing the impact of the researcher’s own biases on the outcome of the study. This again is bolstered through use of an audit trail and ongoing reflection of the impact of my biases throughout the research process. For this purpose, the final portion of the Methods includes a description of my views and belief, as this has been suggested as a method of managing subjectivity (Morrow, 2005). However, it is important to note that ID does not support the notion of “bracketing”, that is, setting aside one’s own beliefs, as the researcher and the research subject are assumed to impact one another. For example, in past clinical experiences, I have witnessed family conflict arise at the end-of-life for people who did not document their wishes in advance. Considering these experiences, I have been a proponent of ACP. During the analysis process, I assumed that there would be family conflict reported by many participants, but this was not the case, thus I had to continually challenge my personal views on the topic and build understanding based on the data collected.

In addition to these commonly-accepted indicators of credibility, Thorne (2016) proposes several additional criteria to be considered. She describes the importance of epistemological integrity which necessitates a logical and defensible process of reasoning from the assumptions underlying the study to the end results of the study. In this study, I take a constructivist approach which includes an assumption that there are multiple constructed realities and I do not assume that there is a single truth that can be known. Thorne (2016) also notes that high-quality qualitative research should have representative credibility in that “the theoretical claims they purport to make are consistent with the manner in which the phenomenon under study was sampled” (p. 234). Considering that purposive sampling was used in this study, and that the sample was relatively small and predominantly Caucasian, I discuss limitations in representation and suggest strategies to gain a more representative understanding of the phenomenon in the Limitations and Future Directions section. Analytic logic refers to making explicit and clear the reasoning used by the researchers throughout the study, often completed through use of an audit trail and use of thick description, discussed above (Thorne, 2016). Additionally, Thorne (2016) discusses the concept of interpretive authority, similar to the concept of trustworthiness discussed above.

Finally, Thorne (2016) identifies five more subtle aspects of evaluating qualitative research. Moral defensibility refers to the strength of the claim that the knowledge gained from the study is important and necessary and how it will be of benefit, particularly when the research involves vulnerable people. Disciplinary relevance refers to the relevance of the research to the furthering of knowledge within a specific discipline. Pragmatic obligation acknowledges that health research has a practical application and that we must consider that our findings may be put into practice before they are fully “proven” and have the risk of causing harm. To address these three aspects, I reviewed the clinical relevance of ACP for people with dementia in the Literature Review section and discuss practical applications of the knowledge gained in this study in the Discussion section, particularly its applicability to the practice of clinical neuropsychology and its role in development of policy. Contextual awareness refers to the grounding of new knowledge within the society in which it was completed (Thorne, 2016). Lastly, probable truth refers to the process of attempting to understand the truth of a situation as best we can while also recognizing that our views of the truth may turn out to be inaccurate. I discuss the limitations of my research in the Limitations and Future Directions sections.

Personal theoretical orientation

As a trainee in clinical neuropsychology, I tend to view the experiences of individuals through the lens of the bio-psycho-social model in which human functioning arises from biological, psychological, and social factors. I strongly believe that it is futile to attempt to understand the experience of another human being while disregarding the context in which they function, both at the micro level of family functioning and at the macro level of the functioning of the society in which they reside. Through both my research and my clinical experience, I believe that each phenomenon can be perceived in an infinite number of ways dependent on the person doing the perceiving because of differences in previous experiences. Thus, I do not believe in one single “true” reality, but rather that each person constructs their own reality through the lens of their perceptions and their underlying beliefs. These underlying beliefs and ingrained patterns of interacting with the world can lead each individual to experience a phenomenon quite differently than it is experienced by another, consistent with the basic tenets of the Cognitive-Behavioural Therapy approach (Beck, 2011).

I have had personal experience with ACP, both as a granddaughter who struggled with helping my family make decisions for my critically ill grandparent who had not engaged in ACP, and through my previous research and clinical work. Further, I have been involved in work regarding assessment of decision-making capacity and its outcomes for the past several years. I have an inherent bias towards perceiving ACP as a positive process leading to better outcomes for the individual, for the family, and for society. I am a strong proponent of the belief that everyone should engage in ACP throughout their lives, though I recognize that this process, as it currently stands, is far from perfect and has many pitfalls and limitations.

Considering my perspective on ACP, I was mindful during interviews with participants not to share my own beliefs about ACP. Although some participants asked questions about my views, I declined to answer and emphasized the importance of understanding their experiences. Throughout the analysis process, I was mindful of my pro-ACP viewpoint and challenged myself to be open to participant experiences that were not in line with my own. For example, although I am a proponent of identifying a substitute decision-maker, many participants described the decedent making assumptions about who would take on this role and not creating a Representation Agreement. Although I initially thought there would be significant consequences to these types of assumptions, I repeatedly went back to the transcripts to understand the participant experiences and questioned whether my belief was borne out in the data.

Results

In the following sections, I will discuss the findings from this study. I will first describe the participant sample, including information about the decedents to provide some context for participant experiences. I will then discuss themes regarding provision of education regarding ACP. Decedent engagement in the three ACP behaviours explored in this study will then be discussed, including an overview of the fit with the TTM. Themes regarding the role of ACP in the caregiving experience as well as the role of ACP in participant perceptions of the quality of the death will be explored. Finally, beliefs about MAiD will be discussed.

Participant and decedent demographics

Individual interviews were completed with 22 participants, with 9 participants in wave 1 and 13 participants in wave 2. Interviews in wave 1 were completed between April 10, 2015 and June 23, 2015. Interviews for wave 2 were completed between March 11, 2017 and March 14, 2018. Two participant-decedent dyads were excluded from analysis as it was discovered during the interviews that the decedent was living in the United States in the years prior to death. Considering significant differences in the healthcare systems between Canada and the United States, as well as differences in legal aspects related to ACP between these countries, comparisons with the rest of the sample were considered inappropriate and likely to obfuscate patterns in the results.

Seven interviews were completed in person and 15 were completed by phone (see Table 1 for summary of participant characteristics). Participants ranged in age from 51 to 85 years, with a mean age of 70.55 years. Most of the participants were female (18/22) and self-identified as Caucasian (20/22). All participants had at least a high school degree, with many having post-secondary education as well. In terms of relationship with the decedent, participants were either the child of the decedent (14/22) or the spouse of the decedent (8/22). Length of relationship ranged from 35 to 79 years, with a mean of 59.90 years. Most participants (16/22) were in contact with the decedent, either in person or by phone, three or more times per week in the final six months of the decedent's life. Time elapsed between the decedent's death and the interview ranged from 0.67 to 8.92 years, with an average of 3.56 years.

Table 1

Participant Characteristics

ID	Interview Type	Age	Sex	Education (years)	Relationship to Decedent	Length of Relationship (years)	Contact Frequency with Decedent	Time Since Death (years)
1	In Person	78	Male	--	Spouse	56	3+/week	3.75
2	In Person	62	Female	16	Child	60	3+/week	1.25
3	In Person	66	Female	14	Child	62	3+/week	3.92
4	By phone	68	Female	16	Child	65	3+/week	3.33
5	In Person	67	Female	14	Child	67	3+/week	1.17
6	In Person	79	Female	16	Spouse	60	3+/week	1.83
7	By phone	74	Female	18	Child	--	3+/week	3.33
8[a]	In Person	85	Male	13	Spouse	65	1-2/week	1.25
9	In Person	79	Female	18	Spouse	55	3+/week	0.67
10	By phone	73	Female	--	Child	66	3+/week	7.00
11	By phone	70	Female	15	Child	61	1-2/week	3.17
12	By phone	67	Female	13	Child	61	3+/week	6.83
13	By phone	78	Female	13	Spouse	60	3+/week	0.67
14	By phone	84	Male	12	Child	79	3+/week	5.83
15	By phone	66	Female	15	Child	65	3+/week	0.67
16	By phone	55	Male	14	Child	46	< 1-3/ month	8.92
17	By phone	84	Female	12	Spouse	55	3+/week	0.92
18[a]	By phone	76	Female	16	Spouse	71	< 1-3/ month	5.83
19	By phone	68	Female	16	Child	63	1-3/month	4.33
20	By phone	56	Female	12	Spouse	35	3+/week	2.58
21	By phone	66	Female	18	Child	58	3+/week	8.25
22	By phone	51	Female	19	Child	48	1-2/week	2.83

[a] Participant-decedent dyad excluded from analysis.

Decedent characteristics are presented in Table 2. Decedent age at time of death ranged from 56 to 103 years, with a mean age at time of death of 88.09 years. The sample was almost evenly split in terms of decedent sex, with 12/22 decedents being female. Most decedents (15/22) were residing in a care facility at the time of death while 6/22 were residing in their own home and 1/22 had been in hospital longer than three months prior to death. For almost half the sample, participants were unsure of the decedent's dementia subtype. For decedents with information about subtype, most were reported to have Alzheimer's Disease (7/12), with an additional 3/12 reported to have Vascular Dementia, 1/12 reported to have Parkinson's Disease, and 1/12 reported to have Frontotemporal Dementia. All participants reported that the decedent experienced functional impairment, that is, problems with daily tasks due to cognitive impairment, prior to death (excluding the last month of life). Informant-reported cognitive decline was noted in multiple domains for most participants, with most commonly affected domains being memory and executive functioning. Time with dementia was calculated as the time between diagnosis of dementia and time of death and ranged from 2.83 to 30.92 years, with an average of 11.17 years.

Table 2

Decedent Characteristics

ID	**Age at Death**	**Sex**	**Residence at time of death**	**Dementia Type**	**Functional Impairment**	**Domains Affected**	**Time with Dementia (Years)**
1	74	F	CF	AD	Yes	Memory, Attention, EF	--
2	96	M	CF	Vasc.	Yes	Memory, Language, Attention, EF	--
3	90	M	CF	--	Yes	Memory, Language, Attention, EF	--
4	83	F	CF	--	Yes	Memory, EF	7.42

5	103	F	CF	AD	Yes	Memory, Attention, EF	11.58
6	82	M	CF	AD	Yes	Memory, Attention, EF	7.50
7	98	F	CF	--	Yes	Memory, Language	7.50
8[a]	81	F	CF	AD	Yes	Memory, Language, Attention, EF, Emotional	30.92
9	83	M	Home	Park.	Yes	Memory, Attention, EF, Emotional	4.50
10	99	M	Home	--	Yes	Memory, Attention, EF	11.33
11	82	F	Home	Vasc.	Yes	Memory, Language, Attention, Emotional	22.00
12	91	F	CF	FTD	Yes	Memory, Language	19.00
13	86	M	Home	AD	Yes	Memory, Emotional	5.83
14	99	F	CF	--	Yes	Memory, EF, Emotional	12.92
15	97	M	Home	--	Yes	EF	2.83
16	95	M	CF	Vasc.	Yes	Memory, Attention, EF, Emotional	12.0
17	85	M	CF	AD	Yes	Memory, Language, Attention, EF	10.0
18[a]	96	F	CF	--	Yes	Attention, EF, Emotional	13.08
19	90	F	CF	--	Yes	Memory, Attention, EF, Emotional	7.08
20	56	M	Hosp.	AD	Yes	Memory, Language, Attention, EF, Emotional	9.25
21	83	F	Home	--	Yes	Memory, EF	--
22	89	F	CF	--	Yes	Memory, EF	6.25

Note. F = Female. M = Male. CF = Care Facility. Hosp = Hospital. AD = Alzheimer's Disease. Vasc = Vascular Dementia. Park = Parkinson's Disease. FTD = Frontotemporal Dementia. EF = Executive Functioning.

[a] Participant-Decedent dyad excluded from analysis.

Receiving information about ACP

Overall, information about ACP was provided in a piecemeal manner. Most participants indicated that they received some type of information about ACP, but sources of information varied. Some participants noted that they received information about ACP from the decedent's family physician; they described these physicians as advocates of ACP and concerned with maximizing quality of life at end-of-life. In one instance, the family physician had reviewed recent statistics about success rates of resuscitation among older adults to ensure that the decedent had accurate information about medical treatments when engaging in ACP. This physician also discussed his own beliefs about quality of life to provide education about exploring beliefs and values in the ACP process. Another participant stated that her family physician booked appointments under a mental health billing code to allow time to discuss ACP and provide more information about the decedent's diagnosis and prognosis. Participants said that they found this to be of benefit, particularly when multiple family members shared the same physician, as information was disseminated more easily and efficiently among the members of the family. In these cases, participants explained that they and the decedent felt adequately prepared to make decisions about ACP.

Many participants appeared to have an implicit belief that family physicians should provide information about ACP and were frustrated or upset when the information was not given. One participant said that his father (the decedent) was too weak to go to the physician's office for an appointment. He stated that the family physician would not make a home visit, thereby limiting his father's access to medical care and discussions about planning for future care. The participant expressed frustration that the decedent's family physician was not more engaged with the decedent’s care and did not provide the decedent or his family with information on planning for future care needs:

> *It’s so easy to put on the blinders and hope that someone else is going to look after it. The doctor will tell me when it’s time to do this. You know, the doctors don’t. Doctors don’t really give a damn when you get to be over 80 ... I get the feeling that he [the family physician] thinks [the decedent] is going to die so make him comfortable and that’s the end of it.*

However, others acknowledged that perhaps family physicians are not in the best position to provide this type of service as they generally only see patients for brief appointments and are very busy. Some noted that the family physician was not consistently involved in the decedent’s care and may not have been aware of the decedent’s cognitive decline. One participant with a great deal of experience with ACP through her work in providing support for older adults with dementia indicated that, in her experience, very few physicians provided information about ACP to patients in a way that was easy to understand and helpful to the patient. She suggested that perhaps physicians are not best-suited to the role of providing education about ACP and that other people can be trained to engage patients in education about ACP in a manner that addresses their needs:

> *It doesn’t seem to come from the doctors. And not clearly from the doctors. They’re under this ten-minute pressure … they need that nurse or layperson out in the front of an office or if a community medical team got together and they’d have the person that somebody could go see … it doesn’t need to happen in the brilliance of a doctor’s service. It just needs somebody to dole it out so it’s clear.*

Oftentimes participants learned about ACP by happenstance. One participant talked about learning about legal documents pertinent to ACP from a conversation with a neighbour. Another described learning about ACP through attendance at a senior's conference and stated that that this was the first time he had heard the term 'ACP' even though his wife had been diagnosed with dementia long before he attended the convention. Still others learned about ACP through interactions with staff at care facilities or from a case manager during the process of moving the decedent into a care facility. Information about ACP was sometimes received through attending caregiver support groups. Participants described gleaning great benefit from hearing about the lived experiences of other people in similar situations and noted that it was common knowledge that information was not forthcoming from the health system. Participants described sharing newly-learned information with the group as members tended to have different bits of information, some of which contradicted one another, thus discussion at support groups was seen as a way to mitigate the gaps in information.

Several participants noted that, in retrospect, there should have been information provided about ACP at the time of their family member's dementia diagnosis as this would have guided their planning and decision-making. Some participants surmised that perhaps healthcare providers were uncomfortable discussing death and dying and preferred to talk around issues of end-of-life, rather than addressing them directly. Several participants stated that they did not fully understand the implications of a diagnosis of dementia, with some noting that it was unclear that this was a life-limiting illness. One participant said she experienced regret for providing consent for her husband to undergo major surgery as she did not understand the possible negative consequences of major surgery for people with dementia. She described her husband experiencing a significant decline in cognitive and functional abilities post-surgery. She stated that she was told post-surgery that this was not an uncommon outcome and noted that she wished she had been given this information before providing consent.

Some participants acknowledged that perhaps they did receive some information about ACP but were not prepared to accept the information. For some this was due to denial regarding the diagnosis while others felt they could not begin to think about ACP due to intense grief. Many described themselves as being completely overwhelmed upon learning that their family member had dementia. One participant suggested that she may have tuned out after hearing the word ‘dementia’, therefore any information following that word was not processed. Several participants further noted that due to denial, stress, or burnout, healthcare providers and seniors’ agencies should not expect that family members will try to reach out for support, but rather should contact families directly to offer education and guidance:

> *I must admit that maybe people did tell us things that we should have known but, um, we were so overwhelmed with the whole thing that we… it didn’t come in the way it should have.*

Others may not have been able to see the relevance of ACP to their family member’s situation due to lack of information or inaccurate beliefs about dementia. In fact, several participants made comments during interviews suggesting that they still had poor understanding of dementia, even after their experiences with the decedent. Still others pointed out that there can be a lack of clarity about the diagnosis itself as it appeared that some healthcare providers were reluctant to make a diagnosis of dementia or even use the word ‘dementia’ in discussions.

Two participants contrasted their own experiences with engaging in ACP following a diagnosis of cancer with the experiences of their family members following diagnosis of dementia. They both noted described receiving education and support through the Cancer Agency in engaging in ACP and were disappointed that such services were not offered to their family member:

> *Well, I'd done my own… you know, through the Cancer Agency and boy, they walk you through … you have to do all your paperwork like when you're diagnosed. You know, you get a nurse and a counsellor and everything so there's lots of support … They want quality of life and part of quality of life is that you make your arrangements and then you have your life – whatever is left of it. And they included my son and he was brought in and had these great conversations, which he's told me he really enjoyed, you know, as much as he could. He felt that he had all the information he needed … So I felt, so why isn't my mom doing it? Such a simple thing.*

Among participants who felt they had enough information about ACP, most had some experience working in healthcare or in a healthcare-related industry. They highlighted the importance of understanding medical jargon as information was generally not freely given and they needed to know how to ask for it. One participant with a medical background stated that she was well-aware of ACP as she had witnessed family conflict and difficult end-of-life of patients who had not documented their wishes. Others were familiar with ACP, particularly creation of the EPoA, as they had work experience in the financial industry. One participant noted that although no information was provided about ACP by healthcare providers, she felt she knew enough about the ACP process as she had had been involved in end-of-life care for another family and had learned about ACP through her past experiences. Many participants who indicated that they had sufficient information about ACP described themselves as being strongly proactive upon learning of the decedent's diagnosis, spending a great deal of time and energy researching about dementia and about issues related to dementia, including ACP. Several noted that they accessed the *My Voice* workbook, which was helpful.

Almost all participants noted significant gaps in education about ACP and identified possible solutions to increase access to information about ACP. One participant explained that her parents moved into a suite in her house so she could provide care. She stated that her father, the decedent, eventually had to move into a care facility because the participant and her mother were burnt out from providing a high level of care. The participant described feeling resentment toward her father and stated that she wishes she had been informed about care facilities early in his dementia trajectory as he probably should have been in care years earlier. She stated that part of the problem was not having enough information about her father's illness to plan for future care needs. She also suggested that part of the problem may be a societal expectation that people will remain healthy forever and there is therefore no incentive to plan for future care:

> *This should be something that is taught to people as you age, as you retire. You know, you go to seminars to learn to retire for Pete's sake: how to handle your life, how to handle your finances. Who talks to you about what happens after 80? It's just… just really insane. The whole system … I don't think any of us, as we get older, know what to expect as we get older… there's no planning. There's no, um, this is your choices as you get older. We just all think we're going to be healthy until the day we die in our bed. It's not going to work that way. We're going to degenerate like out parents did and this is really an eyeful for me.*

A few participants also noted that it would be particularly helpful to receive education about the progression of symptoms and impairment typical in dementia. They stated that they would have benefitted from receiving some type of brochure or pamphlet with basic information about dementia, including a checklist of steps to take and issues to consider following diagnosis (including commencing ACP if this had not yet been undertaken):

> *If there was a document in the doctor's office or in the public health office worded in such a way that it would invite people to pick it up and take a look. What is going to happen to you at the end-of-life? Have you made plans?*

Participants stated that ideally, there should be a centralized repository of information about ACP that is easily accessible. They noted that this would significantly cut down on time taken to gather information and reduce stress associated with asking the same question to multiple people in hopes of finding the correct answer. Additionally, several participants noted that this type of information could be provided in a workshop format. One participant stated that she was aware of a lawyer running ACP workshops for clients who were completing their wills and she described these as being very successful. Other participants questioned why ACP was not included in retirement seminars as this could be incorporated into planning for old age.

It was also suggested that ACP should be integrated into the curriculum and training of healthcare providers to increase their comfort with discussing end-of-life issues. One participant whose work includes supporting older adults with dementia alluded to the importance of sensitivity when discussing this topic with patients:

> *So, I would say now if you [referring to healthcare providers] have the information, you've said it so many times you're bored of it. But the person you're speaking with, it might be their first time in the midst of a turmoil time and so you don't want to up their stress to have to make big decisions… you want them to start to feel what it is.*

Discussions of beliefs, values, and goals with family

Over half the sample of participants reported that the decedent had engaged in a discussion of beliefs, values, and goals for end-of-life. For some participants, learning about legal documents relevant to ACP triggered these discussions, as the family had been unaware of the notion of ACP prior to being told about the legal documents. For others, major life events such as the death of a close family member, near-death experience following surgery, or preparation for a risky medical procedure prompted initiation of discussions about end-of-life. One participant began planning for her own care at end-of-life due to diagnosis of a life-limiting illness and then encouraged the decedent to also consider her own preferences.

Among those families in which these discussions occurred, there was a great deal of variability in the nature of the conversations, with some families having in-depth, detailed conversations about their goals, beliefs, and wishes, and others having more brief discussions about wishes. Many decedents who engaged family members in detailed discussions about preferences for end-of-life care had strong beliefs about the importance of autonomy and independence, with conversations focused on not wanting medical care that was seen as infringing on autonomy. One participant said that the decedent told him that during the decedent's childhood, he had witnessed his father lying naked and restrained in a hospital bed and that this had been very disturbing. He explained to the participant that he did not want the type of care his father received as he viewed this as degrading. Another participant described that his wife, the decedent, specifically outlining her beliefs about quality of life during conversations with the participant and with the family physician. The participant noted that these conversations evolved as his wife's symptoms progressed and they faced the reality that although she valued living at home and being independent, they had to face the fact that she required more care than the participant could provide. The participant said that he felt confident that he understood his wife's beliefs and goals because of these ongoing conversations.

For many, the content of these discussions addressed only a few of the many aspects of decision-making due to lack of awareness of issues that typically arise at end-of-life. For example, some families discussed the decedent's goals and preferences about residence in the future but did not discuss their preferences for medical care, often due to a lack of medical knowledge and understanding about common medical interventions such as ventilation or tube feeding. A few participants shared the experience of having a family member who was adamant about dying at home and refusing to move into care. These participants indicated that although this made sense during the discussions, it later became a problem as they had not discussed what would happen if they could no longer safely stay at home. Many of these conversations seemed to focus on what the decedent did not want at end-of-life, such as having no heroic measures or not wanting to die in hospital. Some participants indicated that in retrospect, it was difficult to ascertain some of the decedent's preferences as situations arose that were not discussed.

Fit with the framework of the TTM. Participants exhibited a wide variety of readiness to engage in the ACP behaviour of discussing beliefs, values, and goals with their family. Almost half of the respondents indicated that the decedent had been in the Precontemplation stage for this behaviour and there had been either no attempt at discussing wishes for end-of-life or the decedent had actively resisted engaging in these conversations if they were initiated by another person. Some participants indicated that they were unable to have these conversations because the decedent was already too cognitively impaired to engage in this behaviour. Interestingly, many families discussed the decedent's preferences for funeral arrangements and other issues that arise after death but did not discuss preferences for care preceding death. Several participants stated that their family members were strongly opposed to discussing wishes for end-of-life due to traditional views wherein death is not discussed or religious beliefs that precluded them from discussing death:

> *Anytime you brought any of those kinds of conversations, it's like "you're… trying to kill me off! ... you just want me to die!" ... She was very much of that sort of older generation where certain things are whispered ... She was very of the traditional school of you do whatever the doctor tells you to do.*

Many others indicated that it did not even occur to them to begin discussions about end-of-life because they assumed the decedent would die in their sleep with no complications or that there would not be any major medical decisions needing to be made in the future. Some stated that, in retrospect, the family was likely in denial of the seriousness of the decedent's disease and preferred to not think about the future. One participant revealed that her mother did not discuss preferences for end-of-life care because she believed this was not needed as her husband would take care of her:

> *We expected that if anybody died, it would be my mother and my father would be looking after her… it kind of upset the applecart when he got sick and died suddenly ... then it was like she didn't really have a 'Plan B' as far as I know.*

For some participants, a lack of understanding of the neurodegenerative process may have impeded the family from realizing that conversations about end-of-life were relevant. They noted that they did not foresee the impact of their family member's cognitive decline on ability to engage in these discussions and assumed that discussions about end-of-life could be held later. This also highlighted a common occurrence among families that did not have conversations about beliefs and goals wherein the decedent was too cognitively impaired to engage in such discussions by the time it was recognized that such discussions could be of benefit (i.e., when a significant decision needed to be made, such as whether the decedent should move into a care facility). A participant whose husband developed early-onset Alzheimer's Disease explained why they had not had conversations about end-of-life care:

> *At 50 years old, it just doesn't … We never talked about terminal illness and, you know, how'd you'd want … to be treated. We never had those conversations… [At the time of diagnosis], he was already at a point where you couldn't really have a thorough conversation with him about it.*

A small minority of participants described the decedent being in the Contemplation stage, noting that the decedent made some vague comments or statements about end-of-life preferences, but did not engage in discussion about their preferences:

> *I don't know if I'd call it a conversation but, uh, she would … she said, "I don't want to… I don't want to live if I'm all messed up… And I don't want to be in bed all the time. If I get to that point, I don't want to be here."*

One participant reported that the decedent had been in the Preparation stage and had begun engaging family members in conversation about end-of-life wishes, though these conversations were not detailed, and no conclusions were reached.

Almost half of the participants in the study described the decedent reaching the Action/Maintenance stage for this behaviour. Some participants stated that discussions about end-of-life preferences were common in their family and had been occurring for many years. They described themselves as lifelong planners and noted that the topic of death and dying was not taboo in their family and they did not shy away from such discussions. One participant described conversations about end-of-life that occurred regularly within her family and noted that they used humor to dissipate any possibly discomfort when discussing death. She said that religious beliefs and spirituality played a role in her family's comfort in discussing death.

> *So, we'd have our glass of wine, you know, and we'd be in the front room and we'd be just chatting … so it's a conversation as in, well, what would you want and what don't you want. And I think our family had enough of those discussions … that we basically had the same philosophy and we had a broad stroke of understanding with each other as to what we wanted … and it's very foreign to me to think that people have anxieties talking about death.*

This participant also stated that she was relieved that these conversations had occurred as a family member (not the decedent) was involved in a serious accident and the family was able to reflect on these conversations to guide their decision to remove him from life support. One participant said conversations about preferences for end-of-life were not always comfortable or easy but her approach to these discussions paralleled the approach she took when teaching her children about sex: these conversations needed to occur to maintain dignity and respect, even if they sometimes made family members uncomfortable.

Identification of a substitute decision-maker

Most participants indicated that the decedent had taken some action toward identifying a substitute decision-maker, either informally through discussions or formally through creation of a Representation Agreement. Several participants noted that the decedent selected more than one substitute decision-maker. In some families, multiple substitute decision-makers were identified because the decedent did not want the burden to rest solely on one person. Many participants were glad to have input from other family members in their role as substitute decision-maker as this decreased their responsibility. In other families, the decedent assigned particular tasks to each substitute decision-maker. One participant said that she was selected to make medical decision because of her healthcare background while another family member was selected to make financial decisions because of his background in banking.

Fit with the framework of the TTM. Similar to engagement in discussions about values, there was a wide variability of readiness to identify a substitute decision-maker. Approximately a third of participants described their family member being in the Precontemplation stage for this behaviour, noting that there were no discussions about a preferred substitute decision-maker. Many participants noted that selecting a substitute decision-maker did not seem necessary as there was a high degree of trust and closeness within the family and that all family members shared the same views on end-of-life. They did not see the need for formalizing the selection of a substitute decision-maker as there was no conflict within the family:

> *It might have been worthwhile to try to pursue a Representation Agreement, but I think there was a lot of trust in our family that we knew what we were doing. Um, you would want a Representation Agreement, I'm sure, if you had no children or if you did not get along well with your children or… I see the benefit of having them. But they weren't required in our situation.*

Another third of participants stated that there was an assumption of who would become the substitute decision-maker once the decedent needed this type of support and were therefore categorized as being in the Contemplation stage. Participants noted that due to the length and closeness of their relationship with the decedent, generally spanning several decades, it was assumed that they would take on the decision-making role. This sometimes came up vaguely in conversation but was not thoroughly discussed. In some families, one or more caregivers were already providing informal support with decision-making thereby making this issue moot in their opinion:

> *She used to ask me questions before she became demented and I would answer questions … so she just relied on us with no difficulty. We were a pretty open family in that regard.*

In some families, it was assumed that a person with a background in healthcare would take on decision-making for medical and personal issues while a person with financial experience would take on decision-making for financial issues. For some decedents with traditional views on gender roles, it was assumed that the male family member would take on financial decision-making while the female family member would take on medical and personal decisions. In other situations, there was a presumption that the person residing closest to the decedent would become the primary substitute decision-making for purely logistical reasons. One participant indicated that she assumed that she would be selected to be the substitute decision-maker as she was the eldest offspring. When asked if she was aware of the legislation outlining the specified order of substitute decision-makers, which does not take into consideration birth order of offspring, the participant stated that she did know about this and was quite surprised. Although most participants described the presumption of a substitute decision-maker as being without conflict, one participant described conflict arising from this very assumption:

> *There was a presumption that it would be my sister … even though I said, you know, she was the least reasonable … because my sister was still living at home … my sister assumed it would be her [making medical decisions] because she had a Power of Attorney … I would have had all of this in writing and, you know, in a directive. But she [the participant's mother] felt that she didn't have to and my sister felt they didn't have to do it. And I felt they did and my brother did also. You know, we just wanted everything on paper so it would be … because that's the useful part.*

A third of participants reported that the decedent had identified a specific substitute decision-maker, either informally or, more frequently, formally by creating a Representation Agreement and were therefore in the Action/Maintenance stage. Most often, these decisions were driven by the closeness and trust between the decedent and the substitute decision-maker. Some participants noted discussions about substitute decision-makers often occurred years before the decedent was diagnosed with dementia as part of ongoing conversations about roles within their relationships. Some participants noted that the decedent chose a substitute decision-maker partly based on who would have the most time to take on this role and who was in closest proximity to the decedent. For example, one participant noted that she was asked to take on this role as she was retired while her other siblings were busy with work and with their own families.

An issue that arose for two participants was the unexpected death of a family member who was named as a co-substitute decision-maker, which led to revisions of the Representation Agreement. In both these situations, there was increased stress and worry for the participant as it was unclear what would happen if they were later unable to take on that role:

> *It was very stressful, particularly after my brother died and I realized that that changed the whole Health Representation Agreement because I was the only one left and we really don't have any other family… and I thought, oh my god, what would happen if something happened to me? … because there's so many restrictions, right, when you go to your alternate substitute decision-makers. There's a protocol that you have to go through, you know, with family … That was never discussed because my parents always assumed that my brother and I would be there. It never came up.*

Creating legal documents

All decedents except for one completed at least one type of legal document. Some participants noted that despite the decedent being too cognitively impaired to engage in other aspects of ACP, the decedent was able to answer questions needed to complete a legal document. An interesting observation after completion of all interviews was that there remained confusion about distinctions between the types of legal documents in British Columbia. Some participants were unable to specify which type of legal document had been created and some referred to types of documents that are not recognized in British Columbia, such as a living will. Other participants noted that only one type of legal document was created and there was an assumption that this would suffice. One participant noted that the decedent created a Representation Agreement and the family assumed that this would also cover financial decision-making but were later informed that an EPoA was also required by the bank. This suggests that there remains a lack of clarity and understanding of legal aspects of ACP even for people with firsthand experience in this area.

Fit with the framework of the TTM. All decedents except one were in the Action/Maintenance stage. Among the three ACP behaviours examined in this study, completing legal documents had the least variability in terms of stage of behaviour change. Most participants described creation of legal documents as being an essential part of medical self-management. Others noted that they were seen as a protection measure to ensure that the decedent was not subjected to medical procedures that he/she did not want. For many, legal documents had been created long before the onset of cognitive impairment often in tandem with the creation of wills and lawyers were often involved in the creation of these documents. One participant noted that within her family, creating legal documents was seen as an essential task:

> *It's just like all the stuff we had to do or our parents had to do to enroll in school. You know? You have to… you have to get that stuff in order to exit life the way that you want…. I think it's that mandatory.*

Others stated that the decedent insisted on creating these documents to lessen the burden on family members who may need to make decisions in the future. One participant noted that having wishes outlined in a legal document provided a sense of security that the decedent would be treated in a way that was aligned with their wishes even if the participant was not able to advocate for the decedent:

> *If something had happened to us, I still think that document … would have provided for whoever was looking after them in the care facility – I think it would have been very clear what they wanted.*

Other reasons for creating legal documents included encouragement from family physicians to do so, onset of serious medical issues, and, most commonly, requirements from care facilities that an AD and/or a Representation Agreement be in place prior to the decedent moving into care. A few participants indicated that the decedent decided to create legal documents after hearing about changes to legal aspects related to ACP in 2013.

Given that there are three types of legal documents related to ACP available in British Columbia, decedents may have been in different stages of behaviour change for each document. For example, one participant recounted that although her mother had created an EPoA and was therefore in the Action/Maintenance stage, she had not created an AD. However, they had discussed the creation of an AD and it appeared that her mother was getting ready to create one. She was therefore in the Preparation stage but did not reach the Action/Maintenance stage for creating an AD. Another participant noted that the decedent did not create an AD because it appeared overwhelming and daunting and therefore relied on the substitute decision-maker identified in the Representation Agreement to make decisions about specific medical treatments in the future. Conversely, another participant described the Representation Agreement as “a real muddle” and noted that the AD was more simple and straightforward.

Across all participants, it appeared that more families completed an Enduring Power of Attorney compared to the two legal documents related to personal/healthcare decisions. Many participants noted that EPoAs were strictly required by banks to allow for substitute decision-making on financial matters, prompting the creation of this type of document. Some participants noted that planning for financial matters was more readily apparent as an important issue in planning for the future as there needed to be a way to continue paying the decedent’s bills.

The one participant whose father did not complete any legal documents (Precontemplation stage) explained that he and his family were not aware that these documents existed. Interestingly, this was the only participant in this sample whose family was living on a reserve. He noted repeatedly during the interview that people on reserve have additional barriers in the healthcare system including a lack of access to resources common in non-reserve areas of British Columbia. The participant noted that by the time he learned about the legal documents, his father's cognitive impairment had progressed to a point at which he could not engage in this process. The participant stated that this prompted him to help his mother create legal documents, as he did not want to again have trouble with decision-making for a person whose wishes were not clear:

> *With the Representation Agreement or whatever … I could have been a better advocate for him with regard to visits with his doctor … I didn't know that I could speak on his behalf if we had a Representation Agreement … Putting down what each person wants for the end and having those things respected … it would alleviate a lot of pain. And it would alleviate a lot of fractures. And it would alleviate a lot of second-guessing. It would alleviate a lot of 'what ifs' and 'why didn't I do this?'*

Engagement in multiple ACP behaviours

A small minority of decedents had reached the Action/Maintenance stage for all three ACP behaviours explored in this study. Interestingly, these were all participants who had received significant support from a family physician in the ACP process. All these participants described having received sufficient education about ACP. Additionally, these participants described engaging in discussions about end-of-life preferences long before the decedent was diagnosed with dementia, all referring to the fact that talking about death was commonplace within their family. These participants all described their family as being supportive and denied any conflict about end-of-life decision-making.

More commonly, participants reported that decedents had variable readiness to engage in the three behaviours and had reached the Action/Maintenance stage for at least one behaviour, save for the participant-decedent living on a reserve described above who were in the Precontemplation stage for all three behaviours. For participants who remained in the Precontemplation phase for one or more ACP behaviours, it appeared that this was frequently due to lack of information about the other ACP behaviours, thus they did not go through the process of consciousness raising that occurred for those who moved into later stages of the TTM. For example, many of the participants who indicated that the decedent had created legal documents indicated that they had not been aware of other aspects of ACP and assumed that the legal documents would suffice. Interestingly, almost all the decedents who were in the Precontemplation stage for selection of a substitute decision-maker were also in the Precontemplation stage for having conversations about end-of-life goals. These participants indicated that they received little or no information from the family physician about ACP following the decedent's diagnosis of dementia. One participant stated that he asked the family physician for help with planning for care but was told that this was not the physician's role. These participants indicated that they did not think about planning for future needs until there was a problem needing to be addressed, such as needing to move the decedent into a care facility, and were therefore reactionary rather than proactive in their approach to planning.

No clear patterns emerged to explain differences in behaviour change across participant-decedent dyads; rather, individual factors as described in previous sections appeared to play a large role in decisional balance. Those who moved towards later stages of the TTM often did so with the help of family members, healthcare providers, or lawyers, a form of helping relationship within the TTM. It was clear, however, that creating legal documents was far more common than engaging in the other two ACP behaviours, with some participants alluding to the fact that they assumed that having legal documents was sufficient to ensure that the decedent would be able to receive the care they wanted at end-of-life. Several participants described creating legal documents as being rote and often without in-depth conversation about the content within the documents. The legal documents may have been viewed as more utilitarian and practical than the other two behaviours, with a notable benefit of not necessarily having to engage in difficult, potentially emotional conversations about end-of-life.

Participant experiences with ACP within the context of the caregiving role

To provide context for participant perspectives on ACP, I will first discuss experiences with providing care and will then focus on the role of ACP in the caregiving process. This will help situate participant experiences with ACP within the broader context of the caregiving role.

Most participants described great frustration with the medical system, both with the ACP process and throughout the decedent’s disease process. Caregivers were involved in providing psychosocial, physical/medical, and administrative support and care. Although homecare services offset some of these responsibilities, due to limited services available, the role of the caregiver remained significant and often overwhelming. Several participants invited the decedent to move into their home to provide more care. Other participants helped the decedent pay for private caregiving services in the decedent’s home as publicly-funded formal caregiving services were limited and were often insufficient to meet the decedent’s needs. One participant noted that although publicly-funded caregiving services were available, her mother (the decedent) was unable to access these services as she lived in an apartment building and, due to cognitive decline, was unable to locate the buzzer to allow the caregivers into the building.

Many participants described significant consequences to their own health related to the stress of providing care over long periods of time, sometimes leading the participant to retire or semi-retire from work or move in with the decedent to provide care and support them in staying at home as long as possible. Many participants also revealed that they experienced some anger and resentment due to the negative impact on their own quality of life, including inability to travel for long periods of time due to caregiving demands or having to move to another house and/or city and/or province to provide support for the decedent. Psychological costs associated with providing care and decision-making for the decedent included increased stress, anxiety, symptoms of depression, and poor sleep. One participant described himself as being so enmeshed in the decedent's care that he stopped taking care of himself even though he experienced serious health consequences due to his own chronic illness.

Many described experiencing guilt and shame when they were unable to follow-through on the decedent's wishes, which commonly meant placing the decedent in a care facility when he/she had expressed a preference to stay in their own home. Many participants stated that they continued to question whether they had made the right decision long after the death of the decedent. This was particularly strong for participants who were the substitute decision-maker and had to make the final decision about placing the decedent into care. One participant said that she became upset every time she visited the decedent in the care facility as the decedent repeatedly begged to be taken home. She stated that her visits became more spaced out because of their emotional impact. Another participant described providing a high level of care for her father (the decedent) who was adamant about dying at home and did not want to move into a care facility. These wishes were expressed in his legal documents and also in conversation with the participant, who was the substitute decision-maker. She described taking steps to keep him at home as long as possible, including paying for full-time care, but noted that he continued to deteriorate and had multiple falls. The participant was in tears when she described the moment she realized that she could no longer safely take care of her father and that he would need to move into care even though this was not what he had wanted:

> *At that point in time, lo and behold if I didn't develop a frozen shoulder and I had… I was on disability at work and I was totally incapacitated myself. So that was another determining factor in saying, "Dad, I can't look after myself, let alone look after you. Time is up. The jig is up. You're going into a home."*

Further, many participants believed that the caregiver experience and perspective was unimportant to healthcare providers and described feeling bullied and belittled by healthcare providers and having to fight for their loved one to receive additional support. This was often due to the onus placed on family members to provide care at home, either formally or informally, and to keep the decedent in their home as long as possible. One participant became quite angry and upset during the interview when he described an emergency room physician who accused him of harming his wife (the decedent) as she had several bruises. The participant said that he was enraged by the accusation as the physician did not understand that his wife bruised easily when receiving care. He also described being questioned about placing his wife in respite care a few times during the seven-year period during which he provided care. The participant stated that this proved to him how little healthcare providers care about the caregiver experience. He said that they did not understand the physical and emotional toll of providing care and making all decisions for another person.

Some participants experienced guilt when considering placing the decedent into care due to outward statements made by healthcare professionals that they should continue to provide care at home. Several participants noted that they were told that it was their responsibility to keep the decedent at home, even when the participants were experiencing significant hardship. Again, this led to an adversarial relationship with healthcare providers wherein participants saw themselves as being unimportant or dehumanized and viewed as caregivers only, not as people with complex and sometimes conflicting needs. One participant described her father (the decedent) becoming aggressive towards his wife, leading to concerns about safety in the home. She said that her father was strongly opposed to moving into care and they had to enlist the help of the family physician to move him into care in a roundabout manner:

> *And the sad part about it was, in order to get my father finally into care, we had to make arrangements with the doctor to accept him into the hospital and then my mother had to trick him into the hospital to go visit a friend of theirs.*

However, the participant stated that once her father was in the hospital, the hospitalist wanted to discharge her father back home and told the family there was nothing more they could do for her father. The participant described experiencing significant stress, anger, and frustration with the healthcare system as, from her perspective, it was clear that her father could not return home safely. She described reaching out to the Alzheimer's Society for support and eventually the asked the family physician to advocate on their behalf by speaking with the hospitalist:

> *Her doctor phoned the doctor at the hospital and said, "um, if you want to have both of them in there within a week, you go ahead and discharge them." And so, interesting how*

> *quickly they can find care for someone in the hospital once they realize that the family is not going to take them home. It's a horrible way to have to do it.*

A similar sentiment was expressed by a participant whose husband developed early-onset dementia in his fifties and who became quite aggressive and paranoid. The participant stated that his situation was unique in that he was unable to be supported by available resources as he was young, strong, and aggressive. She described ongoing conflict with healthcare providers after he was placed in a psychiatric ward in a hospital in a faraway city. The participant reported ongoing conflict with the hospital staff as she believed he was being overmedicated with antipsychotic medications, leading to loss of most functions, including feeding, toileting, and grooming, within a few months of hospitalization. The participant's emotional distress was palpable throughout the interview as she described facing barrier upon barrier when advocating for her husband, leading to an adversarial relationship with healthcare providers. She said that she felt the need to fight throughout her husband's illness trajectory as she was horrified by his treatment:

> *Because he was aggressive, none of the care homes would accept him. They said he had to go at least five days without an aggressive episode and he never did. They said they couldn't put him in a ward with elderly patients with Alzheimer's because he could hurt them. There was nowhere for my husband to go. Nowhere. {crying} ... I feel bad for what he went through. It was the most inhumane thing I've ever witness in my life ... There just has to be another way {crying}. There has to be another way. What they did to him was awful, you know... It's a nightmare that none of us have been able to get over.*

The participant whose family was living on reserve highlighted some additional difficulties experienced within his family, including additional responsibilities he took on, due to living on reserve and being Status Indian:

> *There's a difference between what the provincial healthcare system and what the First Nations Health Authority now in BC covers. They don't seem to be very well coordinated on some things … As our society ages … I think there has to be a better coordination between First Nations people who live on reserve – there's a lot of elders there – and access to what kinds of support they have within communities or hospitals or the Northern Health Authority or the regional health authorities or whatever. Those sorts of coordinations have to be better done because I think if we had lived off reserve and in town, we may have gotten better supports. But because we lived on reserve and we were Status Indians, there was a gap … I was the case manager for my dad … and then, as opposed to in a community setting, you can be assigned a case manager. And part of that whole thing is I didn't have that inside connection to what all the other services are. How all these things are connected.*

Caregiver burnout was a common experience due to the physical and emotional demands of providing care as well as the mental toll of being responsible for decision-making. Several participants described experiencing overwhelming stress, which impacted their functioning at work and in their relationships. This seemed to be especially true for participants who experienced a role-reversal whereby they were now taking care of and making decisions for their parents. One participant stated that she had not expected to be so heavily involved in providing care for the decedent as she thought formal caregiving services would be sufficient. She said that this was not the case and she sometimes had to clean and bathe her father, which changed the dynamic of their relationship and “diminished the man he was.”

Although most participants described negative consequences of providing support for the decedent, a significant minority noted that they did not experience distress or burnout through the process and were able to maintain balance in their lives. One participant stated that she felt honoured to be involved in the decedent’s care as this offered an opportunity to become closer with her parents. Very few participants described experiencing family conflict regarding ACP and end-of-life, with most describing their families being supportive and a source of strength. A loving, supportive, and communicative family appeared to be provide a buffer against experiencing overwhelming distress in the role of caregiver. Among the few who noted some family discord, this was primarily due to frustration and/or resentment based on the participant’s perspective that other family members were not taking on a more significant role in decision-making and in providing care for the decedent, causing the participant to feel even more overwhelmed with responsibility. From the participant’s perspective, this conflict generally arose due to differing beliefs about the decedent’s situation, namely that family members were often in denial of the extent of the decedent’s impairments. These caregivers felt that their family members did not appreciate or value the effort and time they put into providing care. One participant noted that she had only agreed to have her parents move into her house based on an arrangement with her sister whereby her sister would provide caregiving for half the year to allow the participant to have a break. However, the participant said that her sister rarely provided support, and this left their relationship fractured long after the decedent’s death.

A common theme among participant experience was taking on the role of advocate for their family member even if the participant had little or no information about the ACP process or about dementia itself. Many participants indicated that they became better advocates for the decedent through trial and error as they did not fully understand the role of substitute decision-maker. Many described being expected to take on roles and responsibilities for which they were unprepared due to significant gaps in knowledge and understanding about ACP and about dementia. Many participants felt that they had to bear the brunt of the responsibility for the decedent's care with little support from healthcare providers. One participant said that he felt like he became the case manager for his father as they did not receive support from healthcare providers, so he had to take on this role. Another participant said that she felt an enormous amount of responsibility for her father's care as she did not believe care was being provided in a way that was up to her standards considering her background in nursing. She described being afraid to go on vacation or to go out of town in case something were to happen to her father as she was the substitute decision-maker and there was no one else to take on that role in her absence.

Some participants described their role as being less of a family member and more of a go-between to relay information from one healthcare provider to another to ensure that the decedent's wishes were respected. Several participants reported frustration that information was not shared between healthcare providers, such as between care facilities and hospital physicians, and expressed fear that this would result in decedents getting treatments they had previously said they did not want. For many participants, there was an expectation that healthcare providers were overextended and under resourced and therefore the participant was required to bridge the gaps. Several participants noted that they kept copies of the decedent's legal documents in several locations to ensure the decedent's wishes were followed. One participant noted that she kept a binder with all the information about the decedent's ACP and requested that each healthcare provider they encountered make a copy of these records and keep them in the decedent’s chart. For some participants, this somewhat pessimistic view of the healthcare system was actually viewed as a benefit in retrospect, as it forced the participant to become heavily engaged with healthcare providers, sometimes leading to perceived better-quality care for the decedent. Several participants said that they believed the decedent would have been given treatments that were against previously-stated wishes had the participant not been regularly checking in with healthcare providers. There was, however, a common refrain of frustration due to barriers in the healthcare system that did not allow participants to follow-through on decedent wishes:

> *You [the healthcare system] should be supporting the family – letting them understand what’s happening. Not punching them. Because at times it feels like a punishment. Actually, I probably shouldn’t put it that way. It always felt like the bureaucracy was more important than caring for the family.*

Participants with a healthcare background considered themselves to be in a better position to advocate for the decedent. However, despite their understanding of the healthcare system, they too experienced significant challenges in accessing services and resources for the decedent. Throughout the disease and end-of-life trajectory, these participants did not find their background to be of significant benefit, as they still had to be vigilant and fight for the services they knew their family member required.

Participants described involvement in the decedent’s end-of-life process as an eye-opening experience which alerted to them to the possibility that they too may experience challenges with care in the future. Many became strong advocates of ACP for themselves and for other family members and friends based on their lived experiences. They described themselves as being more knowledgeable about the healthcare system and had learned to adapt to the constrains within the healthcare system. There was a strong motivation to avoid the pain and suffering experienced by the decedent and an impetus to take on proactive measures, including ACP, to lessen the future burden on those who may need to provide care for the participant in the future. Most participants stated that they had either already engaged in ACP for themselves or were in the process of doing so. One participant stated that although she understood the importance of engaging in ACP based on her experiences as a caregiver, she felt so traumatized from being involved in her father's care that been unable to face planning for her own needs.

Considering participant responses in wave 1 indicating that many experienced psychological consequences both from providing care and from their role as substitute decision-maker, participants in wave 2 were asked if they would have benefited from counselling services during their decedent's disease process. All participants agreed that counselling services should be made available considering the significant psychological impacts of supporting a person with dementia. Some had been offered these types of services through hospice following the decedent's death and described them positively. However, others noted that they would not have taken part in such services had they been available during their family member's disease process as they felt well-supported and experienced few negative effects from this process. Most participants agreed that these services should be publicly-funded, particularly as many caregivers are on fixed-incomes and cannot afford counselling services, particularly with clinical psychologists whose work is generally not covered by insurance. Some participants further noted that it would be beneficial to have easier access to peer-support groups to learn from the experiences of others who have been in similar situations:

> *You don't have to be in crisis to get help. And that's when people are at their lowest and its hard for them to reach out. If you could reach out when you're still strong, then life could be a lot better.*

Role of ACP in participant's perception of their family member's death

Most participants described the death of their family in positive terms and emphasized the role of ACP in helping their loved one die in a way that was as closely aligned with their values as possible. One participant highlighted the impacted of having engaged in ACP on her experience of the death of the decedent:

> *But this is what happens when you plan ahead. You can celebrate, you know, and play music and have everyone who ever wanted to come in and say goodbye … I mean, you still cry your eyes out – throw yourself on the ground and sob. But man, there's no guilt … Some of the conversations were not easy … I mean, if you care about that person, right, don't you want them to have, like, their final moments really good? … And it's just all dignity and respect for that person.*

There was a caveat for some participants that although they described the death as being 'good', it was not always in alignment with the decedent's wishes due to constraints within the healthcare system limiting choices for services:

> *We have to accommodate the system rather than the system accommodating the individual… she wanted her life to be very different and it couldn't be accommodated in a care facility. She wanted to be in a village atmosphere … darn it, I couldn't accommodate her {crying}.*

A few participants indicated that the decedent did not die the way they wanted to as they were unable to die at home due to being placed in a care facility. One participant whose mother died in a care facility acknowledged that although her mother wanted to die at home, this was not a viable option due to her physical care needs. She described dying in a case facility as being the best compromise between wanting to be at home and needing a high level of care.

One participant whose husband (the decedent) had both created legal documents and engaged in conversations about end-of-life preferences noted that this was beneficial not only for her as a substitute decision-maker but also for healthcare providers. She described a conversation with healthcare providers that occurred after her husband had fallen several times and his medical team wanted to put him in a wheelchair using restraints. The participant advised the team that independence was very important to her husband and that, based on their conversations about his beliefs, he would prefer to take the risk of falling rather than being confined to a wheelchair. The participant said that the medical team seemed to appreciate having guidance:

> *In fact, they [staff at the care facility] almost seemed glad to have somebody say, "no, don't do that. Let's do this or let's not…" and be quite specific about it. It takes the onus off of having them have to make their plans on a dicey subject.*

Several participants shared similar views and many noted that it was of particular value to have the decedent's wishes recorded in an legal document. Participants described healthcare providers as being highly supportive of the wishes recorded in legal documents. One participant said that the decedent began to deteriorate while living in a care facility and the physician wanted to admit her to hospital for IV and feeding because she was not eating. However, the participant showed the physician the AD created by the decedent which indicated that she did not want these types of measures. The participant stated that because of this document, his wife was made comfortable and able to die in her own room. Several participants noted that heroic measures were not attempted in the final days of the decedent's life, as per the decedent's previous requests, and that healthcare providers consulted with the family to ensure that they understood why these measures were not taken. Many described relief that the decedent was not hospitalized in the last few days of life as this aligned with previously-expressed wishes of not wanting to die in hospital. One participant noted the benefit of having an AD to confirm that the decedent did want life-prolonging measures in a situation where her mother was admitted to the emergency department and the attending physician asked the participant if they should discontinue feeding:

> *And I realized what he was saying to me, you know. But that wasn't the situation then – she did have good quality of life when she was 90 … I think having the Advance Care Directive was helpful in that situation too because I knew she didn't want to die, either. But what he was suggesting might have happened… they might have done that… But I do know that she wanted to continue living at that point. And indeed she recovered and she went home so, um, it was helpful having covered all that territory with her and having the directive, too.*

A small number of participants indicated that the decedent was provided with a palliative approach at the end-of-life, either through admission to a palliative care centre, moving into a palliative care floor within a care facility or through palliative care administered at home. These services were unanimously praised for the high quality of care provided. Two participants who described in-home palliative services for the decedent were particularly impressed with the care provided and recommended that others should consider this option. Many participants described having open conversations about death with staff in palliative care and found these conversations to be reassuring. Reasons for not receiving palliative services in a designated palliative care centre included lack of rooms in palliative care centres, not having time to implement the services due to a quick death, or family declining services due to concern about the possible negative effects of moving the decedent to a new location.

A very small minority of participants described conflict or difficulty during the decedent's dying process. A complex issue arose for one participant's mother who initially expressed a desire for no heroics when she was experiencing only mild cognitive decline, but who then changed her request as her cognitive impairment progressed. The participant said that the physician had informed her that medical interventions would be futile at this point and she was advocating for her mother to receive compassionate care. She noted that the situation became even more complex with the differing opinions of multiple family members who argued that she should be given all possible medical interventions:

> *As she progressed, she kept saying "no, I want everything that's available." Yeah, and so it got really interesting because if we knew her beforehand, that was not what she wanted… and then my brother, my younger brother, would just say, "well, you know, I know what she said beforehand, before she became demented, and we should go with that." … and then my uncle – her brother – became more involved and he said, "no, no. I know she wants everything." … if there had been more conversation beforehand, it wouldn't have been quite the drama it was at the hospital.*

The participant living on reserve also indicated that he does not think his father died in a way that was aligned with his wishes. He noted that his father strongly opposed being placed in a care facility due to traumatic experiences with being in residential school during childhood. However, considering the limited resources available on reserve, he was placed in a care facility. The participant described regret that his father died alone in the facility as this was against his wishes.

Perspectives on MAiD

General views on MAiD. Although MAiD had not been legalized when data were collected in wave 1, several participants indicated that they had thought about physician-assisted death during the decedent's dying process. Two participants stated that they became supporters of physician-assisted death after watching their family member become completely dependent for all aspects of care. One said that her father would not have wanted to slowly lose function due to dementia and that physician-assisted death would have been preferable had it been available:

> *If we could have known his wishes and we could have done what he would have wanted done, he would have ended his life sooner… when you get to the point where there's no way of returning, and knowing how he lived his life and what he believed in his life, he would not have liked to have dragged it out as long as it was dragged out … to him, it was a waste of time and resources when you're not going to get any better. Just, you know, let me go.*

There was unanimous support for MAiD among participants in wave 2 of data collection. Participants praised MAiD as a way for a person to retain autonomy and control over the type and quality of their death. One participant with a healthcare background stated that she was glad that MAiD was now legal as she believes assisted death has been happening under the table more than most people realize. She described being happy that it was now being done openly and is more easily accessible to those in need. Most participants noted that they would consider MAiD for themselves in the future should the circumstances warrant consideration of end their lives.

Although this study was completed shortly after the legalization of MAiD, some participants already had experiences with family members or close friends who completed MAiD. One participant described the death of a friend who chose to have MAiD following diagnosis of terminal cancer. The participant said that his friend was very calm and comfortable with his decision, in part due to the physician involved in the MAiD process who was very supportive. He noted that his friend was surrounded by friends and family on the day of his death and that the physician spoke with each person during the process. The participant stated that based on his friend's experiences, he too would choose to have MAiD in the future if he had a terminal illness. However, another participant noted that although she had always been supportive of euthanasia, her views shifted after experiencing the impact of a client who chose to have MAiD. She described conflicting emotional reactions to the assisted death, particularly regarding the 'reverse grieving' she experienced prior to the person's death and the unexpected desire to intervene and stop him from completing MAiD:

> *But then I realized the emotional thing that I went through … and what it's doing to our minds is that it's reversed grieving, which is unusual. Often you will have in life maybe an illness – you're grieving through maybe a longer period of time. And maybe the person dies and then you… part of your grieving has already happened so you feel relief perhaps because you've done some processing … but rarely do you grieve ahead. To say,*

> *I know they're not going to be here on that day at that time. That's different and an unusual experience.*

Perspectives on MAiD for people with dementia. Despite the consensus of a favourable outlook on MAiD in general, there was far less agreement about the role of MAiD for people with dementia (which is currently not legal). Many participants noted concern and hesitation about allowing MAiD in a vulnerable population. However, others noted that there can be significant suffering for people with dementia and that this could be alleviated through MAiD:

> *Life to me, there has to be a quality of life. There has to be pleasure. There has to be joy. None of those things exist for my mom. None of it. There's no pleasure in daily life. There's no life. There's existence. There's a difference. Who would choose that? Honestly, who would choose that? I don't know anybody that would choose that.*

One participant gave an example of a woman with dementia who resided in the same care facility as the decedent. She described this woman experiencing significant distress due to her cognitive impairment as she thought she was back in a concentration camp. The participant asked why this woman shouldn't be allowed to have MAiD considering her emotional suffering.

Some participants supported the right of people with early dementia to request MAiD while they still had capacity to make medical decisions, which could be carried out at a future point when they had increased pain and/or suffering. However, many pointed out the inherent difficulty in ascertaining the point at which MAiD would be appropriate for people who cannot engage in meaningful discussions about their pain and quality of life due to cognitive impairment. One participant said that she was concerned about MAiD for people with dementia due to their detachment from reality and questioned how they could provide input on their degree of suffering. One participant highlighted that the issue of MAiD for people with dementia was much more complicated than for people with other life-limiting disease such as cancer.

Many participants supported the inclusion of MAiD in ADs, though again, there was a lack of clarity on how this could be implemented considering uncertain trajectory of symptoms in dementia. Suggestions included clearly outlining the symptoms and conditions that would trigger MAiD, such as severity of impairment or functional limitations. However, one participant pointed out that it is difficult to clearly demarcate in advance the point at which quality of life is unacceptable because most people do not have experience with the cognitive and functional decline experienced in dementia. She asked how a person could state in advance that requiring assistance with toileting is unacceptable if that person has not had this experience. Other participants further noted that including a request for MAiD would be difficult to accomplish given the current stated of knowledge about the disease and the limited information available about survival time following diagnosis. One participant described a friend who had been expected to live for ten years following diagnosis of Lewy Body dementia but has long outlived that timeline and continues to have a good quality of life. The participant noted that had her friend requested to have MAiD after a specified period, she may have lost out on years of good quality life. One participant stated that clear guidelines about the dementia disease trajectory need to be available before MAiD can be considered for people with dementia.

Several participants described stockpiling medications to euthanize themselves should they develop dementia. This was primarily based on fear and disgust that developed while watching the decedent suffer, sometimes for many years, prior to death. Participants described these stockpiles as a source of relief and control over their potential futures, noting that the decedent did not have control over their own death:

> *My sister and I both fear that we will get Alzheimer's disease and we have a pact with each other … we're stockpiling pills.*

Hypothetical scenario: MAiD for the decedent. Although participants in wave 1 were not specifically asked about MAID as this legislation had not yet passed, two referred to their disappointment that euthanasia was not available for the decedent as the decedent would have preferred euthanasia to the death they experienced. One described her mother's desire to die:

> *She had often asked if I couldn't just give her a pill so that she go to sleep. She well into her hundreds … she was having a hard time and knew it. And she just didn't want to be here, you know? That's very difficult for residents at that age or anyone at that age who is uncomfortable and feeling a lot of pain … to realize that you have no control over what you can do with your life. And despite her dementia, she recognized that.*

In wave 2, participants were specifically asked if they believed the decedent would have wanted MAiD. Many participants indicated that their family member would have welcomed an opportunity to hasten their death once they had little to no quality of life:

> *We treat our animals better than we treat our humans {crying}. It's true. You know, [husband] would have liked to have died with dignity. He didn't. He didn't get that choice.*

One participant stated that her father experienced suffering and a prolonged death and noted that she thought about smothering him with a pillow to end his suffering but could not go through with it. She described being angry that she had to contemplate such an action because MAiD was not available to him. The participant said that allowing MAiD for people with dementia would have prevented him from experiencing five days of unnecessary suffering.

Many participants stated that the decedent would not have been interested in requesting MAiD as they were not suffering or in pain and retained some quality of life. For others, MAiD would not have been an option due to religious beliefs or traditional values about death in which death should not be hastened.

In the hypothetical scenario, participants were asked to imagine their reactions to agreeing to MAiD for the decedent. There were mixed emotions about being involved in these decisions, ranging from discomfort and fear about making the wrong decision to relief that the decedent's suffering would be over.

> *It would be a relief. You just can't even imagine what its like to go visit somebody in that state. Every time I go visit her, I say goodbye to her every time. I beg her to let go: there's no life left for you here on earth… I beg her to go but I don't know why she's still holding on. You know*

Several participants became uncomfortable when asked to imagine agreeing to another person's death:

> *It's scary. It's real scary if someone else says go ahead.*

One participant raised concerns that some substitute decision-makers could request MAiD for a family member due to secondary gain, such as gaining control of the person's estate. Another noted that although she wants to believe that people have good intentions, she knows that some people do not and that there could be risk in giving them the right to choose death for another person.

Summary of results

For most participants learning about ACP occurred in a haphazard and piecemeal manner, with most having an incomplete understanding of the multiple facets of this process. For many, the concept of ACP did not appear to apply to the decedent’s situation due to insufficient or inaccurate understanding about dementia itself and its impact on the decedent’s future cognitive and functional abilities. Interestingly, when education about ACP was provided by a family physician, participants felt that they had sufficient information to help the decedent engage in ACP. Of note, among those who felt they had sufficient information, most had a background in healthcare and considered themselves to be proactive in reaching out for information.

There was variable engagement in the three ACP behaviours explored in this study: family discussions about preferences for end-of-life care, identification of a substitute decision-maker, and creation of legal documents. Creation of legal documents was the most common behaviour, with some suggestion that this was the ‘easiest’ and most obvious aspect of ACP and the aspect most frequently discussed when education was provided about ACP. Families who received comprehensive education about ACP from family physicians were also the ones who engaged in all three ACP behaviours.

Participants often described expectations about the type of care that would be provided for the decedent during their illness. However, these expectations often did not match the type of care and services that were provided, leading to anger, frustration, and stress. There was a sense that participants perhaps did not understand the logistical aspects of healthcare service delivery and how this would affect the decedent’s care. This issue frequently came to the forefront when decedents needed to be moved into a care facility and participants learned about the limited resources available. This was particularly noticeable among participants who had not anticipated the emotional toll of substitute decision-making. In terms of perceptions of decedents' quality of death, most participants described the death in positive terms, noting that engaging in aspects of ACP was helping in guiding decision-making and end-of-life. However, there was again acknowledgement that despite best intentions, the best-laid plans captured in ACP did not always fit within the practical and logistical constraints of a healthcare system.

Discussion

The purpose of this study was to collect rich, qualitative accounts of the ACP and end-of-life process of older adults with dementia living in British Columbia through the lens of their family members. There remains a dearth of understanding of the complexities of this process, particularly a lack of information about the reasons people engage in ACP. This type of information is not only relevant, but necessary, to provide guidance for development of policy within health regions, which is in alignment with previously-identified Canadian healthcare priorities (Johnson et al., 2013). A recent review (British Columbia Ministry of Health, 2016) of the implementation of these priorities noted that this goal has been completed by the publication of the *My Voice: Expressing my Wishes for Future Health Care Treatment* (British Columbia Ministry of Health, 2013) planning guide and the creation of an online ACP workbook, *Speak Up BC* found at http://www.speak-upinbc.ca/make-a-plan/. However, there is a lack of research providing information on the current state of ACP in British Columbia, particularly for older adults with dementia and their families. To that end, the three research questions underlying this study will be discussed below, followed by a discussion of the impact of this research on clinical practice for neuropsychologists and the applicability of the study results to further development of policy on ACP in British Columbia.

When and how do cognitively impaired older adults and their families receive information about ACP?

Information about ACP was not consistently provided to participants, with some receiving no education on this topic at all. Among those who did receive information, sources varied and included family physicians (for a small minority) and caregiver support groups or, more often, when the topic came up by chance in conversation with friends or others who had gone through the ACP process themselves. Those who received information from a family physician were confident in helping the decedent engage in ACP due in part to the breadth and depth of information provided. These also tended to be participants who described their families as being engaged in lifelong discussions about death and dying. This raises an interesting question about the directionality of this relationship: do families who are comfortable discussing death and planning for end-of-life seek out family physicians who have similar views or do families become comfortable talking about death and dying because they have a family physician who encourages these types of conversations? Considering the nature of the data collected in this study, causality in this relationship could not be ascertained but would be of great interest for further evaluation in future research.

By design or by default, the family physician is assumed to play a major role in providing education about ACP, though it does not appear that this has been a deliberate choice within the healthcare system as it remains unclear who exactly should be providing this type of information. There was a general sense that the family physician should be providing this type of information, but some participants acknowledged that perhaps they are not in the best position to do so. Robinson and colleagues (2013) identified several key areas for training for healthcare providers: increased understanding of legal aspects of ACP and a hierarchical approach to division of responsibilities regarding ACP. They suggested that generalists should become proficient in carrying out aspects of ACP but that they should also be familiar with other resources and specialists to whom they can refer people for other aspects of ACP (i.e., a lawyer for creating an EPoA). It is therefore promising that educational initiatives aimed at increasing physician comfort with engaging patients in ACP are occurring and receiving positive feedback (Chan et al., 2016).

A theme among participants was a lack of knowledge and understanding about dementia, which became a barrier to engaging in ACP. Many participants indicated that more information is needed from healthcare providers about the disease itself as this is a baseline requirement to be able to thoughtfully plan for care in the future. Some participants described healthcare providers as being afraid of using the word ‘dementia’, which led to confusion and uncertainty about the nature of the decedent’s decline. This is consistent with previous research showing that family members had difficulty with decision-making due to insufficient information about the nature and course of dementia (Caron, Girffith, & Arcand, 2005). A review of physician opinions and practice regarding disclosure of dementia diagnosis identified several reasons why physicians may not disclose a diagnosis of dementia to patients and their families (Carpenter & Dave, 2004). These reasons include fear of causing psychological distress to patients and/or family members, lack of treatment options for dementia, and avoidance of uncomfortable conversations. However, Byszewski and colleagues (2007) interviewed patients and caregivers following disclosure of a dementia diagnosis and found that most preferred full disclosure of their condition. Further, disclosure of the diagnosis facilitated discussion of the implications of the disease on functioning, including planning for future needs.

Due to similar concerns about lack of knowledge about dementia as a barrier to ACP, Sussman and colleagues (2017) created illness trajectory pamphlets for residents of long-term care facilities and evaluated the impact on ACP. Participants felt more prepared to think about and discuss future medical needs a after being provided with the pamphlets. The authors suggest that providing such information may prime and prepare people to engage in ACP. A randomized controlled trial assigned older adults into two groups, one of which received a verbal reading about dementia while the other listened to the narrative and watched a video depicting a person with advanced dementia (Volandes et al., 2009). Participants in the video group were more likely to choose comfort care as their preferred future care goal if they developed dementia, a preference that remained stable on follow-up six weeks later. The authors suggested that use of a video increased participants' understanding of the realities of the disease, a key component in planning for end-of-life care.

There was an acknowledgement that perhaps education about ACP was provided from some but that participants were not ready to process this information, possibly due to denial, stress or fear in reaction to learning that the decedent had been diagnosed with dementia. Similarly, a pilot study aiming to implement an ACP intervention for people with severe dementia in an acute medical study identified significant difficulty engaging caregivers in creating an advance care plan, often due to opposition to discussing end-of-life (Sampson et al., 2011). However, family members were interested in receiving more information about dementia and end-of-life, despite not creating formal plans. The authors suggest that implementation of ACP interventions in an acute care setting would likely be challenging and should be done at an earlier point in the person's illness trajectories. Further, there will likely need to be an ongoing learning process to familiarize patients and family members with patient-specific illness trajectory and to learn about available resources to prepare for future contingencies.

Overall, there was a consensus that further educational resources are needed, both in terms of general information about dementia and about ACP. Further, this type of information should be offered to families as opposed to assuming families will ask for education as studies suggest that family members of people with dementia living in long-term care facilities tend to wait for members of the healthcare team to give them information, rather than actively seeking the information themselves (Caron et al., 2005). A review of interventions aimed at increasing creation of ADs revealed little to no increase in AD completion following didactic interventions while rates were much higher for studies with interactive interventions (Jezewski, Meeker, Sessanna, & Finnell, 2007). Further, interventions which included repeated contact over time were most effective. These results suggest that successful ACP interventions should include interactive components wherein people can ask questions and/or receive assistance with ACP and should include follow-up to allow ACP to occur over time.

In a meta-analysis of studies investigating the effects of interventions aimed at increasing patient completion of ADs in primary care settings, interventions that specifically included interactions between a patient and healthcare provider was most strongly associated with higher completion rates, particularly if this interaction was done over multiple visits, rather than at one point in time (Ramsaroop, Reid, & Adelman, 2007). Interestingly, the authors found that interventions using written materials (with no direct conversation with a healthcare provider) were ineffective in increasing rates of AD completion.

In which aspects of the ACP process do families of cognitively impaired older adults engage, and why? Does engagement in ACP behaviours fit within the conceptual framework of the TTM?

The results of this study support and expand upon previous research on application of the TTM to ACP behaviours (Fried et al., 2009; Sudore et al., 2008) by applying this theoretical structure to people with dementia. Consistent with previous studies of cognitively intact older adults, participants in the current study were in different stages of readiness of the various ACP behaviours (discussion of beliefs, values, and goals with family, identification of a substitute decision-maker, and creation of legal documents relevant to ACP) and two processes of change were identified: consciousness raising and helping relationships. However, a significant limitation of the TTM is that it does not consider the social context of the decision-maker and ignores social factors that may impact behaviour change (Adams & White, 2005; Burke, Joseph, Pasick, & Barker, 2009; Sorensen et al., 2003). This is of particular concern for this study considering responses from some participants indicating that engagement in ACP was prompted by social factors such as changes to legislation associated with ACP. This suggests that although the TTM is a helpful framework for understanding decision-making regarding ACP, we must also consider other context factors that may influence behaviour.

In terms of discussions with families, nearly half the sample did not engage in any type of discussion about end-of-life preferences, with many decedents described as actively opposing attempts to address this issue due to traditional or religious beliefs wherein death is not discussed. For others, these conversations did not occur because they did not seem relevant at the time due to erroneous beliefs about the course of dementia or assumptions that there would be no difficult decisions needing to be made in the future. This is concerning considering previous research that found low agreement between the healthcare choices of people with mild-to-moderate dementia and their caregivers and, perhaps even more concerning, that caregivers frequently chose to override the decisions of their family member in hypothetical scenarios (Horton-Deutsch, Twigg, & Evans, 2007). Among those families in which these conversations did occur, many stated that talking about death and dying was the family norm. This is consistent with the tenets of a palliative approach wherein dying is viewed as a part of living (Canadian Hospice Palliative Care Association, 2015). Considering that these participants were among those with little family discord about ACP and end-of-life care for the decedent, this may provide some support for promoting such an approach at a family-system level.

In some families, discussions about goals for end-of-life appeared to be quite brief with the decedent simply stating that they preferred no heroic measures. Although it is encouraging that these types of discussions are happening at all, these types of surface-level conversations may not provide the detailed information needed for substitute decision-makers in the future as it is difficult to ascertain the true meaning of ‘no heroics’. Further, many decedents expressed a strong desire to stay in their homes and to die at home. However, for many this became impossible due to the level of care and support required due to significant cognitive and functional decline or due to lack of resources available to keep the decedent in their own home. This suggests that conversations about end-of-life care need to incorporate an exploration of underlying values and beliefs within the context of what is possible within the healthcare region.

There was greater variability in terms of readiness to select a substitute decision-maker, with the sample nearly evenly split between the Precontemplation, Contemplation, and Action/Maintenance stages. Assumptions appeared to underlie readiness to engage in this process, either by assuming that selecting a substitute decision-maker was not necessary (Precontemplation phase) or assuming a specific person would take on this role but not formalizing that selection in a legal document (Contemplation phase). This is concerning considering assumptions made by some participants, such as believing that they would be named the substitute decision-maker due to being the eldest offspring. This is not in line with the TDSM legislation, suggesting that understanding of the relevant laws is inadequate.

Among the ACP behaviours explored in this study, creation of legal documents was the most consistent behaviour, with all but one decedent creating at least one type of legal document. In comparison to the other two ACP behaviours, creating legal documents was perceived by participants as the most obvious aspect of planning for future needs, especially creating an EPoA to plan for financial decision-making. There were often prompts to create legal documents from healthcare providers, from care facilities, or from lawyers. This is consistent with previous research that found that older adults were more likely to have completed an AD if the document had been explained to them by a healthcare provider or if the provider asked them to complete the form (Alano et al., 2010). Somewhat unexpectedly, there remained a great deal of confusion among participants about the types of legal documents in British Columbia even after having firsthand experience with these documents, further suggesting that there remains a lack of understanding of legal aspects of ACP.

What role does ACP play for family members? How does this relate to the way in which they perceive the quality of death of their loved one?

Most participants described significant physical and emotional costs associated with providing care for the decedent, often related to taking on the role of advocate for the decedent. Many described their relationship with healthcare providers as adversarial in their attempt to help the decedent access the care or services requested through ACP. They described guilt, anger, and sadness when they were unable to follow through on the decedent’s wishes, which was often a result of systemic barriers or a lack of resources. Many described this process as being eye-opening and noted long-lasting effects on their own perspectives on death and ACP. This is consistent with research by Amjad and colleagues (2014) who found that although personal experience with a serious illness was not associated with increased engagement in ACP, experience with end-of-life care and/or end-of-life decision-making for others increased readiness for engaging in ACP. Interestingly, participants who were involved with someone who had a poor-quality death and received too little care at end-of-life were more likely to engage in ACP than those who witnessed people at end-of-life who received too many medical interventions. The authors suggest that this could be used a way to promote ACP and facilitate discussions.

Considering previous research suggesting that engagement in individual aspects of the ACP process is associated with improved quality of care at the end-of-life (Bischoff et al., 2013), it is perhaps unsurprising that most participants described the death of the decedent in positive terms and highlighted the value of ACP. Among those who described poor quality of death for the decedent, there was frustration with healthcare providers who attempted to prolong life through medical means even though this contradicted the decedent’s previously-stated wishes. Participants described unnecessary suffering and prolongation of life, many alluding to regret that MAiD was not available (discussed in more detail below).

An issue raised by one of the participants was the lack of access to services for First Nations people living on reserve. This is concerning considering data suggesting a higher prevalence of dementia among indigenous populations compared to non-indigenous populations (Warren, Shi, Young, Borenstein, & Martiniuk, 2015). Similar deficits have been noted in the literature and there is an attempt to mitigate some of these issues through implementation of community-based palliative care services in some First Nations communities in Ontario and development of culturally-appropriate ACP materials (Fruch, Monture, Prince, & Kelley, 2016). However, further work is likely needed to fully address the barriers to ACP and quality end-of-life for First Nations people in British Columbia.

One of the participants in this study was providing support and caregiving for a spouse with early-onset dementia and identified several additional barriers to good care at end-of-life as her spouse had limited access to resources due to his young age. This experience is consistent with previous research in a nationally-representative Canadian sample investigating the impact of early-onset dementia on health and life stress (Novek, Shooshtari, & Menec, 2016). The authors found that people with early-onset dementia had longer delays in diagnosis and experienced more life stress than people with onset of dementia after age 65. This highlights the necessity of developing services for people with early-onset dementia, including ACP interventions.

Limitations and future directions

Several limitations to this study must be noted. First, I did not have access to medical records for decedents in this study and was therefore unable to confirm diagnosis of dementia. However, I attempted to mitigate this issue by asking participants to provide information that is in line with DSM-5 diagnostic criteria for dementia and to provide subjective perspectives on cognitive and functional abilities. Nonetheless, it is possible that I may have had incomplete information about diagnosis based on third-party report. Although the sample size in this study was relatively small, this is not surprising as this is a first step in exploring ACP among a specific population, that is, older adults with dementia in British Columbia.

It is possible that participants were not privy to all aspects of decedent engagement in ACP and could therefore assume the decedent was in a different stage of change than they had been. For example, participants may have discussed their goals for end-of-life care with a family member who did not participate in this study; thus this information was not captured.

Additionally, although inclusion criteria for this study specified that the decedent's date of death was within ten years from the date of study participation, participants may have forgotten some aspects of the decedent's illness trajectory and/or ACP. In terms of application of the TTM, I was unable to explore internal processes of change as this study relied on third-party information.

An additional limitation is that all decedents in this study had at least one family who was involved in their care; therefore, their situations may be quite different from older adults with dementia who do not have family or have family members who are uninvolved in their care. Considering the demographics of the participant-decedent dyads in this study, most of whom were of Caucasian background and of high educational attainment, results of this study may not represent the experiences of people of other sociodemographic status.

To my knowledge, this is the first study to explore the process of ACP in British Columbia and to explore the applicability of the TTM to ACP for people with dementia. Considering the small sample size in this study, it would be of benefit to gather further data from British Columbians to more fully understand the ACP process in the context of dementia. It may be of interest to over-sample people with experiences that are generally underreported in the research, including people with early-onset dementia and those living in remote areas (including on reserve). A prospective study following people with dementia from the time of diagnosis until after death, which includes longitudinal data collection with the patient and a family member, would provide complimentary data on the process of ACP over time. Together, this type of research can help guide policy to further improve care for people with dementia.

Implications for the practice of clinical neuropsychology

Neuropsychologists are often involved in the diagnostic process for people with dementia, either through their role in a dementia clinic or through standalone neuropsychological assessment in public or private settings. We are in a unique position to not only offer information relevant to diagnosis, but to also engage in therapeutic feedback sessions following completion of assessments. This may be an opportunity to begin engaging clients in discussions about planning for future care needs, possibly breaking this into several sessions to allow time to process this information and begin to accept the situation.

All participants in the second wave of data collection agreed that counseling services should be available for family members providing care for people with dementia, though very few had access to these types of services. A review of interventions to mitigate negative consequences of providing caregiving for people with dementia found support for psychosocial interventions, which either include psychoeducation, psychotherapy, or a combination of the two (Richardson, Lee, Berg-Weger, & Grossberg, 2013). Similarly, Dickinson and colleagues' (2017) review of psychosocial interventions for caregivers of older adults with dementia suggested that the most effective interventions should include an educational component to increased caregiver knowledge about dementia and a psychotherapeutic component to address the psychological sequalae of providing care. There has been support for both Cognitive Behavioural Therapy and for Acceptance and Commitment Therapy in decreasing depressive symptoms of caregivers of people with dementia in a RCT (Losada et al., 2015). The authors speculate that although the approaches differ theoretically and in their mechanisms of change, they share common mediators of change: increasing the frequency of pleasurable events (through behavioural activation in CBT or through commitment to values-based actions in ACT) and decreasing dysfunctional thoughts.

Given the unique training in many clinical neuropsychology programs, which provide training in both general clinical psychology and neuropsychology, neuropsychologists have a great depth of knowledge and experience not only with the biological aspects of dementia, but also the psychosocial sequalae of such a disease on individuals and their family members. Neuropsychologists may therefore be in an ideal position to spearhead efforts to provide support for family members of people with dementia.

Implications for policy on ACP

Although ACP is often completed in a haphazard manner, several groups have recently evaluated the impact of targeted interventions to increase engagement in ACP. In a recent ACP intervention for cognitively intact community-dwelling older adults in Quebec, 80% of the participants created a legal document outlining their future medical wishes following the intervention (Bravo et al., 2016). A unique aspect of their intervention was a focus on discrepancies in preferences between the older and their future substitute decision-maker to highlight the difficulty inherent in substitute decision-making. Including this experiential component in the intervention may have provided further motivation for participants to document their wishes to ensure that the substitute decision-maker understands their preferences. However, a systematic review of randomized controlled trials of ACP interventions revealed a great deal of heterogeneity across nine studies included, including vast differences in quality of the studies (Weathers et al., 2016). The authors concluded that there was some benefit from ACP interventions, there remains a dearth of high-quality RCTs that incorporate the impact of ACP on quality of care from a multitude of perspectives, including older adults, their family members, and healthcare providers. The authors also identified a lack of high-quality research on the economic impact of ACP interventions which could be used to inform policy.

Livingston and colleagues (2013) first described the implementation of an intervention in a nursing home for people with dementia, which involved a ten-session manualized training program for staff regarding care at the end-of-life for people with dementia, including ACP. Family members reported increased satisfaction with their relative's care at the end-of-life and increased involvement in and satisfaction with decision-making during end-of-life. This study provided preliminary evidence of the benefit of ACP interventions for families of people with dementia, but further research is required due to small sample size and homogeneity of patients.

Recently, Aasmul, Husebo, and Flo (2018) described the barriers and facilitators of an ACP intervention in nursing homes for older adults with and without dementia in Norway that was part of a large RCT. Staff at the nursing homes reported that having clearly delineated roles and responsibilities couched within the structure of the organization helped them implement the ACP intervention. The authors noted that a key component of the ACP intervention was providing education about ACP to patients and families with a focus on its importance and relevance to quality care. Barriers to implementation of the ACP intervention included lack of time to engage in ACP, lack of staff competence, and cultural differences affecting views on ACP. Interestingly, many staff members did not believe that patients with dementia should be included in ACP and were therefore reluctant to do so, even though staff training materials highlighted the fact people with cognitive impairment can participate in ACP. The barriers identified in this study, particularly about staff beliefs concerning the ability of people with dementia to engage in ACP, should be kept in mind when considering promotion of ACP in British Columbia.

It has long been suggested that the framework of the TTM can be used to help clinicians address taboo topics with patients, including planning for end-of-life (Rizzo et al., 2010; Westley & Briggs, 2004). Sudore and colleagues (2014) developed a website, PREPARE, to support engagement in ACP that is based in part on the TTM. Although people with dementia were excluded from a recent RCT, recent evidence suggests that this website can increase engagement in aspects of ACP for older adults with multiple medical conditions (Sudore et al., 2017). A Canadian website, *Speak Up*, has also been developed to help people engage in ACP and includes workbook specific for people living in British Columbia.

Fried and colleagues (2016) pilot-tested a method to provide information on ACP based on people' stage of readiness to engage in various ACP behaviours. Participants were provided with brochures and individualized feedback based on their readiness to engage in several aspects of ACP, which were well-received by a small group of older adults. Further research is needed to more thoroughly assess the impact of ACP interventions based on the TTM but Fried and colleagues' (2009) study provides an exciting step towards providing ACP interventions tailored to a person's readiness to engage in various aspects of the ACP process, which could perhaps be further modified in the future to include information pertinent to those with dementia.

Designing interventions to increase ACP based on the TTM appears to be gaining traction and fits well with a motivational interviewing approach (Ko, Hohman, Lee, Ngo, & Woodruff, 2016). The goal of motivational interviewing is to facilitate behaviour change by helping clients explore ambivalence about making change and is seen as a means of facilitating change within the TTM (Britt, Hudson, & Blampied, 2004). In terms of application to ACP, a pilot study was completed in which participants were provided with motivational interviewing-based counselling based on their stage within the TTM (Ko et al., 2016). The authors found that most participants moved to the next stage within the TTM even after a single session of motivational interviewing (i.e., from precontemplation to contemplation or from contemplation to preparation, etc.).

Taken together, there is preliminary evidence to suggest that targeted interventions to increase ACP can have positive impacts not only at the family level but also at a systemic level. In fact, Nguyen and colleagues (2017) supported the implementation of a national policy on ACP in Australia and internationally based on the cost-effectiveness in a simulated population of older adults at risk of dementia. They noted several factors necessary for successful implementation of such a program: access to community care and/or palliative care, increased education of healthcare providers about ACP, increased education for the public about ACP, introduction of ACP to patients by primary care providers, and improved communication between primary and tertiary care. Interestingly, the authors highlighted the importance of early intervention as introduction of ACP later in life was significantly less cost effective.

MAiD. Questions about MAiD were added in the second wave of data collection following the legalization of MAiD in Canada in 2016. Although participants unanimously supported MAiD for cognitively intact people, there was far less certainty regarding its hypothetical application to people with dementia, which is currently not legal. Debate continues regarding the moral and ethical acceptability of physician-assisted suicide, including the slippery slope argument that there may be unintended consequences for vulnerable people, including those with dementia (Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen, 2016). There was significant concern about the role of a substitute decision-maker choosing MAiD for another person and the ethical and moral ramifications of such a decision. There was also concern about the possibility of secondary gain driving a substitute decision-maker's choice to end another person's life. However, potential benefits of MAiD in this population were also noted, particularly regarding a person's right to autonomy. To date, a small number of people with dementia have received physician-assisted euthanasia in the Netherlands (de Beaufort & van de Vathorst, 2016). These people were all in early stages of dementia and were deemed competent to make this decision for themselves, thereby eliminating the burden of decision-making that a substitute decision-maker would need to take on once a person with dementia becomes incompetent of making such a decision.

There was a suggestion that this type of request could be included in an AD, though again there was uncertainty of how this could be implemented. It has been argued that people with dementia should be able to request assisted death by including this in an AD created when they are still competent (Menzel & Steinbock, 2013). The authors argue that people with dementia can experience significant suffering and have a right to autonomy, supporting the moral argument for assisted death. However, the issue is complicated by the heterogeneous disease trajectory for people with dementia, the difficulty imagining what life is like with advanced dementia, and debate about identity changes (and possible accompanying values changes) with progression of cognitive impairment. The authors argue that there are circumstances in which ADs requesting physician-assisted death can be appropriate even for people with severe dementia, particularly if they are informed, thoughtful, and based on fact and the person is experiencing significant and unrelenting suffering. On the other hand, a multitude of concerns have been raised about the feasibility of including a requested for assisted death in an AD, notably that this does not allow people to change their mind later due to eventual incompetence related to progressive neurodegeneration (Mitchell, 2010). Some argue that an ethical requirement for physician-assisted death should be competence both at the time of making the decision and at the time of the assisted death, therefore precluding inclusion in an AD (Gather & Vollmann, 2013). This is an ongoing debate fraught with ethically- and morally-complex issues. However, considering participant views in this study and ongoing public debate about the role of assisted-death for people with dementia (Picard, 2017; Woods, 2017), it is one that will need further scrutiny.

Conclusions

The current study provides a first step towards an in-depth understanding of the ACP process within families of people with dementia residing in British Columbia. Although ACP was generally considered to be of benefit, several gaps and barriers were identified including a lack of clear structure to provide patients and family members with education about dementia and about ACP as well as person-level, family-level, and system-level barriers to engagement in ACP behaviours. The TTM appears to be a useful framework for understanding ACP and for creating patient-centered individualized interventions to increase engagement in ACP, though more research is needed on its applicability in this population.

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Appendix A – Ethics Certificates

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Victoria British Columbia V8W 2Y2 Canada
Tel 250-472-4545, Fax 250-721-8960
ethics@uvic.ca www.research.uvic.ca

University of Victoria

SCANNED

Certificate of Approval

PRINCIPAL INVESTIGATOR:	**Anna Jeznach**	**ETHICS PROTOCOL NUMBER** Minimal Risk - Board members	**14-121**
UVic STATUS:	**Ph.D. Student**	ORIGINAL APPROVAL DATE:	18-Jul-14
UVic DEPARTMENT:	**PSYC**	APPROVED ON:	18-Jul-14
SUPERVISOR:	**Dr. holly Tuokko**	APPROVAL EXPIRY DATE:	17-Jul-15

PROJECT TITLE: **Advance Care Planning: A Qualitative Study with Families of Deceased Cognitively Impaired Older Adults**

RESEARCH TEAM MEMBER Holly Tuokko (Supervisor, UVic); Mauricio A. Garcia-Barrera (Doctoral Committee Member, UVic); Kelli Stajduhar (Doctoral Committee Member, UVic)

DECLARED PROJECT FUNDING: **Technology Evaluation in Elderly Network**

CONDITIONS OF APPROVAL

This Certificate of Approval is valid for the above term provided there is no change in the protocol.

Modifications
To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.

Renewals
Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.

Project Closures
When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.

Dr. Rachael Scarth
Associate Vice-President Research Operations

Certificate Issued On: 06-Aug-14

14-121 Jeznach, Anna

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Modification of an Approved Protocol

PRINCIPAL INVESTIGATOR:	**Anna Jeznach**	**ETHICS PROTOCOL NUMBER** Minimal Risk Review - Board members	**14-121**
UVic STATUS:	**Ph.D. Student**	ORIGINAL APPROVAL DATE:	18-Jul-14
UVic DEPARTMENT:	**PSYC**	MODIFIED ON:	07-Jul-15
SUPERVISOR:	**Dr. Holly Tuokko**	APPROVAL EXPIRY DATE:	17-Jul-16

PROJECT TITLE **Advance Care Planning: A Qualitative Study with Families of Deceased Cognitively Impaired Older Adults**

RESEARCH TEAM MEMBER Holly Tuokko (Supervisor, UVic); Mauricio A. Garcia-Barrera (Doctoral Committee Member, UVic); Kelli Stajduhar (Doctoral Committee Member, UVic)

DECLARED PROJECT FUNDING: **Technology Evaluation in Elderly Network**

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[redacted]

Dr. Rachael Scarth
Associate Vice-President Research Operations

Certificate Issued On: 07-Jul-15

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Certificate of Renewed Approval

PRINCIPAL INVESTIGATOR:	**Anna Jeznach**	**ETHICS PROTOCOL NUMBER** Minimal Risk Review - Board members	**14-121**
UVic STATUS:	**Ph.D. Student**	ORIGINAL APPROVAL DATE:	18-Jul-14
UVic DEPARTMENT:	**PSYC**	RENEWED ON:	07-Jul-15
SUPERVISOR:	**Dr. Holly Tuokko**	APPROVAL EXPIRY DATE:	17-Jul-16

PROJECT TITLE: **Advance Care Planning: A Qualitative Study with Families of Deceased Cognitively Impaired Older Adults**

RESEARCH TEAM MEMBERS: Holly Tuokko (Supervisor, UVic); Mauricio A. Garcia-Barrera (Doctoral Committee Member, UVic); Kelli Stajduhar (Doctoral Committee Member, UVic)

DECLARED PROJECT FUNDING: **Technology Evaluation in Elderly Network**

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[redacted]

Dr. Rachael Scarth
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Certificate of Renewed Approval

PRINCIPAL INVESTIGATOR:	**Anna Jeznach**	**ETHICS PROTOCOL NUMBER** Minimal Risk Review - Board members	**14-121**
UVic STATUS:	**Ph.D. Student**	ORIGINAL APPROVAL DATE:	18-Jul-14
UVic DEPARTMENT:	**PSYC**	RENEWED ON:	26-Jul-16
SUPERVISOR:	**Dr. Holly Tuokko**	APPROVAL EXPIRY DATE:	17-Jul-17

PROJECT TITLE: **Advance Care Planning: A Qualitative Study with Families of Deceased Cognitively Impaired Older Adults**

RESEARCH TEAM MEMBER Holly Tuokko (Supervisor, UVic); Mauricio A. Garcia-Barrera (Doctoral Committee Member, UVic); Kelli Stajduhar (Doctoral Committee Member, UVic)

DECLARED PROJECT FUNDING: **Technology Evaluation in Elderly Network**

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Certification

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[redacted]

Dr. Rachael Scarth
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Certificate Issued On: 27-Jul-16

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Modification of an Approved Protocol

PRINCIPAL INVESTIGATOR:	**Anna Jeznach**	**ETHICS PROTOCOL NUMBER:** Minimal Risk Review - Board members	**14-121**
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UVic DEPARTMENT:	**PSYC**	MODIFIED ON:	22-Sep-17
SUPERVISOR:	**Dr. Holly Tuokko**	APPROVAL EXPIRY DATE:	17-Jul-18

PROJECT TITLE: **Advance Care Planning: A Qualitative Study with Families of Deceased Cognitively Impaired Older Adults**

RESEARCH TEAM MEMBER Holly Tuokko (Supervisor, UVic); Mauricio A. Garcia-Barrera (Doctoral Committee Member, UVic); Kelli Stajduhar (Doctoral Committee Member, UVic)

DECLARED PROJECT FUNDING: **Technology Evaluation in Elderly Network**

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Certificate of Renewed Approval

PRINCIPAL INVESTIGATOR:	**Anna Jeznach**	**ETHICS PROTOCOL NUMBER:** Minimal Risk Review - Board members	**14-121**
UVic STATUS:	**Ph.D. Student**	ORIGINAL APPROVAL DATE:	18-Jul-14
UVic DEPARTMENT:	**PSYC**	RENEWED ON:	07-Jul-17
SUPERVISOR:	**Dr. Holly Tuokko**	APPROVAL EXPIRY DATE:	17-Jul-18

PROJECT TITLE: **Advance Care Planning: A Qualitative Study with Families of Deceased Cognitively Impaired Older Adults**

RESEARCH TEAM MEMBER Holly Tuokko (Supervisor, UVic); Mauricio A. Garcia-Barrera (Doctoral Committee Member, UVic); Kelli Stajduhar (Doctoral Committee Member, UVic)

DECLARED PROJECT FUNDING: **Technology Evaluation in Elderly Network**

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[redacted]

Dr. Rachael Scarth
Associate Vice-President Research Operations

Certificate Issued On: 07-Jul-17

14-121 Jeznach, Anna

Appendix B – Participant Recruitment Poster

Have You Lost a Family Member Who Suffered from Cognitive Impairment or Dementia?

Seeking Family Members of Older Adults who were Cognitively Impaired

for a UVic Dissertation Research Study on

Advance Care Planning

What is Required?

- Voice your story/issues/concerns in a 1-hour individual interview

Where/When?

- Flexible dates and times
- Phone interview

How Will You Benefit?

- Discuss concerns about care received by your loved one
- Become actively involved in research to inform healthcare practice and policy
- Provide suggestions on improving care for a vulnerable population

If you would like to participate, please contact graduate student, Anna Jeznach, at [redacted]

THANK YOU FOR YOUR INTEREST!

Appendix C – Recruitment Email

Hello,

My name is Anna Jeznach and I am a doctoral student in Clinical Neuropsychology at the University of Victoria. I am writing to inform you of a study I am conducting for my dissertation, under the supervision of Dr. Holly Tuokko, which examines challenges in the process of advance care planning among older adults with cognitive impairment and their families.

I will be holding individual interviews with family members of older adults who suffered from cognitive impairment prior to death. In order to facilitate participant recruitment, I would greatly appreciate if you could share this information with your members.

Dr. Tuokko and I greatly appreciate distribution of this information to your members. Attached is a flyer that can be given to individuals and placed on bulletin boards. Please let me know if you would like me to send copies of the flyer to your office.

Thank you for your interest,
Anna Jeznach, M.Sc.

Appendix D – Demographic Questionnaire

Your age: ____________ **Your gender**: ☐Female ☐Male

Years of education: __________ **Ethnicity**: _____________________

Relationship to the deceased: ______________________

Length of relationship with the deceased: _________________________

How often were you in contact with the deceased in the 6 months preceding his/her death? (e.g., visits in person, telephone, Skype)

☐ 3 or more times per week ☐1-2 times per week ☐1-3 times per month

☐Less than 1-3 times per month (specify): ______________________________

Date of death: _________________

Age of deceased at time of death: ____________

Gender of the deceased: ☐Female ☐Male

Where was the deceased living at the time of death?

☐ His/her own home ☐Another private home ☐Nursing/ seniors home

☐Palliative care unit ☐Hospital stay longer than 3 months

☐Hospital stay less than 3 months ☐Other (specify): ______________________

Cause of death: ___________________________________

Type of dementia, if applicable (e.g., Alzheimer's disease):

____

When was he/she diagnosed with dementia by a physician (if applicable)**?**

____

Prior to death but excluding the last month of life, did he/she have problems with any daily tasks (e.g., shopping, cooking, paying bills) **<u>due to cognitive impairment</u>?**

☐Yes ☐No

Please check all types of cognitive abilities that were impaired, that is, declined from his/her previous level, prior to the month before death:

☐ Memory ☐Language ☐Ability to recognize people or objects

☐Attention/focus ☐Planning/organization/problem-solving

☐Controlling his/her emotions ☐Other (specify): ______________________

Please list the deceased's other major medical and/or mental health diagnoses that affected their functioning in the final years of life:

____

____

____

Appendix E - Individual Interview Questions, First Wave

1.) What do the words “advance care planning” mean to you? What do they make you think of?

2.) When did the issue of advance care planning, or planning for end-of-life, arise in your family member’s care?
    a. Did this issue arise at the time of diagnosis?
    b. Who brought up this issue?
    c. How was advance care planning explained to your family member or to yourself?

3.) Was advance care planning discussed in the context of cognitive impairment?

4.) Did your family member and/or yourself receive any education about advance care planning (e.g., pamphlets, websites, discussions with healthcare team)
    a. If yes, who provided the information?
    b. Was it helpful?
    c. Did he/she, or the family, receive information about different types of healthcare treatments at the end of life (e.g., tube feeding)
    d. Were there any areas in which you would have liked more information?

5.) Was your family member encouraged to explore his/her beliefs, values, and goals?
    a. If yes, how so?
    b. Did he/she express these to you?
    c. Were they documented?

6.) Had your family member made arrangements for a substitute decision-maker, that is, someone to make health care decisions in case he/she was unable to do this him/herself?

   a. Who was the substitute?
   b. How did he/she choose a substitute?
   c. Was there any conflict regarding this choice of a substitute decision-maker?

7.) Did you family member complete legal documents regarding their healthcare wishes?

   a. How did he/she, as well as the family, come to understand the legal aspects of advance care planning in British Columbia?
   b. Were there any difficulties that arose in the creation of these documents?

8.) Overall, do you feel that the deceased's wishes regarding end-of-life were respected?

   a. Did his/her wishes align with what occurred at the end of life?
   b. If not, why do you think this disconnect occurred?

9.) What advice would you give to others who may be in similar situations as you were in?

Appendix F – Individual Interview Questions, Second Wave

1.) What do the words “advance care planning” mean to you? What do they make you think of?
2.) What are your expectations from the healthcare system in terms of end-of-life care?
3.) Participants told us that they received information about ACP in a piecemeal manner – learning different bits of information from different sources – and often felt they did not receive enough information. How does that fit with your experience?
    a. Role of the GP in providing information?
    b. Was the relationship between cognitive impairment and decision-making explained to you?
4.) If counseling services had been available to you during the end-of-life process, would you have taken them? If not, why not?
    a. If so, would you had to pay for these services out of pocket?
    b. Do you think these kinds of services should be provided?
5.) Did your family member explore his/her beliefs and goals for end-of-life with you?
    a. What prompted these conversations?
    b. Were there any barriers to having these conversations?
6.) Did your family choose a substitute decision-maker, that is, a specific person to make decisions for him/her when he/she would be unable to do so?
    a. If not, was there a presumption of who would take on this role? How was this determined?
    b. Was there a representation agreement in place?

    c. Did you and your family member know about the order of decision-makers outlined in the legal acts (used if no specific person named to make decisions)? If not, did you have assumptions about who would be asked to make decisions?
    d. Was there any conflict between involved parties or legal issues with the decision-maker?

7.) Did your family member complete any legal documents relevant to ACP?
    a. What was covered in these documents
        i. Specifics: residence, medical procedures, finances

8.) Do you think that your family member's wishes about end-of-life were respected?
    a. Was this how/where he/she would have wanted to die?
    b. Was palliative care ever discussed or considered?

9.) Recently there has been a lot of media attention on the Medical Assistance in Dying legislation which came into effect in 2016. At this time, to qualify for MAID, a person must be at least 18 years old and mentally competent, have a grievous and irremediable medical condition, make a request for medical assistance in dying that is not a result of being pressured or unduly influenced, and give informed consent to receive medical assistance in dying. This means that, at this time, persons with dementia are excluded from participating in MAID but I'd like to discuss your views on this topic. To begin, how do you feel about MAID?
    a. Do you think there could be a role for MAID for persons with dementia and for their caregivers?
    b. Under what circumstances would this be appropriate?
        i. Inclusion in an Advance Directive?

   c. If this had been available for your family member, do you think they would have wanted to have medically-assisted death?
      i. If yes, what do you think that would have been like for you as the caregiver, given that you would have had to make the final decision when the person wasn't competent to make their own decisions?

10.) Any suggestions/recommendations for other people who may go through a similar situation as you experienced?