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Characterizing Readiness for Advance Care Planning: An Interpretive Descriptive Study in Supportive Living

by

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Abstract

Currently, patient wishes for healthcare at EOL are not readily followed due to a lack of effective communication as well as discordance between patients’ preferences and medical orders. Advance Care Planning involves reflection on and communication of a person’s future healthcare preferences. In Supportive Living, residents are at risk of cognitive decline and frailty, requiring healthcare decisions. ACP is recommended but readiness to engage is not known. The purpose of this study was to explore perceptions of readiness, factors influencing readiness and strategies to improve ACP interventions of SL residents, their families/decision-makers and clinicians. This qualitative study utilized an Interpretive Descriptive approach. For SL residents, ACP is related to making the transition to SL. Families of SL residents draw on experience as a prior decision-maker. Clinicians vary in their comfort with ACP engagement. Themes across the groups include: variable definition of ACP, roles in ACP, readiness for engagement and barriers/facilitators. These findings can be used to contribute to the understanding of ACP engagement, inform the clinical approach and provide future direction for ACP research.
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Chapter 1

Introduction

Advancements in medical technology allow for interventions that can prolong life (Seymour & Horne, 2011). However, interventions are not always benign and their availability does not mean that patients want them. In fact, at end-of-life (EOL), patients often prefer treatment that is focused on comfort rather than the extension of life (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Gillick, 2004; Silveira, Kim, & Langa, 2010). Unfortunately, patients are not always able to communicate their treatment preferences during an acute emergency or near EOL. This concern is a particularly important issue for older individuals. Advance planning can help ensure that the interventions administered and the type of care provided are those wanted by older patients.

Research shows that there is discordance between the treatment patients wish to receive and that which is actually provided to them (Simon, Porterfield, Bouchal, & Heyland, 2013). Sub-optimal quality in the communication between patients, their families and clinicians is a major barrier to aligning the treatment delivered with patient wishes (Heyland et al., 2013). Poor communication regarding the severity of illness and treatment options can lead to patients having unrealistic perceptions about their prognosis and consequently request more invasive treatments (Weeks et al., 1998). Not discussing their treatment preferences with families and clinicians is associated with more invasive care at the EOL, poorer quality of life and death, and family members experiencing worse bereavement after the person has passed away (Wright, et al., 2008; Zhang et al., 2009).

Advance Care Planning (ACP) is a process that encourages effective and ongoing communication and reflection on wishes between patients, their families and clinicians (Horne,
Seymour & Payne, 2009). The purpose of ACP is to provide a framework for addressing treatment preferences and values that can guide health decision-making even when a person becomes incapable of consenting to or refusing health care (Sudore et al., 2008). ACP has been shown to be effective in improving adherence to patient care wishes at EOL. Those who engage in ACP are less likely to die in hospital or spend more than two weeks there during the last month of life and more likely to enroll in hospice (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013). ACP has also been associated with improved patient quality of life, better outcomes for family caregivers and less resource-intensive treatment at the EOL (Detering, Hancock, Reade, & Silvester, 2010; Seymour, Horne, Thomas & Lobo, 2011; Silveira, Kim, & Langa, 2010; Wright et al., 2008; Zhang et al., 2009). The potential positive impact of ACP on patient and family quality of life makes its widespread adoption an important health service target (Teixeira et al., 2013).

In spite of the known benefits of ACP, a low percentage of Canadians are currently engaging in this process. A recent national public opinion poll demonstrated that only 9% of adults have had discussions with a physician about this issue (Teixeira et al., 2013). Less than 30% of frail older adults have discussed their EOL wishes with health care professionals (Dexter et al., 1998; Heiman, Bates, Fairchild, Shaykevich & Lehman, 2004; Landry, Kroenke, Lucas, & Reeder, 1997; Richter et al., 1995). At the general population level, completion of advance directives is estimated to be between 5-15% (Kirschner, 2005). For ACP rates to improve, more effective information-based and clinical interventions for ACP uptake must be designed and successfully implemented.

Among older adults, readiness is an important predictor of engagement in ACP discussions (Simon, Porterfield, Bouchal & Heyland, 2013; Walczak et al., 2011). However,
older adults can be at variable stages of readiness to engage in the multiple constituent activities of ACP (Fried et al., 2010). Despite its importance, there is little understanding of how readiness was achieved for those who have engaged in ACP and how it can be achieved in those who are currently not ready (Fried et al., 2010).

ACP is especially relevant for residents in supportive living (SL) facilities. These individuals have functional limitations often due to multiple morbidities and often suffer from progressive dementia. The cognitive and physical decline seen in many SL residents over time, may eventually make the expression of health care choices difficult, if not impossible. These individuals frequently reach a point where they are no longer able to reflect on their current situation, consider their care choices and/or communicate preferences, which places them at a heightened level of vulnerability to not having their wishes about their care attended to (Blasi, Hurley, & Volicer, 2002). These circumstances can force caregivers and health care providers (HCP) into having to make difficult ethical decisions regarding utility or futility of treatments for chronic illnesses like diabetes and heart disease or acute ones like pneumonia (Caron, Griffith, & Arcand, 2005). The currently low rates of ACP of SL residents can have a negative emotional impact on family decision makers during EOL care, including guilt, psychological distress and depression (Mezey, Kluger, Maislin, & Mittelman, 1996). ACP could be done with residents in SL with dementia during the early stages of this condition when individuals are capable of making and communicating care goals and values (Dukoff & Sunderland, 1997; Mezey, Teresi, Ramsey, Mitty, & Bobrowitz, 2000).

Please note that since most literature on ACP uses the term ‘patient’, this term will be used when referencing existing literature. However, it is not applicable when referring to those
living in SL, as they are referred to as residents of the SL. As such, the term ‘resident’ will be used when discussing the participants of the current study.

**Study Purpose**

The purpose of this study is to explore the perspectives and experiences of SL residents, families and HCP in order to better understand ACP readiness. An Interpretive Descriptive methodology will be used to explore the research questions. At this stage, readiness for ACP will be defined as a willingness to engage in ongoing discussions of underlying values and wishes for EOL care with family and HCP.

**Research Questions**

1. How do patients, families and HCP perceive their readiness to engage in ACP?
2. What factors impact readiness to engage in ACP for the participant groups?
3. What could be included in ACP interventions to make them more appropriate and effective?

**Study contribution**

Alberta Health Services (AHS) is a publically funded provincial healthcare system in Alberta, Canada, which is implementing a multi-sector provincial roll out of ACP and a framework for medical decisions and orders (Goals of Care Designations) policy and procedure. The introduction of this policy, with the aim of improving health care delivery, provides a unique and timely opportunity to investigate the population-based implementation and impact of ACP at a provincial level. This study is part of a larger province-wide research program seeking to improve ACP implementation across Alberta.

The study can also make a broader contribution beyond local, provincial planning. To increase the rates of ACP in SL residents, interventions should be effectively tailored to their
expressed readiness and cognitive stage. The proposed study will explore factors predictive of ACP readiness in SL residents, their families and clinicians. The unique contribution this study will make to existing literature and practice is to increase knowledge about readiness, especially in the SL context, where understanding of factors limiting the use of ACP is limited. Furthermore, to date there are no other studies that explore readiness and its contributing factors from the perspectives of all relevant stakeholders, namely residents, family and clinicians in a single care setting. Consequently, the findings from this study will contribute a vital understanding of the interactions among these three groups and how each uniquely perceives of and contributes to the ACP process. In addition to its contribution to knowledge of ACP in the SL context, this study is clinically relevant in virtue of its potential to inform the design of ACP interventions for the study population. Based upon an increased understanding of readiness for SL residents, their families and HCP, hopefully more effective interventions tailored to individuals in this population can be developed. This may include the dissemination of print material, educational workshops and one-on-one discussions.

Through improved ACP interventions, this work can contribute to reduction of unnecessary and invasive treatment at EOL. Further still, this study provides an important platform for SL residents, who are vulnerable as a result of physical and cognitive decline, to express their current perspectives and critiques of how they have been and hope to be engaged by the healthcare system as they near EOL. Although ACP engagement is not strictly or necessarily a primary role for social workers, this area is of particular relevance for social work research and practice in virtue of the vulnerability of the patient population that is impacted. Older adults are especially vulnerable as they near EOL and their quality of life can be severely impaired if their wishes for care are not effectively known and followed. Social workers are in the unique position
of having expert understanding of individuals within their social environments. This is the crux of ACP effectiveness, as it can only be achieved when communication and understanding between patients, families and clinicians are optimized. In addition, social workers are often in the good position to be clinical and research advocates for patients who are at-risk due to their vulnerable circumstances. As such, social workers can play an important role in the study and clinical application of ACP knowledge. These study implications will be discussed in further detail in the discussion section of this paper.

**Organization of thesis**

This thesis is organized according to the following chapters. First a literature review identifies existing literature on the topic, highlights current gaps in knowledge and makes a case for the relevance of this study and its function in generating needed knowledge. Next, the methods section describes how the study was conducted and the data analyzed. The findings section details the results from the study. Finally, the discussion section provides an analysis of the findings and their implications.
Chapter 2

Review of the Literature

First, this chapter defines ACP along with its component activities for patients, family/decision-makers and clinicians. Next, current challenges of ACP engagement are discussed. A possible theoretical foundation of ACP engagement is reviewed and readiness is described as an important factor in potentially increasing ACP uptake. Finally, the relevance of these ideas to the SL context is discussed. While there are many stages in the ACP process, including assessing patient capacity and enactment of ACP documentation, the scope of this review is focused on readiness for engagement. In addition, although academic and clinical work on ACP readiness is both a health and social work issue, in virtue of its direct relevance for health care decisions and aim to enhance health care for vulnerable patients respectively, the literature is dominated by research from the health care perspective. Consequently, very few social work related articles are discussed here. Also, it should be noted that ACP terminology varies across Canada and that each term used in this manuscript is defined in this chapter as it pertains to an Alberta context.

Advance Care Planning

ACP is defined as “the development and expression of wishes for the goals of medical treatment and the continuation or discontinuation of such treatment and care” (CHPCA, 2012). ACP is aimed at facilitating improved communication and understanding of patient wishes for care to clinicians and decision makers, in order to improve the alignment between patient preferences and the care they actually receive at EOL (Covinsky et al., 2000; Heyland et al., 2013). This is significant as up to 76% of patients will not be able to participate in at least a portion of decision making regarding health care at EOL (Silveira, Kim & Langa 2010). As such,
ACP is a process that empowers patients to articulate their wishes and to determine the direction of their future health care in the event that deterioration in their health prevents them from making decisions for themselves (Brinkman-Stoppelenberg, Rietejens, & Van der Heide, 2014). ACP includes planning for EOL care, namely care received right at the EOL, but ACP is meant to generate a broader consideration, discussion and documentation of values around quality of life rather than simply health care interventions. Due to the fact that ACP is a new concept and literature on this topic is limited while literature on EOL care is rich, some arguments pertaining to ACP discussed in this paper will cite relevant evidence from the EOL care literature.

ACP consists of three discreet activities: 1) patients thinking about their values and wishes for health care for a time when patients are no longer able to communicate care decisions, 2) ongoing communication of values and wishes for care with family and clinicians, and 3) documentation of values and wishes for care including Advance Directives and Goals of Care Designations (Sudore & Fried, 2010; Fried et al., 2010; Sudore, Schickedanz & Landefeld, 2008). The comprehensive process, including thinking, discussing and documenting, solidifies patient values and generates a guide from which clinicians and families can make appropriate medical and other care decisions. A growing body of literature has shown that relying solely on a written advance directive and hypothetical decisions about aggressive medical procedures does not adequately prepare patients or their surrogate decision makers for real, complex, and often unpredictable medical decisions that can occur over the course of serious medical illness, including weighing the risks and benefits of beginning a new medication, having surgery, or deciding on nursing home care (Briggs 2004; Smith et al., 2008; Sudore & Fried, 2010). Therefore, ongoing contemplation and discussions are necessary to build a broader understanding of quality of life values and meaning, from which concrete medical decisions can be extrapolated.
by decision makers, as needed (Heyland et al., 2013). Thus, ACP requires the development of skills that are necessary for patients to engage in the comprehensive process. The literature on ACP and EOL care currently shows that barriers to patient engagement exist for all three ACP activities. A lack of engagement can result in poor concordance between patient wishes and care received. The ACP literature pertaining to each of the three activities for patients, as well as the literature on family and clinicians is presented below.

**Patients.**

**Thinking.** Thinking about preferences for future health care is an essential step in advocating that one’s wishes be followed. However, research suggests that individuals do not spend sufficient time considering their wishes within a realistic framework of their health situation. Some older adults, particularly those who have not extensively encountered the health care system (either alone or with a family member) report not having had a reason or opportunity to think about care at end of life (Simon, Porterfield, Bouchal, & Heyland, 2013). Others, who are currently ill, are often overly optimistic about their prognosis and still see no pertinent reason to consider EOL issues (Heyland et al., 2013). In addition, patients have reported not wanting to think about issues related to illness, death or dying (Fried, Bullock, Iannone & O’Leary, 2009; Schickendanz et al., 2009; Winzelberg, Hanson &Tulsky, 2005,). There has been limited inquiry into the thinking component of ACP, perhaps due to the fact that it is not readily measurable like discussions and documentation, in addition to its relative novel introduction to the ACP process (Schickendanz et al., 2009). This study will contribute to the existing ACP literature by helping to characterize the contemplation process for older, frail and institutionalized adults. This information will provide an initial basis for comparison to other clinical settings, and generate
ideas for how to affect the contemplation process in a way that is relevant to the target population.

**Communication.** Communication with both family/decision makers and clinicians is important for ensuring that wishes and preferences for care are known by others who will be responsible for making decisions at a time when patients are not able to do so. Some research suggests that discussions are a catalyst for the other two behaviors. Thus, an argument could be made for an increased focus on the promotion of discussions with patients, their families and participating clinicians. Sudore et al., (2008) measured ACP engagement for each of the three ACP steps in response to an online intervention for healthy, older adults. Six-month follow up for self reported ACP contemplation as well as discussions with family/decision-makers and clinicians and documentation were measured. Post-intervention, most participants reported contemplating and discussing wishes with family/friends. However, few reported discussions with physicians and fewer still documented their wishes. Still, findings showed that discussions with physicians and documentation of wishes were more likely to happen for participants who had already had a discussion with family or friends. This work illustrates that perhaps participants only complete those ACP steps with which they are most comfortable and some actions increase comfort for other actions.

Barriers to effective EOL care communication include lack of sufficient time with physicians and decision makers (Simon, Porterfield, Bouchal & Heyland, 2013), as well as concerns around negatively affecting one’s relationship with decision makers (Schickendanz et al., 2009). A sense that discussions are unnecessary is an additional barrier, as some older adults feel that their loved ones should know their preferences, despite failing to engage in conversation regarding relevant information (Malcomson & Brisbee 2009). The failure to engage in EOL
discussions and poor communication when discussions do occur, contributes to negative outcomes that do not align with patient wishes for EOL. In Heyland, Lavery, Tranmer, Shortt and Taylor’s (2000) analysis of where older Canadians die, it was found that although most individuals stated they prefer to receive care and die at home, dying usually occurs in the hospital and approximately one-fifth of hospital deaths take place in an intensive care unit. Sudore and Fried’s (2010) review of patient preferences at EOL found that although most older adults value quality of life over unnecessary prolongation of life through invasive measures, life supports are often provided to patients, even when patients would prefer comfort care.

Thus, in considering how to target uptake in future interventions, it might be important to address behaviors specific to discussion with family and friends in order to affect ACP completion as a whole. How to do this is not well understood. It is clear that an insufficient number of conversations are taking place with clinicians. While more discussions are taking place between patients and family members, the quality of these conversations is not known. Further, it is not known why some individuals might engage in good communication while others do not. This study may contribute to knowledge on ACP discussions by providing insight into motivations for initiation of ACP discussions from the perspectives of all three stakeholder groups, as well as the factors impacting the nature of these conversations when they do occur.

**Documentation.** The earliest approach with legal documentation is an Advance Directive (AD) (Goodman, Tarnoff, & Slotman, 1998). This document was first sanctioned in the USA in 1976. It sought to enhance patient autonomy for those who lose their decision-making capacity. In Alberta, this document is often referred to as a Personal Directive (PD). An AD is a legal document in which a person names a surrogate decision-maker who can make healthcare
decisions for them in the event that person loses capacity. An AD can also outline preferences on treatments to be withheld or withdrawn in specified circumstances.

Advance Directives have demonstrated limited efficacy in ensuring adherence to patient wishes at EOL. The fact that AD are legal documents complicates patient communication for EOL preferences. The main difficulties include poor readability due to complex language, health care agent or surrogate restrictions as well as execution requirements needed to make forms legally valid (Castillo et al., 2011). For example, many states do not allow oral advance directives and most require a notary public to witness signatures. Those with limited literacy or English proficiency, in same-sex or domestic partnerships, and patients institutionalized or homeless (and may be without witnesses or suitable surrogates) can be adversely affected by these requirements. In addition, it is often the case that advance directives do not provide sufficient instruction to determine treatment for patients during hospitalization. In one large-scale study, only 13% of AD provided additional instructions for medical care beyond the naming of a surrogate or stating the standard preferences of a living will (Covinsky et al., 2000).

It has also been shown that patients with advance directives were no more likely than patients without advance directives to have preferences for or against cardiopulmonary resuscitation (CPR) documented in the medical record or to have do-not-resuscitate (DNR) orders written among those who preferred not to have CPR (Covinsky et al., 2000). There was little evidence that completing an advance directive facilitated patient-physician communication about care preferences, as very few patients (12%) were counseled by a physician when they completed their advance directive. Of patients with an advance directive, only 25% of their physicians were aware of the advance directive.
A qualitative study of hospitalized, seriously ill patients examining the limitations of AD when it comes to decision making found the interaction of several key factors: (1) patients were often not seen as hopelessly ill, so the advanced directive was not seen as applicable and as a result, a transition to palliative care did not occur; (2) family members or the surrogate were not available or were overwhelmed, and (3) the content of the advanced directive was vague or not applicable to the clinical situation (Teno, Stevens, Spernak, & Lynn, 1998). For the aforementioned reasons, there is a strong argument for shifting focus away from the traditional documentation of Advance Directives and instead, adopting a relational, patient-centered process that focuses on broader goals of care. This is the goal of system-wide ACP implementation, whereby ADs are simply one part of a much more comprehensive planning process. The current study will contribute to this goal by increasing the understanding related to readiness for each ACP activity, including ways in which readiness can be increased for the other two activities as well as barriers and facilitators to engagement in each activity.

The Goals of Care Designations (GCD) framework was created as an Alberta-based medical care guide in 2008. GCD are medical orders that help to direct health care providers when rapid decision making is needed and also help to inform more general care that is to be provided. GCD are determined by ACP conversations and/or AD documentation. GCD has demonstrated face validity as well as successful audit outcomes but has not been otherwise studied (Alberta Health Services, 2011). Patient involvement in GCD completion is voluntary. GCD requires that physicians check a box corresponding to the level of medical care that a patient is to receive. Medical care categories are divided into seven options ranging from comfort care to all medical care and interventions. Although advance directives can be updated and GCDs can also be changed, if these changes are not made, these documents may not reflect one’s
current health status and current wishes. Little is known about how patients perceive of the completion and utility of ACP documentation, as well as their trust that these documents reflect their future wishes for care. This study will explore these related to ACP documentation from both patients and family members’ perspectives.

**Family/designated decision-makers.** Family members/designated decision makers are in the difficult position of having to make medical decisions for someone else. In their study of family caregivers at EOL, Rabow, Hauser and Adams (2004) found that decision makers describe feeling unprepared to make decisions and report high stress around decision-making (Rabow, Hauser, & Adams, 2004). Furthermore, decision makers report finding it more difficult if they do not have a sense of what patients want and often feel that they do not have this sense, which could be the result of insufficient communication between patients and decision makers (Desbiens, Mueller-Rizner, Virnig & Lynn, 2001; Zuckerman, 1999). In their study on concordance between patients’ stated wishes and decision maker interpretation using data from SUPPORT, Wenger et al. (1994) found that without targeted discussions, family and decision makers fail to accurately understand patients' preferences regarding whether goals of care should be directed at comfort or extending life. Data from SUPPORT (The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) shows that surrogates can be inaccurate in their understanding of whether patients are willing to live in a nursing home, especially among patients willing to live in a nursing home. Surrogates identified correctly 85% of the patients unwilling but only 37% of those willing to live in a nursing home. Of the patients who stated that they would be very willing to live permanently in a nursing home, surrogates indicated 14% of patients would rather die (Connors et al., 2004).
Thus, the literature shows that family members feel burdened by the responsibility of decision making, that they are further burdened when they are unsure of patient preferences and that they often are in the position of being unsure of patient preferences. This study will contribute to the literature by exploring the factors that contribute to decision maker confidence in the ACP information that has been provided to them by the patients/residents for whom they are making decisions.

**Clinicians.** Like patients, clinicians also have difficulty engaging in EOL discussions. For example, Hancock et al.’s (2007) review of studies on clinician engagement in EOL conversations found that although the majority of healthcare professionals are of the opinion that patients should be told of their prognosis, in practice this information is often avoided or withheld. They found that physicians present fewer facts and details concerning prognosis than any other topic of conversation with patients at a medical visit (Hancock et al., 2007). Known barriers to EOL communication experienced by clinicians include discomfort with EOL conversations, uncertainty about illness trajectory, limited time and concerns regarding the negative impact of EOL conversations on patient well-being (Hancock et al., 2007). The physician role is further complicated by the responsibility to determine when a patient lacks sufficient capacity that their ACP documentation is to be enacted. Until a patient has been deemed incompetent to make decisions, ACP documents, including the appointment of a substitute decision maker, cannot be acted upon. The difficulty of this physician decision in the context of dementia is discussed in a review by de Boer, Hertogh, Droes, Jonker & Eefsting (2010) on issues around the use of Advance Directives in dementia. The authors describe the complexity of the physician’s responsibility with dementia patients, where cognitive decline is
slow, and physicians struggle to make a determination on when a patient’s cognitive status has rendered them incompetent.

Lack of effective communication on the part of clinicians is associated with poor patient care. According to analysis from the SUPPORT study, when end-of-life communication is not specifically targeted, physicians are only slightly better than chance at understanding patients' preferences for life-sustaining interventions (Covinsky et al., 2000). This gap in understanding can result in documentation directing patient care that is not reflective of patient wishes. Covinsky et al. (2000) found that while physicians understood 86% of patient preferences for cardiac pulmonary resuscitation (CPR), they understood and documented only 46% of preferences to forgo CPR (Covinsky et al., 2000). This lack of concordance between patients and physicians is also demonstrated in areas outside medical care. Using data from SUPPORT, a prospective observational study to improve EOL decision-making by Connors et al., (1995) found that physicians were shown to misunderstand seriously ill, hospitalized patients' preferences for other health outcomes, such as patients' willingness to live in a nursing home. For example, physicians identified correctly 86% of those unwilling but only 18% of those willing to live in a nursing home. In 40% of the cases of patients who said they would be very willing to live in a nursing home, the physician believed the patient would rather die than live in a nursing home (Connors et al., 1995). The gap in understanding between patients and clinicians has also been examined in a Canadian multicenter, prospective study, ACCEPT (Algorithms for Critical-Care Enteral and Parenteral Therapy), examining patient characteristics as related to ACP engagement in hospitalized older adults through a quantitative survey (Heyland et al., 2013). Alarmingly, the concordance was poor, at 30% between patients’ expressed preferences for life-prolonging medical interventions and documentation found in medical order forms.
Thus, what is described in the literature is that clinicians do not appear to have an adequate understanding of patient wishes and this lack of understanding results in treatment that is incongruent with patient wishes. A better understanding of how clinicians can engage with patients to increase congruency between wishes and care given is needed. This study seeks to contribute to this understanding by exploring how communication between patients and clinicians comes to occur in the SL setting, the level of satisfaction that patients and clinicians find from this communication and ways in which communication can be improved from the perspectives of these two groups.

Optimal ACP consists of three discrete but related activities: thinking, communicating and documenting. Although engagement in all three is necessary for optimal care delivery and experience, patients do not effectively engage in these activities. Research further indicates that despite being poor predictors of patient wishes for care, surrogate decision makers and clinicians feel some discomfort in engaging in the ACP process.

**ACP Engagement**

There is strong indication from the literature that ACP is associated with improved clinical outcomes, including care that aligns with patient preferences at EOL, fewer resource-intensive treatments, better quality of life and improved well-being for caregivers (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Detering, Hancock, Reade, & Silvester, 2010; Seymour, Horne, Thomas & Lobo, 2011; Silveira, Kim, & Langa, 2010; Wright et al., 2008; Zhang et al., 2009). ACP has become an established standard of care from the perspective of Accreditation Canada. Accordingly, many practitioners world-wide have begun to implement various ACP tools and to make the systemic changes that would embed ACP into health care practices (Heyland et al., 2013). Despite demonstrated benefits and widespread healthcare system
support, a low percentage of the general population within Canada engages in ACP either through discussing plans with a healthcare provider or formally documenting a surrogate decision-maker and wishes for healthcare in a document such as an advance directive (Taxiera et al., 2013). Since ACP is a voluntary process, older adults can choose to engage freely and research indicates currently poor levels of engagement.

In their Canadian study of over 500 hospitalized patients and family members, Heyland et al. (2013) sought to characterize the frequency with which ACP activities were being completed as well as patient preferences for EOL care. They found that although most older, hospitalized people had thought about EOL care, less than 50% had completed an advance directive. Less than 30% had discussed wishes with physicians, while 70% had discussed wishes with a surrogate maker (Heyland et al., 2013). Due to the fact that there are currently low rates of concordance between the care patients want and that which they receive, coupled to the known benefits of ACP in improving this concordance, it is important to develop successful strategies for improving the currently low rates of ACP engagement. How to best increase uptake to participate in ACP remains to be determined. This is a current focus of research across many healthcare systems.

**Interventions aimed at improving ACP engagement.** There have been a number of efforts aimed at increasing ACP engagement in older adults. The majority of these interventions have involved the dissemination of broadly generalizable educational and planning materials (Bravo, Dubois, & Wagneur, 2008). Such interventions have provided materials to participants either through direct mail or at the time of a scheduled health professional visit. Interventions using mailed materials have used: 1) work-books that describe AD, depict case scenarios and include exercises for completion in order to extract values regarding quality of life; 2) descriptive...
and educational pamphlets, and 3) educational and informative videos. Interventions using the dissemination of materials during health professional visits have used: 1) informative videos; 2) educational lectures; 3) structured discussions with social workers, consisting of a single or multiple visits; and 4) a single structured visit with a physician (Bravo, Dubois, & Wagneur, 2008; Ramsaroop, Reid, & Adelman, 2007).

Results from two systematic reviews of interventions aimed at increasing ACP engagement, found modest to moderate outcomes favoring the interventions (Bravo et al., 2008; Ramsaroop et al., 2007). Some types of interventions were consistently effective while others had consistently poor results. The effective interventions implemented direct patient-healthcare professional interactions and also used iterative interactions with a professional over multiple visits. Conversely, the interventions that were found to not be effective used generic, impersonal materials over a single contact point.

The relatively low success of the use of passive materials to improve ACP uptake has resulted in a shift in the conceptualization of how individuals engage in ACP. The demonstrated efficacy of personalized interventions has generated support for the proposal that ACP engagement is a health behavior, best captured by health behavior theories and most effectively addressed through tailored interventions (Westley & Briggs, 2004; Zimmerman, Olsen, & Bosworth, 2000).

In order to maximize the current ACP roll-out opportunity in Alberta, it is critical to design interventions that are effectively tailored to relevant populations. The literature demonstrates that there is little understanding of how to best tailor interventions in order to effectively increase ACP uptake. Further still, there is a gap in the literature on local and context specific factors that must be addressed when designing tailored interventions. This study will
contribute to the literature by helping to address these gaps in knowledge.

**ACP As a Health Behavior**

The argument for conceptualizing ACP engagement as a health behavior has emerged from exploratory and intervention-based research for improving ACP uptake (Fried, Bullock, Iannone, & O’Leary, 2009). Noar, Benac and Harris’ (2007) meta-analysis of interventions aimed at behavior change supports the superiority of tailored, personalized interventions over passive information transfer and exposure. This aspect of how individuals engage in ACP is reflective of how action is captured by health behavior theories and as a result, some researchers were motivated to move away from an atheoretical understanding of ACP engagement (Zimmerman et al., 2000). Instead, it has been suggested that ACP engagement might be better understood through a theoretical framework that incorporates how individuals process health information and engage in decision-making. An improved understanding of how individuals engage in ACP can lead to more effective development of interventions for increasing its uptake (Pearlman, Cole, Patrick, Starks, & Cain, 1995).

Theoretical models seek to understand and predict health behaviors (Prochaska, DiClemente, & Norcross, 1992). Although different in construct and purpose, the models are interrelated and can be used to highlight different aspects of the complexity of ACP engagement (Fried et al., 2009). The two models most often associated with ACP are the Transtheoretical Model and the Health Belief Model (Prochaska et al., 1992). Each of these models is described in detail below.

**Transtheoretical Model.** The Transtheoretical Model (TTM) is used for explaining intentional behavior change (Prochaska et al., 1992). Although this is an older model, Prochaska et al.’s (1992) guide for behavior change continues to be basis for current understanding on the
topic. The key feature of TTM is that it describes behavior change as a process rather than an event. The process is broken down into five stages through which individuals pass as they engage in behavior change: 1) pre-contemplation, 2) contemplation, 3) preparation, 4) action, and 5) maintenance.

During the precontemplation stage, an individual does not specifically engage in structured thinking about future health and care. This is followed by contemplation on treatment preferences and wishes for future care. Next is the preparation stage, during which an individual decides and plans how to act. Once these decisions have been solidified, an individual takes up actions that, for ACP, would include conversations with family and clinicians and documentation. Finally, the individual engages in maintenance or reflection of the choices and actions that have been taken. In the case of ACP, this final stage is of paramount importance, as individuals can change their mind about healthcare decisions, particularly if their health status changes (Sudore & Fried, 2010).

Readiness is thought to be the key component necessary for moving between the stages. According to TTM, individuals use different processes or strategies during the stages of change to influence readiness (Prochaska et al., 1992). Most of these strategies are used between the contemplation and action stage (Marcus, Rossi, Selby, Niaura, & Abrams, 1992). The strategies include: 1) consciousness raising: efforts by the individual to seek new information and to gain understanding and feedback about the problem; 2) dramatic relief: involves intense emotional experiences related to the problem behavior; 3) environmental re-evaluation: consideration and assessment by the individual of how the problem affects the physical and social environments; 4) self-re-evaluation: emotional and cognitive reappraisal of values by the individual with respect
to the problem behavior; and 5) social liberation: awareness, availability and acceptance by the individual of alternative life-style (Prochaska et al., 1992).

A qualitative exploration, into how older persons and their caregivers think about ACP has provided evidence in support of the conceptualization of ACP according to TTM (Fried et al., 2009). Focus groups revealed that older persons are at variable stages of change, as described by TTM, and consequently, expressed variable readiness to engage in the multiple ACP activities. Participants also described a variety of processes that had helped increase their readiness for ACP participation and consequently move through the stages of change. For example, dramatic relief was a commonly cited powerful strategy that impacted readiness to act. When participants had gone through a negative hospitalization or EOL experience with a loved one, they were more likely to feel ready to engage in ACP actions in order to ensure that this negative experience did not happen to them. Similarly, consciousness raising was cited as a factor that impacted the transition from contemplation to preparation and action. When participants had more information about the benefits of ACP and the risks of forgoing ACP, they felt more ready to engage in discussions and documentation of their wishes.

TTM thus highlights the potential importance of designing ACP interventions to target individuals at their current stage of change and to appropriately help them move through the stages to the action and maintenance stages (Fried et al., 2010). Although a large body of exploratory and explanatory data on how ACP engagement can be explained by health behavior theories has been collected, there is a significant lack of evidence-based guidance for how to encourage movement between the stages (Fried et al., 2010).

**Health Belief Model.** Additional factors that may contribute to ACP readiness are captured by the Health Belief Model, which characterizes how motivation and self-efficacy can
predict whether someone will take an action to prevent illness (Green & Murphy, 2002). The model suggests that action is dependent on the individual’s perception of: 1. Susceptibility to the illness, 2. Severity of the consequences of the condition, 3. How likely an action is to reduce the impact of the threat/condition, 4. How difficult the advised action is to enact, 5. Cues to action which are events that influence motivation, and 6. Self-efficacy or one’s confidence in his/her ability to take action.

Motivation and self-efficacy are the keys to the first four components of this model. If an individual believes that they are susceptible, their motivation to prevent the condition increases. This has been a demonstrated barrier to ACP engagement as individuals often cite that their health is far too good to plan for a time when health has deteriorated. This belief about planning is true even when individuals rate their overall health as poor (Sudore & Fried, 2010). Similarly, if individuals feel a strong sense of self-efficacy, they are more likely to believe that their actions could reduce the threat. Studies have shown self-efficacy to be a common barrier to ACP engagement, illustrated by the belief that ACP will make no difference in what is done to patients at EOL (Fried et al., 2010; Sudore & Fried, 2010). The health belief model thus suggests that if an individual’s motivation and self-efficacy can be increased, he/she is more likely to act to prevent illness. Although ACP does not prevent illness, it is an action that can prevent negative and unwanted health-related care. While TTM helps to describe the steps that one moves through in order to achieve behavior change, the health belief model contributes to the understanding of behavior change by elucidating some personal characteristics that play a crucial role in determining whether one moves through the stages. Both TTM and the Health Belief Model provide a framework by which to better understand how and why individuals engage in ACP. In addition, these theories provide practical, guiding principles that can be used to effectively tailor
ACP interventions to foster effective engagement. Still, Rosen’s (2000) meta-analysis on the sequence of behavior change processes for health behaviors, suggests that change process strategies are not consistent across all health behaviors and therefore, it cannot be expected that the change processes observed most commonly in smoking cessation or weight loss would be the same for ACP. Thus, for smoking cessation, consciousness raising might be a common strategy, while for mammography screening, dramatic relief might be more often used. It could be the case that accounting for, or incorporating known change processes will not be effective for ACP. While dramatic relief is a known strategy, there might be others that have not yet been considered that have considerable impact on likelihood of engagement.

Not only might ACP engagement entail the use of unique change processes, but also ACP might altogether be a different health behavior from those that are traditionally associated with TTM and the Health Belief Model. More specifically, ACP is not a health behavior in the same way as lifestyle change behaviors like weight loss, exercise or smoking cessation. These require daily motivation, which is not necessarily true of ACP. On the other hand, ACP could be more emotionally draining, as it requires a direct consideration and discussion of mortality compared with lifestyle behaviors. ACP might also be dissimilar from health behaviors like scheduling and getting regular mammograms, colonoscopies or other health checks, which only require an annual visit. While these might also be associated with some anxiety, they do not require the extensive thought and consideration, discussion and planning as ACP.

Thus, going forward with implementation research, it is important to maintain flexibility about the ways in which ACP engagement may be unique compared with other health behaviors that have been studied extensively and modeled by TTM and the Health Belief Model. It may be the case that readiness is only part of an explanatory mechanism for behavior change or that the
current understanding of readiness is incomplete. This study will contribute to the theoretical understanding of ACP engagement by enabling patients to elucidate the factors and circumstances involved in moving them to action, including the role of readiness, motivation and other behavior change strategies. Consequently, it will be possible to adjust the theoretical framework of ACP engagement, currently based upon the concept of readiness, if necessary, in order to accurately depict this behavioral process.

**Incorporating behavior change theories into ACP intervention design**

Researchers have generated a rich body of knowledge that encompasses the identification and explanation of what the different stages of change look like for individuals in the ACP setting. It is now well documented that individuals find themselves at various stages of change for each of the three ACP behaviors (Fried et al., 2010). Individuals also express variable barriers that prevent them from ACP engagement (Sudore, Schickedanz, & Landefeld, 2008; Schickedanz et al., 2009). It is further evident that readiness for action for one ACP activity does not correspond to readiness for action in either of the other two activities (Fried et al., 2009). For example, participants express having completed an EOL care document because their living-facility required it but not feeling ready to think about EOL care or to discuss it. Also, individuals do not move sequentially through the three ACP activities (Schickedanz et al., 2009). Thus, once an individual has thought about their plans, this does not necessarily lead to readiness and action in communicating those plans, followed by readiness and action in documenting those plans (i.e., thinking→communicating→documenting). Finally, during the pre-contemplation stage, cons for action far outweigh the pros for action but as individuals move through the stages, this balance shifts to favor pros (Hall & Rossi, 2008). Thus, when an individual is not ready to engage in meaningful reflection on values and preferences, their negative beliefs regarding acting on values
and preferences far outweigh the possible gains from those activities. As an individual begins to feel ready to think or talk about their wishes, the perceived benefits of doing so outweigh the risks and barriers. Thus, the TTM is useful for describing stages of behavior change while the HBM provides insight into motivation for change, highlighting the possibility that ACP engagement can be explained through a combination of the two models. The link between them is the concept of readiness to act. What is not yet understood is how readiness for one ACP activity predicts readiness and actual action on the other two.

**Readiness**

Readiness has been demonstrated to be of paramount importance in the ACP engagement process. It is consistently cited as the foundational piece on which tailored interventions for uptake should be developed (Fried et al., 2012; Sudore & Fried, 2010; Sudore et al., 2013). However, it is not obvious that there is a clear understanding of what readiness is. It is unclear whether readiness is simply the reduction of barriers to engagement. If known barriers were eliminated, would individuals feel ready to participate in ACP? Are there other factors that influence readiness? Evidence for the fact that readiness is not thoroughly understood is the fact that it is not consistently defined in the literature. Sudore et. al, (2008) suggest that readiness, self-efficacy and information all lead to behavior change but do not define the concept or its relation to self-efficacy and information. In another study, Sudore et al. (2013) suggest that readiness is synonymous with the ‘preparation’ stage of the TTM. A study of stages of change for the component behaviors of ACP (Fried et al., 2010) suggests that readiness is captured by the stage of change at which individuals find themselves for each of the three ACP behaviors.

Some researchers have suggested that motivation and self-efficacy are highly correlated factors that, if strengthened, can impact readiness for ACP. Schickedanz et al., (2009) have
examined barriers to ACP for each step: contemplation, discussion and documentation. They found that the key overarching barrier was that ACP was considered irrelevant. This response is reflective of low motivation for action. However, lack of motivation seems to be heavily related to a lack of information in this area. The main reasons for believing that ACP was irrelevant was that: 1) patients thought themselves too healthy to engage in ACP, and 2) patients wanted to leave it in God’s hands. The reality however, was that 70% of these patients reported being in poor health and over one-third had a recent ICU admission (Schickendanz et al., 2009). It can be argued that more information about prognosis and the realities of inadequate planning can increase motivation and consequently, readiness to act. Using information and motivation in interventions based in behavior models have been very successful in bringing about behavior change for other clinical settings, such as regular mammography, smoking cessation and medication adherence (Redding, Rossi, Rossi, Velicer & Prochaska, 2000). These interventions can be studied and important elements extracted to potentially inform the development of ACP engagement strategies.

Finally, although readiness is cited as the key indicator of intention to act, there is no research in the ACP literature that actually links readiness to action. Most evidence has been around preparing for communication and decision-making. Thus, there is no evidential basis for the assumption that feeling ready to act will result in imminent action. Since action is the final outcome that is being sought, it is important to examine how readiness to act translates to action. Consequently, there is a need to better understand the nature of readiness and how it can be influenced in practice. The three main ACP participants, patients, families/decision makers and clinicians, are crucial contributors to such an exploration, as they can define what readiness means for them and elucidate the factors that they believe make them ready to participate or that
they believe prevent them from feeling ready as well as how readiness to act impacts actual action. This information will help to inform how ACP interventions can be best targeted to readiness for this population.

**Supportive Living Context**

ACP is especially important for patients in SL facilities as these individuals are often physically frail and or are suffering from cognitive decline. It is therefore a population whose health trajectory means that they will likely lose capacity to communicate health care preferences and will need someone else to make these decisions. In addition, this population is unique due to the fact that dementia patients may remain in a state that prevents them from communicating for many years. This population faces unique barriers as a result of its vulnerability. SL residents are largely marginalized and isolated, often having moved to SL out of necessity rather than preference. The move to SL indicates significant loss of independence and ability to care for oneself. This position further implies limited power and diminished ability to advocate for oneself as health declines.

Some research suggests that nursing home and SL residents do not receive optimal EOL (Casarett et al., 2005). Residents are often transferred to acute care settings to receive aggressive treatment in the last weeks of life (Levy, Fish & Kramer, 2004; Miller, Gozalo, & Mor, 2001). In fact, 49% of dementia patients who died in a hospital received one or more invasive, non-palliative treatment at EOL (Ahronheim, Morrison, Morris, Baskin & Meier, 2000). In addition, physicians often determine their patients’ resuscitation status without patient consultation (Fassier, Lautrette, Ciroldi & Azoulay, 2005; Sayers, Schofield & Aziz, 1997). Patient care may be further compromised by the fact that agreement on treatment goals between family caregivers of older frail adults and physicians is low (Bogardus et al., 2001).
The literature indicates that EOL care planning for patients with dementia is possible. For instance in early cognitive decline, patients are able to engage in decision-making, formulating goals, appointing a decision-maker and completing a living will (Finucane, Beamer, Roca & Kawas, 1993). However, individuals in residential care report some unique barriers to ACP engagement, including the fear that completing medical order forms would mean that nothing will be done for them at all, including aggressive pain and symptom management (Norlander & McSteen, 2000). The lack of ACP engagement in residential facilities, such as SL, prevents individuals and their families from retaining autonomy and authority over decisions. In addition, there is some evidence that limited ACP discussions actually impede the acceptance of a role in ACP by clinicians, thereby further preventing residents from expressing their wishes and values (Jeong, Higgins, & McMillan, 2010).

The uniqueness of the SL population suggests that when exploring ways to increase ACP uptake, it might be relevant to target interventions to a specific clinical context. In order to do this effectively, it is important to understand context-specific factors that impact ACP engagement. Since readiness is thought to be most relevant and predictive of ACP engagement, it is necessary to understand the readiness of the relevant parties, residents, families and clinicians, to engage in ACP in SL.

**Chapter Summary**

Although the benefits of ACP have been demonstrated, researchers and practitioners still do not know how to overcome barriers that exist to effective engagement in each ACP component: thinking, discussion, and documentation. In addition, there is insufficient understanding of how clinicians engage patients in ACP. There is also a need to better understand the factors that can help family and decision makers feel equipped to make decisions.
Currently faced with low levels of ACP engagement, there is a need to better understand how to effectively tailor ACP interventions. Specifically, the literature suggests that ACP engagement is a type of behavior change best captured by the TTM and health belief models. Readiness is theorized to be a requirement to achieve behavior change according to these models. Readiness is not well understood, and has not been studied in the SL context, where ACP is of paramount importance due to the physical and cognitive vulnerability of residents. This study will contribute to knowledge and practice by exploring readiness to engage in ACP in the SL context. Specifically, this study will provide answers related to how key participants perceive readiness, the factors impacting readiness and what kinds of things should be included in ACP engagement interventions in SL. Thus the findings from this study can contribute to existing literature, practice and quality of life for vulnerable SL residents.
Chapter 3

Method

This chapter presents the methods used to increase understanding of readiness for ACP engagement. First, the research approach is presented and its rationale is explained. Next, the study is situated as part of a larger research program. Following this, the setting, participants and recruitment, and protocol of data collection are explained. Next, a detailed discussion of data analysis is provided. The chapter concludes with a discussion of ethical considerations.

Research Approach

Qualitative research is a systematic, subjective approach to describe lived experiences and their meaning (Creswell, 2009). A qualitative approach enables participants to express aspects and stages of readiness that may not be accounted for in a predetermined quantitative measure. Researchers utilizing a qualitative approach are also able to identify and expand themes that have not been previously considered.

Interpretive Description (ID) is the specific qualitative approach that was used in this study to most effectively answer the proposed research questions. ID is a generic qualitative methodology that aims to understand perspectives and experiences relevant to applied health disciplines (Thorne, Reimer Kirkham & MacDonald-Emes, 1997). ID is epistemologically based in constructivist and interpretive naturalistic orientations (Thorne et al., 1997). Although not yet a mainstream methodology, ID is increasingly utilized in nursing research and is expanding into other health related fields as well as health service research (Clark, Spence, & Holt, 2011; Kalengayi, Hurtig, Ahlm, & Ahlberg, 2012; Olsen, Bradley, Lomborg, & Nortvedt, 2013).

The unique contribution of ID to qualitative research is its propensity to enable the translation of research findings to clinical practice. This approach evolved out of necessity, when
nurse practitioners found that their clinical inquiries were constrained by the frameworks of traditional qualitative methodologies such as grounded theory, phenomenology and ethnography. For instance, grounded theory requires researchers to approach a study phenomenon void of expectations or clinical knowledge, phenomenology entails a meticulous and detailed narrative coding of participants’ lived experiences, and ethnography involves long-term immersion into the culture of group or community (Creswell, 2009). ID appreciates the breadth of clinical experience that applied health researchers bring to research inquiry, is focused on broad questions of meaning and involves guided emersion into clinically relevant participant perspectives with the goal of informing practice.

The products of ID have the potential for clinical application because this methodology recognizes the knowledge and experience of practitioners within a given clinical field, even in the absence of formalized research, and positions this background knowledge as the basis on which to build new inquiry and create meaningful connections to other findings (Payne & McPherson, 2010). A critical analysis into existing knowledge regarding the clinical phenomenon being studied is the basis for an analytical framework that guides the development of the ID study design (May, 1989). The philosophical underpinnings of ID assert that the complexity of experience relayed in qualitative data must be understood to be contextual, constructed and subjective. The researcher cannot be separated from the data and ultimately determines what/how data is interpreted as well as what findings are generated. Finally, although theory can serve as a basis for research design, it cannot be permitted to overwhelm the interpretation of the data. Rather the findings must be derived from the data itself.

A number of challenges in using ID have been identified. Since ID is a new methodology, and as such, is not extensively described in the literature, it can be difficult for researchers to find
concrete applications of its use and to use these as a template for use in their own research (Hunt, 2009). This can make it challenging to be certain that the practical application of ID is done according to the intended process. In addition, because of its relative novelty, it is difficult to gauge the ideal balance between description and interpretation in data analysis. In particular, researchers have to be careful to develop sufficient interpretation, and not simply focus on the descriptive aspect of ID in order to gain optimal results from this methodology (Hunt, 2009).

Despite the challenges mentioned above, ID was determined to be the most appropriate methodology for this study due to its practical applicability. ID is suitable for exploring readiness because it is used to answer highly complex and contextually embedded questions and to generate knowledge related to clinical practice (Thorne, Kirkham, & O'Flynn-Magee, 2004). Further, ID allows for both a descriptive and interpretive exploration of the phenomenon under study. Description is important for gaining a better understanding of directly expressed perspectives. Interpretation is used to explore the deeper meanings that are expressed through responses to questions. The combination of description and interpretation helps to generate a complete understanding of the issues and factors predictive of ACP readiness.

ID is suited to social work research by virtue of its ability to recognize the field experience that researchers bring to academic inquiry, emphasize the meaning of participants’ subjective experiences, and have as its purpose the discovery of clinically relevant, action-oriented data. ID fits well with the current priorities of social work research, by virtue of its clinical applicability and relevance as well as its appreciation of the wider context of participant perspectives. There is evidence to suggest that social work research is overly reliant on descriptive and explanatory techniques at the expense of work on intervention and application (Rosen, Proctor, & Staudt, 1999). Consequently, a methodology that respects the perspective of
the participant while also being clinically relevant for guiding intervention can be important for enhancing the impact of social work research. Clinical and social problems do not exist in isolation from environmental factors and social workers are specifically trained to grasp and look for the context of a presenting problem (Shaw, 2007). It is often that context, which is key in formulating solutions. Additionally, by inviting participants to share their experiences and using their input to direct intervention design, ID enables the researcher to uphold key social work values: service, social justice, dignity and worth, human relationships, integrity, and competence.

Philosophical Position of the Researcher

My philosophical approach in this study was defined by my position as a Master of Social Work student. ACP work is primarily situated within the healthcare field but its impact on vulnerable patients at EOL renders it a meaningful target for social work attention. My philosophical stance was guided by the ACSW Standards of Practice and the CASW Code of ethics (Mullaly, 2006). Social work values specifically relevant for this study include: 1. Respect for the inherent dignity and worth of persons and self-determination, 2. Ethics, and 3) Social justice. First, it was important to me to understand how and whether elderly individuals and their families/decision makers are treated with dignity in SL regarding the elucidation and enactment of ACP and EOL wishes. I was cognizant of residents’ and families’ levels of satisfaction with the respect they had received during ACP engagement as well as the approach that clinicians took to engage residents in this process. Second, I was aware of the potential ethical issues that could arise both from the entire research process and also as a result of residents’ ACP engagement, particularly because resident participants were quite elderly, frail and vulnerable. For the research process, I took caution to ensure that participants were able to take part in a setting that was comfortable to them, that the questions I asked invited sharing, were respectful
and honored any position that residents or family members might take. When interviewing clinicians, I was attuned to their approach to ACP engagement in the clinical setting and whether or not they were aware of and had considered the ethical challenges and implications of the ACP process. Finally, the social work lens is particularly appropriate for issues related to social justice. I feel strongly that ACP engagement is such an issue, and it is essential to recognize the areas where social justice is needed. The ACP process, especially in SL, has the potential to decrease vulnerability of elderly residents, including those who are frail or in cognitive decline, by giving them the opportunity to voice their wishes and have them be heard and respected. Still, ensuring this process is adequately enacted, respectful of residents’ willingness to participate, and accommodating to their capacity to comprehend, are all necessary steps that must be taken.

The social justice emphasis, as part of the social work position, is a unique lens that allows me to recognize these key factors pertaining to optimization of resident or patient empowerment and guide research and clinical practice in a direction that is not a predominant focus for other disciplines involved in the ACP process.

**Larger Research Program**

The current study was part of a larger, five-year, Alberta Innovates Health Solutions (AIHS) funded, research program knowledge creation and knowledge translation program. This program is headed by principle investigators: Dr. Neil Hagen, Dr. Jessica Simon and Dr. Konrad Fassbender at University of Calgary and University of Alberta respectively. Using the knowledge-to-action cycle, the aim of this research program is to support adoption and understand the impact of ACP/GCD across Alberta. As part of the knowledge creation portion of the program, the first research activity seeks to assess readiness, barriers and facilitators to ACP uptake across various clinical settings in the local, Alberta context. In addition to this current
study in a SL context, corresponding studies were conducted, using the same interview guides, to examine the perspectives of patients, their families and HCP in oncology clinics, heart-failure clinics and renal clinics across Calgary and Edmonton.

My contribution to the current study was through the selection of the research questions, selection of the methodology, design of the interview guide, data collection and subsequent analysis for this thesis, as a distinct but linked component of the larger study. Study findings were analyzed and reported separately and will also be compared between each clinical setting. The findings from this study have been used for my thesis and will be used in the between-context comparative analysis. For the purpose of this thesis, only findings in the SL setting were considered.

Setting

SL facilities provide long-term living accommodations for individuals who want to remain independent but require increasing support with daily activities due to age, chronic conditions, frailty or physical disability (Supportive Living Guide, 2013). Typically, SL facilities provide 24-hour nursing assistance, all meals and daily physical activity/therapeutic programming. The SL philosophy is to preserve quality of life while meeting the health and social needs of residents. The SL facilities participating in this study house approximately 100 residents each.

Completion of goals of care designation documentation, although technically a voluntary form, is encouraged upon entering into residence in a SL facility. Residents are not required to complete this documentation but clinicians are expected to pursue the issue. The GCD documents can be completed by a nurse practitioner with input from residents, but a physician must oversee their completion (Advance Care Planning and Goals of Care Designation, 2014). In
addition, ACP documents, are re-evaluated in two circumstances. The first is when there is a change in the health status of the patient. Specifically, if the patient’s health condition worsens, the ACP documentation is accessed and can be modified, as necessary. The second is during annual meetings. Once per year, patients are asked to attend a meeting with their family and their SL healthcare providers. Their care, health status and goals of care designation documentation are reviewed at this meeting. The patient’s designation can be changed at this time, if necessary.

Patients are selected in SL because they are at a high risk of being in medical situations in which they may not be able to communicate their preferences for medical care. They are a population that is in real need of being involved in ACP discussions with HCPs to ensure that they are given the choice to have their goals of care defined to ensure that their values and preferences can be respected. Although all SL residents are expected to complete a goals of care document upon becoming a resident, it is not clear that they always take on an active role in the completion of this document or are fully aware of its implications.

Participants

Three participant groups were purposively recruited who represent the key individuals involved in the ACP process in a SL context. The three groups consist of residents, family members/decision makers, and health care providers (HCP). Twenty-seven participants were individually interviewed: 10 patients, eight family members and nine HCP. As a qualitative study, sample size was evaluated on an ongoing basis to identify when saturation was reached. Saturation was determined to have been reached when no new information emerged from the data for each participant group.

Health Care Providers. Nine English speaking HCP working in SL (i.e., physicians, nurse practitioners, registered nurses, nurse aides and social workers) were recruited for
participation. These HCP were selected as they represented the disciplines most often involved in the completion of ACP documents (i.e., goals of care designation, personal directives, etc.) as well as discussions regarding ACP with patients and families in SL. Nurses and social workers are often the primary discussion initiators, while physicians are obligated to oversee goals of care designation documentation. HCP were eligible to participate as long as they served patients in SL. Not having participated in ACP activities was not an exclusion criterion for participation.

Participants consisted of three physicians working in SL, one social worker, one nurse practitioner, two registered nurses and two nurse aides. One of the participants was male, and all other participants were female. The distribution of clinician subspecialties and gender is largely reflective of the professional make-up in the SL context. Nurse subspecialties significantly outnumber other professionals, including physicians, while social workers are the lowest in frequency. Registered nurses and nurse aides are the most common healthcare professional working in SL facilities.

Residents/Families. Ten English-speaking SL residents who were able to provide consent to participate and engage in a conversation about ACP and eight family members of patients who were SL residents were recruited. Cognitive capacity to participate was determined by the nurse practitioners (NP) at each SL facility. Residents who were not believed to have capacity to participate were not contacted by the NPs with information about study participation. Two family members were related to the resident participants.

Eligible participants included males and females of any age and ethnic background. The study was limited to English-speaking patient/families/caregiver participants because the Alberta Health Services budget does not yet support translation of the ACP information tools. The study was aimed at patients who are capable of making health care decisions for themselves; thus, the
study required that patients had the capacity to partake in ACP discussions with HCPs and, if they so choose, make health care decisions relevant to ACP.

**Recruitment**

Data collection took place at four SL facilities in Calgary where the research team had contacts, which facilitated recruitment. Some potential limitations to this recruitment strategy were that only a limited number of SL facilities were approached for participation in this study and consequently, variability in ACP approach and participant perspectives may have been missed. Prior to data collection, the researcher provided recruitment materials to two nurse managers at each of the two SL facilities. The nurse managers decided it would be best to disseminate these materials to NPs at the four facilities mentioned above and asked them to approach potential participants (both patient and family members) whom they felt met the eligibility requirements for participation. NPs were thought to be most suitable for this role as they know residents well and have extensive knowledge of the residents’ health status. NPs were instructed to only approach individuals who they felt would have sufficient cognitive capacity to participate in the study. NPs provided potential participants with preliminary study information and the recruitment flyer. They asked whether the researcher could contact them (either in person or by phone) to provide them with further information regarding the study. If individuals agreed to be contacted, the researcher either called them or visited them in their room and provided more detailed information about the study and nature of participation. Individuals were then invited to participate and informed that participation was voluntary and could be terminated at any time. Two residents declined to participate at this stage. There were no family members who declined to participate. Informed consent was obtained from all participants. One limitation in recruitment outcomes for these participant groups was the disproportionate numbers of female versus male
participants. This was mainly due to the fact that there is a disproportionate number of females residing in SL facilities. Additionally, women are most often the caregivers for family members in SL facilities.

Clinicians at the four SL facilities were also approached by the nurse managers with recruitment flyers and asked to participate in the study. In addition, the researcher presented the study at a morning meeting with nurses and other clinicians from a number of facilities. Those willing to participate were provided with the contact information of the researcher and given the option to schedule a meeting at this time. For those who contacted the researcher, the study and participation details were explained and for clinicians who were interested in participating, a meeting time was set up. Three clinicians were recruited using snowball sampling. These clinicians provided their contact information and the researcher contacted them for participation.

**Data Collection**

Semi-structured one-on-one interviews were used to collect data. Specific questions were formulated relative to each type of participant (patient, family, clinician) and informed written consent was obtained prior to beginning each interview. An interview guide, developed specifically for the purposes of this study, was used with the questions and probes that were discussed with each participant (See Appendices 1-3) (Creswell, 2009). The semi-structured interview allows the direction of the interview to be determined by the participant within the parameters of the topic area. Individual interviews also enable participants to engage in deeper reflection and more private individual exploration than other forms of data collection (e.g., focus groups, survey), thereby ensuring richness in data content. Readiness for ACP uptake is an emotional and complex process. In order to gain an optimal understanding of the factors that influence ACP readiness, an interview strategy that enables participants to move beyond the
interview guide is ideal. A rigorous and systematic process was used to develop the interview guide for patients, families and clinicians. First, an extensive literature review was completed using the PubMed, Medline and PsychINFO databases. Search terms used were: ‘patient perspectives readiness’, ‘patient readiness’, ‘perspectives readiness’, ‘ACP patient perspectives’, ‘barriers perspectives’, ‘barriers facilitators perspectives’, and ‘end of life perspectives’. Relevant studies were summarized and categorized according to topic and study population. The findings from these studies, in combination with the essential components of ACP as defined by this study, were used to identify relevant themes related to barriers, facilitators and readiness for ACP engagement. These themes were used to help determine all pertinent factors that impact barriers, facilitators and readiness for the three populations. Interview guides from the relevant studies were also examined for content and wording of open-ended questions. Two meetings were held with the researchers studying the other clinical contexts to review the information gathered from these sources to develop the categories of the interview guide and the content for each. Open-ended questions were then crafted to include all known information related to the topics of interest, while also providing opportunities for participants to introduce new information. A draft of the interview guide was reviewed with a social psychologist who specializes in discourse analysis and the wording of questions was edited to invite maximum discussion and sharing from participants. In addition a patient advisor on the steering committee of the ACP CRIO study reviewed the interview guide. The interview guide was further enhanced once the data collection process had commenced as the fit and appropriateness of the questions was evaluated. For example, it became apparent that a significant proportion of patient participants did not associate medical orders (GCD) that are part of their medical green sleeve folder, with the term ‘ACP’. Consequently, in order to thoroughly explore participants’ experiences with all ACP activities,
including medical orders, it was necessary to specifically ask about their ‘green sleeve’.

Interview guide changes were made accordingly.

The audio recorded interviews were downloaded to the Health and Research Data Repository (HDR) and sent to a transcription service. The HDR is based within the Faculty of Nursing at the University of Alberta. It is a secure and confidential virtual research environment (VRE) created to support health related research projects. Additionally, I formulated field notes following each interview to provide additional information that may not have been captured in the audio recording. Field notes were taken during the interviews to ensure comprehensive data capture including pertinent characteristics of both the physical environment (e.g., noise, distractions, etc.) and participant (e.g., shyness, cognitive or memory difficulties, etc.). These notes became part of the data analysis, informing the context of study findings and adding depth to the interpretive process. Interviews continued until data saturation was accomplished.

Participants were interviewed at a time and location best suited to the participant, most often at their SL site. A couple of family members were interviewed at coffee shops. Interviews lasted between twenty minutes to one and a half hours, with most ranging from thirty minutes to an hour.

**Trustworthiness**

Qualitative validity and reliability are established differently than in quantitative research. The process of incorporating measures to deal with issues of validity and reliability in qualitative work is encapsulated by trustworthiness (Creswell, 1998). A trustworthy study must address key concepts: a) credibility, b) transferability, and c) dependability.

**Credibility.** Credibility most closely resembles the concept of internal validity in quantitative research. In qualitative research, credibility is established by the researcher through
reflective and exploratory analysis, whereby the meaning in data is determined through the development of themes that accurately depict participants’ experiences. All findings and results presented are that of actual facts stated in the interviews. All participants’ experiences and perceptions are portrayed as they have done so in the interviews, no false information or accusations were included in dissemination of the findings. Credibility can be further strengthened through a number of processes. The following strategies were used to enhance credibility.

**Verbatim accounts.** With verbal and written consent from participants, all interviews were audio-recorded in order to ensure that participant’s exact wording is captured. Verbatim accounts were used whenever possible to help ensure the authenticity of the data when writing up the study and for further dissemination. Likewise, directs quotes from participants were used to support emergent themes and maintain authenticity. Authenticity refers to reporting each participant’s experiences in such a way that it maintains respect for the context of the data and presents all perspectives equally so that the reader can arrive at an impartial decision.

**Reflexive analysis.** I engaged in an ongoing examination of my personal biases, perceptions and interests in framing questions, responding to participants and interpreting the findings. This was done through a dedicated journal in which I recorded all notes pertaining to these topics as well as regular discussions with clinical supervisors and the larger research team.

**Triangulation.** This was established through the use of multiple sources of data, including interviews with a wide range of informants (patients, families and clinicians), multiple data-collection sites as well as field notes to ensure a rich picture of attitudes and behaviors of all individuals involved in the ACP process (Shenton, 2004).
**Weekly debriefing sessions.** I debriefed weekly with supervisors and researchers working on other parts of this study, which helped to develop ideas as well as to reflect on personal biases and preferences.

**Multiple peer evaluations.** This involved immersion in data analysis and refinement of themes of researchers and supervisors working on other parts of this study. This process ensured a wide range of perspectives on the data helping to strengthen arguments and promote a rigorous analytic process.

**Transferability.** Transferability is most closely related to external validity and is concerned with the extent to which understandings from one study can be applied to similar contexts, rather than the generalizability of findings to other contexts, settings or groups as is the norm in quantitative research (Shenton, 2004). Transferability is enhanced through my in-depth description of the context of this study. This information will be useful for researchers who want to conduct studies on ACP in SL facilities and to compare findings from this study to other studies. Additionally, the enhancement of transferability will allow for the future development of applicable interventions beyond the sites included in this study.

**Dependability.** Dependability refers to consistency during the data collection phase and the extent to which results are consistent given the data collected. Dependability during data collection was enhanced through maintaining similar interaction style with all participants, using the same interview guide as well as consistently following the protocol. Dependability in data analysis was strengthened through an audit trail, involving the maintenance and referral to all transcripts, field notes, and meeting notes.
Data Analysis

ID uses small-scale investigation of a clinical phenomenon for the purpose of capturing themes and patterns within subjective perception and generating a framework for informing clinical understanding and practice (Thorne et al., 2004). Accordingly, ID uses small sample sizes and a variety of qualitative data collection methods including interviews, focus groups and participant observation. For the purposes of answering the proposed research questions, individual interviews were selected as the collection method that is most suitable to the unique needs of participants in SL facilities. This decision is based on two factors: 1) participants may have health limitations (e.g., difficulty hearing, cognitive impairment, fatigue, difficulty with mobility) that would make it difficult to hold a focus group, at one specific location, for a long period of time while ensuring that all participants are able to participate equally; and, 2) as the interview questions ask participants to consider their personal health care preferences and past experiences with ACP, this topic is potentially difficult and emotional, which could make it difficult for some participants to share their experiences in a group setting.

A thematic analytic framework was used to analyze the audio-recorded interviews after transcription. Analysis of data according to ID is focused on the inductive generation of a coherent framework derived from addressing broad questions of meaning, rather than coding small data units. The broad goals of ID analysis are to comprehend the data, synthesize meanings, theorize relationships and interpret findings (Morse, 2003). The analytic technique involved repeated immersion in the data prior to initiation of coding, classifying or creating connections (Giorgi, 1985; Knafl, 1988), concurrent data collection and analysis, and constant comparative methods throughout the process (Parahoo, 2006; Thorne et al., 2004). Also, detailed line-by-line coding is avoided in favor of asking broad questions of the data. As data was
continuously collected and reviewed, coding categories were revised and refined. All coded data was entered into the computer software NVIVO. Data was analyzed separately for each of the three participant groups. Then, the interpretive process enables the researcher to define themes both between the three participant groups as well as to present findings on collective themes among the groups. The analytic process is described in detail below. 

Familiarization with the data. Thorne (2008) suggests repeat emergence and re-emergence in the data prior to starting the coding process. This step was especially important for me, as I did not personally transcribe my interviews. I wanted to ensure that I was very familiar with my data so that I could ask questions of the data throughout the analytic process. First, I read every interview along with my detailed field notes, while data collection was still ongoing. I then re-read each interview, making notes about my general impressions and ideas regarding main messages and themes that were salient in the participant’s interview. I then reflected on the key parts of the interviews that stood out in my mind by asking myself why these were the parts that had captured my attention. Thorne (2008) emphasizes the importance of this step in helping the researcher to recognize potential biases, based upon what kind of information is making an initial impression. For example, I found myself very sensitive to a couple of clinicians’ descriptions of how the ACP process was enforced in SL. My focus was entirely situated on portions of the interview where the clinicians described forcing patients to participate in GCD completion. I was able to recognize that I was feeling an ethical objection to these practices. By challenging this bias, I felt I was able to ensure that my feelings did not taint my approach to the interview, as it might otherwise have done.

Coding. Next, I coded each interview in NVIVO. ID suggests the use of broad-base coding and discourages excessively fine-tuned coding. Consequently, I focused my coding on
larger units of meaning in participant message throughout the interview. I still used line-by-line coding when participant stories contained many meanings and messages.

Thorne (2008) encourages continued challenging and mentorship throughout the analytical process, in order to ensure that the integrity of the data and analysis is maintained. To do this, I met with the Principal Investigator of the larger ACP CRIO study in the initial stages of coding. During these meetings, she challenged my coding strategy for each of the three participant groups, asking why I chose specific codes and why I coded specific sections of the text as I had done. This process helped me to reflect on my coding and initially, helped me to recognize that I was imposing a thematic structure on my coding. Consequently, I changed my coding strategy to a very neutral, descriptive one.

**Classification.** Once the coding was complete for a participant group, I copied all of the codes onto a separate spreadsheet and used the constant comparative method to classify all codes into categories. The goal of classification is to help the researcher move beyond superficial impressions and begin to understand their data as a whole unit (Thorne, 2008). In order to do this effectively, Thorne (2008) recommends the use of any technique that feels natural to the researcher. I decided that what I needed was to have my process challenged by an objective expert. A copy of all categories with corresponding codes and quotes was sent to the Principal Investigator for assessment. We then met face to face for a two-hour meeting, per participant group, during which she challenged my classifications. Some classifications were changed, some codes were moved and some categories combined. As part of these meetings, she also encouraged me to describe my classification thought process to her. During my description, she took notes of what I was saying and later, provided me with these notes. I found this exercise very useful in helping me understand my thought process and capturing authentic thematic
impressions as I was beginning to form linkages in the data. This process also fits in what Thorne (2008) refers to as the documentation of ‘analytic thinking’, which she encourages and is the basis for creating linkages and interpretations. After my meetings, I reviewed the classification changes that were made as well as my documented analytic thinking for each participant group.

**Linkages and interpretation.** Once I felt that my classifications were reflective of the data, I began to focus on linkages in the data. I was mainly focused on two types of linkages. The first was around group themes. For example, I found that family members uniformly expressed significant investment in the ACP process. I also found that family members, very often, had been caregivers or decision makers for another relative who had died. Since ID values researcher knowledge on the topic under study, I was able to utilize my knowledge that being a prior health care decision maker is a known facilitator of ACP readiness. Thus, I was able to begin to use linkages to interpret my findings, by postulating that family members of SL residents, might be exceptionally supportive of ACP because they have prior EOL decision making experience. The second type of linkage on which I was focused was individual. Here, I began to generate an interpretive explanation of individual participant profiles. For example, one SL resident was adamantly against ACP engagement. I found it helpful to use key codes and corresponding quotations to generate an interpretive profile of this participant to help me understand her position. I discovered that she strongly believed in taking life one day at a time, that she had never made medical decisions for anyone else, and that she had very limited experience with the medical system. Creating linkages between these key parts of a participant’s sharing was very helpful in understanding how readiness for ACP is achieved and manifested in the context of personal experience. An important aspect to the interpretive step was to ensure that I tested many different possible linkages between data pieces as well as challenging various interpretations to
see if alternative explanations exist. The purpose of this final interpretive step is to elucidate something from the data that is beyond the self-evident (Thorne, 2008).

**Ethical Considerations**

**Risks and benefits to participants.** This study was granted ethics certification by the Conjoint Health Research Ethics Board at the University of Calgary. The study findings will benefit and caused no harm to the participants and society since the focus was to explore perceptions about readiness to engage in conversations about ACP to contribute to clinical practice and improve standards of care.

The main risk to participants came from the nature of the interview topic. Participants were asked to reflect on highly personal, emotional and difficult issues around EOL values and care. For residents, it may have been difficult to think about EOL, their current and future health problems, as well as the difficulty in having to discuss these issues with family and clinicians. For family members, it may have been difficult to think about an ill relative dying or deteriorating physically and also having to discuss wishes around EOL care with that relative and health providers. Finally, for clinicians, EOL discussions can be uncomfortable and reflecting on how they might not be ideally equip to initiate these discussions may have been a source of distress. Contact information to a counseling service was provided to two participants who became visibly upset during participation in the study. However, both of the participants declined the contact information, sharing that they were not distressed but simply felt that becoming emotional was a natural part of discussing some of their past experiences. These two participants were not distressed by the end of the interview. Participants did not have to answer any questions that made them feel upset and were able to withdraw their participation at any time. Two
residents who initially indicated interest in participating decided to decline to participate once the researcher met with them and explained the details of the study.

Privacy and confidentiality were maintained at all times, all findings are portrayed in a confidential manner; no personal or identifiable information has been recorded or printed in the study. Confidentiality was maintained through a participant identification coding system. Audio taped interviews were transcribed verbatim, but no names were recorded during the interviewing process. Once transcribed, the data was stored in password protected folders with restricted access and stored on an external hard drive which only the researcher had access to. Upon completion of data analysis, manuscript completion and a final report to CHREB, all data will be destroyed after five years.

The benefit of participating in this study for all three participant groups was that the knowledge developed from the interviews will be used to improve patient care around EOL issues. Participation in this study may result in both direct benefits to participants in addition to benefits for future patients. Because the findings from this study can inform the creation of a provincial ACP framework, this study will help to determine how care surrounding EOL issues is delivered. The participants from this study may encounter the new ACP framework as they age and move through the healthcare system. Without expressed and properly documented wishes, patients may not receive EOL care that is congruent with their wishes. In order to improve patient care, EOL wishes must be known and these interviews will help the researchers better understand how patients, family and clinicians move to a state of readiness to have conversations about EOL care. This information can be used to tailor services and care delivery in order to appropriately improve readiness for ACP in these participant groups.
Autonomy. Participants were only approached to participate by staff familiar with their cognitive capacities, ensuring that they had the ability to provide written consent and participate in the study. All participants received a letter of information outlining the researcher’s background and the rationale for the study. Staff were instructed to detail the voluntary nature of participation as well as participants’ freedom to withdraw at any time, it was expected that participants did not feel coerced to participate. Although SL staff provided potential participants with the contact information of the researcher, they did not know whether residents ultimately chose to participate. Participants were informed verbally and through the written consent form that their decision to participate or not to participate would not impact any services they were receiving. Participants were informed that they could choose to withdraw from the study at any time without giving a reason. All participants provided written consent.

Ethical issues may arise at any point during a study regardless of scrupulous planning, therefore it is important that possible ethical issues are identified, prevented, and reviewed as best as possible prior to, during and after the study. Ethical principles provide direction to the possible issues not answers. An ethical consideration pertaining to participant recruitment arose prior to commencement of data collection. In conjunction with the corresponding studies in other clinical settings, participant recruitment was designed such that the researcher would approach patients near the end of their clinical appointments, present the study and ask if they wanted to participate. In the SL setting, the nurse management staff felt that this protocol was not ethically sound for their population because residents who are not cognitively competent might be coerced into participation and other residents might feel increased pressure if approached by a researcher they did not know. The staff felt that coercion would be minimized if a familiar clinician
introduced the study and allowed participants time to decide whether or not they wanted to participate. For this reason, the recruitment protocol was altered for the SL setting.

**Chapter Summary**

This chapter provided a detailed description of the methods used in this study for the purpose of advancing understanding of readiness around ACP engagement. An overview of the research approach, study rationale and explanation of the broader research program was provided. Details of the study setting, procedure and data collection were explained. Finally, a complete account of the data analysis process was also provided as well as ethical considerations.
Chapter 4

Findings

The purpose of this study was to explore readiness and associated factors from the perspectives of patients, their families and clinicians in SL. The findings are organized according to each of the participant groups. First, demographic information about the participants is provided. Next, themes that are unique to each participant group are presented. Finally, themes that were common among all three groups are described. Supporting quotes are provided that best illustrate the themes. Words like ‘uh’, ‘um’, ‘you know’ and duplicate words have been removed and replaced with ‘…’.

Demographic Information

Residents. Ten individuals, including nine females and one male participated in the interviews. This distribution of gender is representative of the SL population, especially among non-cognitively impaired residents. Most males who are in SL facilities have significant cognitive impairment or frailty. All participants had been deemed cognitively capable of participating in the study. All participants had children. One participant was never married, two lived in SL with their spouse and the remaining seven had been widowed. Participant age ranged from 72 to 87 years, with most participants being in their 80s. All participants had completed ACP documentation.

Family Members. Family members consisted of eight females with a family member in SL. Only two family members were related to resident participants who were interviewed for this study. Six participants were middle-aged, ranging from 45-60, with a parent living in SL. Two participants were in their 80s, living with a spouse in SL. All participants had engaged in ACP discussions and documentation, either for themselves or with their parent.
Clinicians. Nine clinicians, seven females and one male, who work in SL participated in the study. Three clinicians were physicians, who split their time between family practice and working in SL. The remaining six participants consisted of one social worker, one nursing practitioner, two registered nurses and two nurse aides. Clinicians ranged in age from early 30s to 60s. All clinicians had engaged in ACP discussions with patients.

Resident Perspectives

The main characteristics displayed by residents in their discussion of ACP, was their practicality and acceptance when it came to matters of health, the ACP process and EOL. Residents were clear on the fact that they did not wish to prolong life at any cost, rather they were interested only in limited health interventions. Acceptance was further displayed through participant’s representation of the ways in which their prior experiences had shaped their current EOL and ACP perspectives. Finally, practicality and acceptance were emphasized again in participants’ description of the nature of ACP conversations that they had with family and decision makers.

Not at all costs. Participants reflected an overall acceptance of EOL and the limitations of interventions. Limitations to interventions that were mentioned included length of time undergoing medical interventions or hospitalizations, symptom control, and only those for treatable conditions. One female participant poignantly described the relationship between the desire to live and the inevitability of death: “…you’re supposed to live as long as you want, you know. But I always feel if uh if they pull the plug, that’s the time you’re supposed to go.” Another stated: “nobody wants to die. [Chuckling] It’s just human nature to wanna keep living. But...I think we got a sensible plan.”
There was a definite sense that individuals did not want to pursue medical intervention at all costs, and that in fact, interventions had to be weighed against quality of life. One participant described her perspective: “...we don’t want any tubes and only pursued if chances of recovery are high...let’s not, you know, put me through a lot more stuff than I might have to go through.”

The desire to limit interventions was apparent even when participants did not demonstrate a high level of health literacy, as indicated by some misunderstandings around the reality of medical interventions. For example, “We discussed it. And if I need life support I don’t want it and if my brain’s still working then they can just help me by giving me a little help just to get back into shape, that’s okay.”

Participants emphasized that medical interventions should be short lived, not indefinite: “But you really do have to start thinking about this and thinking, ‘Do I really wanna have thirty days of treatment?’”

**Importance of prior experience.** Broadly, prior involvement in EOL care or decision-making, as well as ACP, were identified by participants as paramount in shaping their current perspectives. Some discussed personal health problems and crises as indicators of the importance of preparing. As one participant stated, “... after I got through that operation and got back home, I realized that there was things that people should’ve known if I hadn’t have made it through. You know?”

Others shared how EOL experiences with family members enlightened them to the unpredictability of life and consequently, the importance of planning. For example, “… I’ve watched my mother and my dad, my sisters, you know, my brother. And to me, those kinds of things have to be planned ahead because strange things happen to people. Like my brother got ALS.”
Many participants reflected on how their upbringing has shaped their views on EOL and ACP. One discussed the potential difference between an only-child and someone who has had to care for siblings, “... everybody’s life experience is what makes the difference. I suppose if you’re an only child and you’ve never had to consider other family members or anything like that, you’d have a whole different life experience. Now, I was almost an only child in the fact that I had older siblings but they were all hugely older than me.”

Another shared that experiencing EOL makes one more prepared for what to expect and what one’s wishes might be, “I mean, and your life experiences in this kind of situation, because I’m the youngest of the family, I’ve watched my grandmother, who lived with us, my mother, my dad and all three of my family. And to me, those life experiences make you more aware of what’s gonna happen ...and how you wish it to be.”

One participant who had not previously engaged in any type of EOL decision making, was influenced by this lack of experience and could not see the value of ACP engagement mentioning, “You know, that’s a tough one for me to answer having never had occasion to think about it.” Right now, she explained, “I am very independent, I make my own decisions. I take it day by day.” This participant had a very practical stance, explaining that her son will make decisions if necessary and that she has full faith in the medical system to make appropriate judgments.

Resident participants also presented with acceptance of their perceived advanced age, which possibly made them more open to ACP. As one participant mentioned, “I’m 71 years old and so it’s not as if I’m 21. You know? So there’s a difference there with your age pattern and your lifestyle, if I was still at home and ambulatory, able to take care of myself, that would be totally different um situation in- in itself.”
**Comfort with ACP Conversations.** Participants largely reflected a high degree of comfort with having ACP and EOL life conversations, usually with family and designated decision makers. Many participants conveyed the ease and sense of normality with which these conversations were had. For example, “Well I don’t know, it’s just normal, I’ve never been touchy about talking about death and pain and troubles.”

Another participant shared having to overcome initial disagreement between some family members but feeling determined about her wishes and satisfied about the ultimate agreement: “A lot of them didn’t agree. You know, at first. So we talked about it and, ‘Oh no, you don’t want that. You want, you know, get it, if you want to live and type thing,’ and when you get into 90 and you’re not, you don’t have the best of health and- and I wouldn’t put my family through that. You know, so we did talk about it and they all agreed at the end.”

Finally, some participants acknowledged that their family members are not as comfortable discussing EOL issues as they are. As one participant stated, “They don’t like to talk about it, naturally… and it’s been done kind of in passing.”

However, there was still a practical understanding that this conversation had to happen, as exemplified by another participant, “Because how else can they handle it? I mean they need the form and so it’s a discussion that’s very difficult, but it’s still one that has to happen.”

The findings from the perspective of those living in SL suggest that residents have considered the type of medical care they wish to receive and that their wishes for care are limited. Resident participants recognize the value and influence of prior experiences in shaping their current perspectives on ACP and EOL. Finally, residents reflected on the ease of and need for ACP conversations with family members and decision makers.
Family Member Perspectives

Family members of SL residents came from the unique position of having had prior experience of making medical decisions for someone else. Usually, children of SL residents had dealt with the death of one parent, which resulted in the other moving to SL as they were no longer able to live alone. Spouses of SL residents had prior decision-making experience as they were the designated decision maker for someone who was no longer able to make decisions. This unique position of having engaged in the complexity of medical decision making gave family members an appreciation of the limitations of the medical system and the benefits of ACP. Finally, family members were quite impacted by having to make difficult decisions.

Experience in ACP and Medical Decision making. Some participants indicated that prior decision making had made their current situation easier: “I think the only reason it was probably… easier with my mom is that I had to do it for my dad.” Prior experience with EOL and decision making gave family members an appreciation of the limitations of medical intervention. Family member knowledge and appreciation of health and decline at EOL was apparent in their reflections. One participant expressed a common frustration with a relative’s unrealistic expectations of what physicians can do for her husband stating, “She thought that the doctors could just get him up and movin’ and fix him. But I said, ‘They’re not magicians. They can’t.’”

Appreciation of ACP. Family members indicated feeling very appreciative of the positive ways in which ACP had enabled them to experience their loved one’s EOL. One family member indicated that ACP completion allowed her family to spend quality time with their father at EOL, rather than worrying about the medical decisions that otherwise had to be made explaining, “It meant that we were able to spend time being with him and…caring for him and supporting him the
way that we knew he wanted and not worrying about what they were gonna do if something happened because they...knew that.”

A number of family members shared that engaging in ACP had helped them gain confidence in knowing what to do for their loved one: “if they call me up and say...she’s had a stroke or she’s fallen or whatever, I know what to do.” Similarly, another participant indicated feeling grateful that she knew what to do as a result of ACP when her father experienced a rapid health decline: “When my dad died, I had his directive and...he had had like a hip fracture and then he...developed pneumonia and just was going, he was unresponsive the next morning and just going downhill... And when I got there that morning, the morning after, I knew there was something really, really wrong. And so I thought well now, what am I gonna do...if things really go sideways? And I knew what I had to do.”

Providing ACP documentation to physicians was indicated as allowing participants to advocate for their loved ones, with one participant sharing that she was able to ensure her father received the care he wanted against medical opinion: “…the ICU team was there and the doctor said, ‘...we would like to intubate him and do this and do that,’ I said, ‘No, absolutely not.’ ‘Well, we need to see the personal directive.’ So I gave them the copy that I had.”

Another participant shared that although she was upset when hospital staff initially prompted her to consider her father’s wishes in order to prepare ahead of a crisis, she later reflected on the importance of considering his wishes for care. She explained, “I suppose it does make me think...certainly when it happened to my dad, it made me go away...a bit angry at the moment when it first got asked. But I did go away thinking, ‘well, would I know that and how would I know that?’ And so then I had to think about the person, who they were, what they- what their value
system was, what I’d seen all MY life growing up to know what he would or wouldn’t say in that situation... yeah, I think it probably forces us all to do that.”

**Making Difficult Decisions.** Although family member participants saw great value in ACP, they nevertheless expressed struggling with difficult decisions. Sometimes decisions that have to make went against parent’s wishes. One participant shared an example explaining, “....she had a UTI and she was feverish and kind of delirious and not making a whole lot of sense, and plus she had fractured ribs. So at THAT point, because I was sort of between a rock and a hard place, I thought, well she shouldn’t be there, I don’t think it’s safe, but...there was no convincing her into moving.”

Another participant described the difficulty of the decision making process, even when a parent’s wishes are known, “...It’s still a very difficult process, even though we were, I thought, pretty well prepared, and that my dad had really done his due diligence too by giving me everything...so I’d know exactly where it was and what to do. So...it’s still, I mean there were still...hoops we had to jump through and that kinda thing but at least we had the information.”

In summary, family members had usually had previous experience with EOL and decision making for loved ones. This appeared to relate to their stated appreciation of the benefits of engaging in ACP. Finally, family members struggled with having to make difficult decisions, even after having engaged in ACP with their loved ones.

**Clinician Perspectives**

While the views and positions of residents and family members were quite consistent, much less commonality was found among clinicians. All clinicians reflected on the utility and benefit of providing patients the opportunity to engage in ACP; however, they expressed variability in their approach and comfort with ACP. Further, they had varied beliefs about patient
expectations of EOL care in SL. Clinicians were also quite varied in the strategies they used to introduce ACP to patients and to engage them when they encountered a lack of readiness. Finally, clinicians seemed to fit along a continuum of being ethically conflicted around aspects of ACP.

**Varied approach to ACP.** Clinicians all expressed having a unique position toward ACP. One clinician reflected on encouraging continued care by focusing on positive interpretation of quality of life, “...I tend to be less fatalistic...with some families who are saying C1 [level of care] ...has got dementia, not the man he used to be, wouldn’t want to live like this, we promised he wouldn’t go to nursing home and, and I look at him and I say well he’s attending programming, and he’s eating full meals, and he still recognizes his family”. Other clinicians expressed having a very practical approach to ACP, wanting to ensure that the process is complete, “I go through and find out if they have it, if they’ve covered all their bases, and I’ll talk to them if they’re their own person, the decision-maker, and, offer them any kind of a resource or assistance with it.”

**Perceptions on patient expectations.** Clinician views were equally varied when it came to interpreting patient perspectives on ACP and EOL care. One clinician asserted that individuals who come to SL want to be saved, as they are still mobile and somewhat independent, stating “I believe most clients...have the ‘are you going to save me?’ approach.” Similarly, another clinicians stated that residents do not see SL as EOL, “People see long term care as end-of-life. It’s a preconceived idea. They do not see Supportive Living as that.”

However, others expressed that individuals do not want everything when it comes to medical interventions at their advanced age stating for example, “we find that most people for sure don’t want everything, especially when they get to this age.”
**Varied strategies for ACP engagement.** Clinicians shared their varied strategies for approaching and engaging in ACP with patients. Some emphasized the importance of providing clarity to patients such as, “I think where the physician’s strength is in providing that individual, individual lens for that person...so we can talk generalities ... in terms of treatments but I think for individuals ...I think being able to try and be more specific is great for patients.”

Another clinician suggested that deciding how to best provide clarity can be aided by examining the language and level of understanding displayed in the patient’s personal directive commenting, “you would look to the personal directive, look at the language and then it might be the clue as to what was understood at the time.”

A number of clinicians discussed the importance of waiting until trust and a relationship has developed with patient/residents before initiating ACP conversations, “You have to draw people out through your relationship and understand their values.” Similarly, another clinician stated taking her time with ACP, “I don’t do it on the first ‘Hello, how are you?’”, while a third clinician also added, “I like to develop rapport with patients before introducing the topic.”

**Recognition of ethical dilemmas.** The findings also revealed a varied perception on the ethical dilemmas associated with ACP in the SL setting. A number of clinicians expressed ethical comfort with ACP. For example, one clinician recognized that ACP requires significant decision-making but did not feel that these need be difficult ones, “it is a significant decision but it’s most of the time not a difficult decision”. Other clinicians expressed deeper ethical conflict. Some highlighted the difficulty in decision making pertaining to the determination of quality of life for those who are cognitively impaired, “I mean the bigger philosophical question is whether or not...the life is worth living at that point and that, that becomes very hard especially with dementia.” One clinician stated that quality of life should be determined based on the resident’s
current capacity, not who they used to be, “…it’s not uncommon…to see them have a reasonable quality of life, I mean people will challenge that…they would say… they’re not doing crosswords anymore, and they’re not meeting friends for coffee, but… I guess what I’m saying is who is to judge what is a reasonable quality of life, I think many people would argue that, well that’s really up the person right, as we have.”

A number of other clinicians argued that what is important for family to consider is who their loved one used to be and what they valued when they were able to communicate explaining that “…what I do is I take a softer… approach and just ask them…back in the days when your parent really had full awareness and was in charge of their own life…did you ever have any discussions about life support, or what their wishes were about that?”

Similarly, another clinician voiced struggling with how the family and clinicians can determine patient wishes when patient wishes have already been neglected at entry to SL. As one clinician described, “Somebody may say… “never admit me to a nursing home, I never want to go to a nursing home.” And…then you get your family to promise that, to make a promise I’ll never send you to a nursing home. It’s tricky, right? So then they get dementia, they’re alive, they’re not really aware they’re in a nursing home, is there broken promises? Are you respecting a person’s wishes if you…if they’ve said explicitly “I do not want to go to a nursing home?”

**ACP documentation transfer between healthcare settings.** Clinicians discussed the fact that individuals came to SL having engaged in ACP to varying degrees. There was a general impression that when residents moved to SL from the hospital setting, they had completed GCD and this document was transferred to SL from the hospital. One clinician said, “Most come from the hospital with a GCD.” Still, clinicians acknowledged some ongoing challenges with the transfer of this documentation, “So to the last one…it’s gotten better, but certainly there’s many
times…that clients are transferred to Acute Care and the green sleeve doesn’t follow them back.

And so one of the challenges with that is that we don’t know what discussions may have been held with regards to that in Acute Care.” A further challenge is that sometimes, GCD documentation that comes back to SL from the hospital is not congruent with the resident’s health status. For example, one clinician shared, “Now we will often get orders from Emerg and...then I think we still have to follow up.”

In summary, although clinicians widely agreed on the benefits of ACP, they expressed variability in their personal comfort with ACP initiation. Similarly, clinicians were varied in their interpretation of SL resident ACP expectations. Clinicians were also quite diverse in the strategies that they use to facilitate ACP engagement. Further, clinicians expressed a range of struggles with ethical dilemmas for SL residents. Finally, clinicians discuss the transferability of ACP documentation between various healthcare settings.

Summary of Individual Group Themes

Unique themes emerged from the data for each participant group. Resident’s overarching practicality and acceptance was reflected in their desire to limit interventions, application of prior experience to ACP perspectives and approach to ACP conversations. Family members were mainly impacted by their previous decision-making and EOL experiences, their appreciation of ACP and their struggle with having to make difficult decisions. Clinician perspectives were varied for most emerging theme. They had varied approaches to ACP, differing perceptions of SL resident expectations, varied engagement strategies and varying degrees of recognition of ethical dilemmas on ACP in SL. There did appear to be more agreement around challenges of moving ACP documentation with residents between healthcare settings.
Themes Across Groups

The following themes were found among all three participant groups. These themes were developed through a comparative analysis, examining commonalities and differences among the groups. These common themes do not always indicate areas of convergence or agreement among the groups but they do allow for an in-depth contextual understanding of some ACP factors in the SL setting. The first theme presented describes the varied conceptualizations of ACP among the three participant groups. Next, each group’s conceptualization of the roles of key ACP players are described. The perception of readiness is explored from each group and finally, key barriers and facilitators to ACP engagement are detailed.

Defining ACP. All three participant groups reflected on their understood definition of ACP. Residents described ACP mainly as planning for living transition and for events after death. Family members displayed a high level of understanding of the intended definition and purpose of ACP. Similarly, clinicians had a high level of comprehension of the ACP terminology.

Although all resident participants had engaged in at least some ACP behaviors, very few associated the term ‘advance care planning’ with either thinking, communicating or discussing wishes for future care. Instead, the term was most commonly associated with the decision process around moving from independent living to SL as well as planning one’s funeral and the creation of a will. One resident, when asked to describe her experience with ACP, provided this interpretation, “I thought I just can’t do this. So that’s how I got thinking about it... ‘cause I was 90 and I was living there all by myself, so it was...difficult. And...I didn’t want to leave.” Another participant referred to funeral arrangements when asked about whether or not she had engaged in ACP, explaining, “Yeah, we have done that...we have our funeral arrangements all
made.” However, when prompted further to elaborate on engagement in each ACP component activity, residents described their understanding of the importance of the comprehensive process. One resident described her and her husband’s preparation, “Oh, we spent a lot of time thinking about what we wanted. This isn’t something you can just sign, you have to really think about it.”

Family members, although not knowledgeable on each ACP activity, had a clear understanding of the broad process and purpose of ACP. One family member emphasized the importance of ACP in providing guidance from her mother so that she can be prepared when it comes time to make decisions explaining, “I suppose well just a little bit of guidance as to what they...because when the time comes, then...we’ll be prepared. And it’s always better to be prepared.” Some family members were focused specifically on the documentation portion of ACP to help solidify wishes and be used to justify decisions for example, “I’d say yeah just to have a clear plan, so that if something WERE to happen, then...somebody has a document that says oh, this is what they wanted.”

While the clinician group demonstrated a clear understanding of the broad meaning and purpose of ACP, as a plan for what to do, they differed in their focus when it came to defining the term. Many clinicians were very focused on a communication of values in a strict definition such as “…I do my best to elaborate the conversation to...get a better understanding of the patient’s values, attitudes and beliefs.” However, when clinicians described how ACP happens in SL, the focus was mainly on completion of GCD. As one clinician explained, “…typically, those Goals of Care were being reviewed at annual conferences.”

Residents, family members and clinicians all presented with different interpretations of the ACP term. Residents were not clear on the definition of the term, often associating it strictly with transition to SL and planning for after death. Family members’ interpretation of ACP was focused
on the process utility in providing guidance for future decision making. Finally, clinicians’ interpretation of ACP was split between a focus on the communication of values and the completion of GCD.

**Roles in ACP.** Another theme identified across the groups pertained to the perceived role of each group in the ACP process. Residents communicated clarity about their own role and the role they expect their loved ones to take. The role of the clinician in the ACP process was muted, and had made a minimal impression on residents, even when prompted. Family members were also very clear on their anticipated role in the ACP process and as decision makers. Clinicians, on the other hand, while recognizing that they have a key role in ACP, expressed a lack of clarity around accountability in ACP roles.

Residents had clear roles for their family members as helping with decisions and making decisions. As one resident explained, “...I’m still in complete control of everything but he’s there when we need. They also displayed high confidence that decisions would be made well, “The family will be there, and they can make...they would be all there to make a decision if they had to be.” The clinician’s role in the ACP process, however, was described as minimal and mainly referred to the context of those guiding medical care in hospital. Very few residents reporting having had an ACP conversation with clinicians. When prompted, residents recalled completing at GCD but could not recall details of the conversations.

Family members were very accepting of the fact that they have a clear decision making role, “Well first of all, I’m her daughter. And she trusts me. And I would do it in her best interest, what was ever best for her.” Family members were also aware of the challenges of the role: “You do leave it to those around you but you’re hoping that they are going to know what you want and that is not the easiest thing to ask.” Although family members expressed some frustration with
physicians at EOL, particularly in hospital, they were very grateful for the role that clinicians could play in the ACP process in SL: “I think it’s a good idea... I think maybe the fact that the nurse was there...was a good thing because it wasn’t ME asking those questions—it was the nurse, right?” A family member of a cognitively impaired person, who had not engaged in detailed ACP discussions also expressed being accepting of her role, stating, “I make decisions for him. I know what he would want.”

Clinicians also acknowledged their roles in ACP. For example, one clinician stated they were a facilitator of ACP. Another stated they listen to the discussion and sign the forms. A couple of participants stated that the role of the nurse was to review ACP with all new clients and communicate health changes to the family. The social work role was perceived to be one of educator on ACP. Despite acknowledging individual roles in the ACP process, clinicians also expressed uncertainty about who is ultimately accountable for which role. As one clinician explained, “They don’t know whether - how far they should go, what they should do.” Another clinician expressed similar uncertainty when asked whether they felt like there was clarity around who should be initiating ACP conversations: “Not totally, never.” Yet another clinician discussed a lack of role clarity among the multidisciplinary team when it comes to ACP, explaining, “…I really think that the multi-disciplinary team don’t know... there’s this huge role.” Lack of clarity was also apparent on the topic of who is best equipped to conduct ACP conversations. Clinicians conceived of various specialties being best suited to take on the major ACP role. In addition, one clinician mentioned the potential challenge of having a main ACP component consist of an order made by one practitioner when other practitioners are involved in other aspects of the process.
Residents and family members both expressed a clear conceptualization of roles in ACP, with family members being accepting of their role as decision-maker. Clinicians, however, were less clear on role accountability and who is best equipped to engage in ACP with patients.

**Readiness for ACP.** Residents and family members both reflected on their level of readiness for ACP. These two participant groups expressed high readiness for ACP participation. Clinicians reflected on their response to variable patient readiness and they shared different and at times, conflicting approaches.

When asked about whether or not they felt ready to have ACP conversations, residents typically commented on the ease of the discussion. One resident said it was “easy because my daughter-in-law is a nurse”, another stated that “it is easy to discuss dying in our family”, while a third said that her family is “easy to talk to. It wasn’t hard for me.” Although the majority of residents expressed high readiness for ACP, lack of readiness was not seen as preventative to making decisions and having conversations. As one resident explained, “I guess…at the time, I think that you’re not ready to make those decisions. But you know that you have to.”

Family members generally expressed wanting to engage in ACP conversations and highlighted that having conversations early, prior to having to make decisions, was ideal. One family member suggested that understanding the basics of someone’s wishes early on, enables decision-making when it is necessary: “And I think it- that the sooner we can ask some basics then we can fill in parts of it later when hopefully when we need to.” Another family member acknowledged that ACP conversations are difficult but indicated that it is best to have them with loved ones: “it’s difficult ‘cause you’re talking about your parents and what’s going to happen... and their wishes and can you carry out their wishes. And you just do the very best that you can. But it was very difficult, absolutely. But I would rather do that than them have a stranger do it.” Other
family members felt that ACP conversations were easy to have for their family: “We are all pretty open, I have four brothers and we all have talked about it.” Family members similarly indicated readiness for ACP even if their loved one wasn’t ready for example, “Yeah…we’re ready to have that conversation. I don’t know if she is, but we are.” Some family members felt it pertinent to have all relevant information regarding parent or relative wishes so that they could make appropriate decisions. As one family member explained, “I think it’s very important. A lot of people are never really prepared for stuff like that and I guess most people don’t like to think about it but you know that’s part of life, and we feel really good about it, so. Yeah I think that would be a real helpful thing, I really do.”

Clinicians expressed variability in their stated comfort with ACP. Some clinicians expressed high levels of comfort: “It is like second nature to me.” Most clinicians however, expressed some degree of hesitation when it comes to ACP in the SL context. One clinician eluded to discomfort engaging resident in ACP due to the sensitivity of the topic stating, “I admit, I’m not a pro at this, I’m taking in what I want or can…it’s a sensitive subject but it does have it’s place.” Another clinician expressed uncertainty and discomfort around ACP expectations in her SL facility noting, “I’m a little bit unsure…sometimes I feel we push…and I’ve been challenged a little bit on the team here because…I’ve actually been told that anyone coming in here must have it.” Another explicitly stated personal anxiety around ACP that results in a biased approach explain, “I think I’m expressing some personal anxiety… I definitely tend towards ongoing interventions…families are usually supportive of that even in the context of dementia.” Perhaps as a result of their own varied comfort with ACP, clinicians had very different perceptions about how to approach different levels of patient readiness. Some took a more indirect approach and encouraged residents to speak with family for example, “Right now, maybe suggest that ...if
you’re not ready …they could have some conversations with their families.” Other clinicians react to lack of readiness by respecting residents’ decision to refrain from engaging, “…I’ve been asked to come and see you about this. “Is this something you wanna talk about?” If they say no, then that’s just fine.” Other clinicians were more forceful in their reaction to lack of readiness, feeling that information regarding residents’ wishes overrides readiness barriers stating, “I have to make some choices about care planning and about where we’re gonna send this person, whether we’re gonna keep them, medical choices, so I don’t really evaluate whether they’re ready to make a choice or not…I’m forcing them to make a choice.”

Although clinicians expressed varying degrees of comfort around ACP, they did not express difficulty with having to determine cognitive capacity related to resident competence to make decisions. Only one clinician referred to this issue, stating “It’s usually a family I am meeting with, most of my patients here have an agent already.”

Residents and family members expressed readiness to engage in ACP, explaining that it was necessary and important to start the process prior to a health crisis. Clinicians felt that ACP engagement was important but demonstrated having varied comfort levels with initiating discussions. Furthermore, clinicians were also varied in their approach to influence readiness among patients.

**Barriers and Facilitators.** For residents, barriers to ACP engagement were theoretical and related to the individual. Residents provided insight into what might prevent individuals from engaging in ACP and barriers included beliefs such as, “You don’t have to pay attention if you’re healthy”, or “It’s not going to happen to me.” Facilitators of ACP engagement included the potential to ease stress and burden on family as well as the notion that planning is essential since
the physician at the hospital does not know you. One resident stated, “You have to plan so that they know what to do.”

For family members and clinicians, barriers and facilitators were either system-based or personal. System based barriers to ACP that were mentioned by family members included the fact that GCD forms are unclear and difficult to understand and the fact that ACP is sometimes introduced for the first time during a crisis. Personal barriers included the difficulty in helping elderly family members recognize the reality of their health decline. System-based facilitators included the changeability of the GCD form and the approach of clinicians who ensure that all ACP concepts are thoroughly understood. The main non-system facilitator was prior experience with decision-making.

For clinicians, system barriers included poor ACP communication in emergency departments, the lack of an ACP evaluation mechanism, lack of time, lack of structure and lack of GCD understanding. System facilitators are the changeability of the GCD form. Personal barriers include a lack of knowledge, difficulty engaging dementia patients in ACP and the challenge of reaching consensus between family and patients. A personal facilitator was the clinician’s ability to build trust and rapport with patients prior to ACP initiation.

Chapter Summary

This chapter provided a detailed overview of the findings of this study. These were presented according to salient themes for each participant group as well as themes that emerged as common to all groups. The next chapter will provide a discussion of the findings, including how they address the research questions and their potential implications.
Chapter 5

Discussion

This chapter discusses the key findings according to the three research questions guiding this study and the overall purpose of the study. Next, implications of the findings for practice, policy, research and theory are discussed. Finally, a discussion of study limitations is provided.

Perception of readiness to engage in ACP

A central question this study sought to explore was how patients, families and HCP perceive their readiness to engage in ACP. Although in the literature readiness has not yet been established as the undisputed guiding force of ACP engagement, this study found that feeling ready coupled with high motivation for engagement was reflective of resident participation in ACP. SL residents expressed that they felt ready to engage in multiple ACP components. This finding is inconsistently supported by the literature. Malcomson and Bisbee’s (2009) qualitative study on perspectives of elders on ACP found that older adults were ready and eager to discuss ACP. Conversely, Fried et al.’s (2009) qualitative study on ACP as a health behavior change process and Fried, Bullock, Iannone and O’Leary’s (2009) qualitative study found that older adults were at variable stages of readiness for ACP component activities. The high resident readiness found in this study might be accounted for by the advanced age of study participants. Indeed, when Black, Reynolds and Osman (2008) looked at factors associated with ACP engagement, they found that increasing age is predictive of engagement.

In this study, readiness for ACP engagement was also associated with completion of related activities, such as transitioning to SL, planning one’s funeral and completing a living will. This finding is consistent with existing literature, which has found that planning for after-death has been associated with ACP readiness (Fried et al., 2009; Fried et al., 2010). Thus, it is possible
that once residents had participated in planning their funeral and completing a will, in addition to having planned and moved to SL, they had experienced so much planning and transition, that ACP seemed much less daunting in comparison.

Finally, residents reported engaging in ACP by thinking about their wishes and discussing these with family, however, although most had engaged in ACP with clinicians as per SL protocol, residents could often not recall these conversations. This may indicate, that older SL residents do not place high importance on clinician involvement in the ACP process. This could be due to two related factors. The first is that residents have a very clear understanding of the decision making role that their family members will take, usually strengthened by the fact that family members have already been helping making decisions (i.e., the decision to move to SL). This prior experience and current understanding of family members’ pivotal role in EOL care might help to strengthen memory of family involvement in ACP. Conversely, residents might be less likely to recall discussions with clinicians due to the fact that the GCD, which clinicians discuss with residents in ACP conversations, is very difficult to understand both conceptually and practically, making it less likely to be remembered with any accuracy.

Like residents, family members also expressed high readiness for ACP engagement. Additionally, however, family members were much more cognizant of the importance of involving clinicians in ACP compared with family members. There is no exploratory literature looking at readiness of family members to engage in ACP, so it is not possible to compare these findings to existing knowledge. Family members associated readiness to engage with a need for information to guide decision-making and they felt that while the SL relative provided information on values and wishes, the clinicians were instrumental for clarifying complex language around options for intervention. These findings are consistent with the literature, which
suggests that surrogates are burdened by a lack of information and decision-making is eased with clear communication from clinicians and patients (McMahan, Knight, Fried & Sudore, 2013). Interestingly, family members did not discuss any experiences or understanding around how ACP documents are enacted (i.e., when the patient is deemed incompetent). In addition, although emphasis was placed on the importance of ACP discussions, there was no mention of the importance of documentation, in particular, and the transfer of this documentation to the appropriate clinicians for reference in decision making when needed. Again, it is not clear whether family members had already gone through these processes and had not been impacted by them or whether these were things that they might encounter in the future with variable preparedness.

Clinicians expressed strong beliefs about the utility of ACP and the belief that it should be done. They expressed an appreciation around the fact that they have a role in the facilitation of ACP with residents. However, they were divided on whether or not they felt comfortable to have those conversations and were also unsure about role division in the SL facility. There are very few studies on non-hospital clinician engagement in ACP but studies have looked at related concepts. For example, in a systematic review of non-hospital physicians discussing prognosis in advance illness, lack of comfort and uncertainty were found to be major barriers to conversations with patients (Hancock et al., 2007). It is not surprising that since ACP requires discussion around prognosis in advanced terminal disease, clinicians may express discomfort and uncertainty.

Factors impacting readiness to engage in ACP

In addition to exploring perceptions about readiness, this study also sought to identify which factors impact readiness to engage in ACP for the participant groups. A number of factors
appear to impact resident readiness for ACP engagement. First is the desire to limit the extent of medical interventions. This may again be due to residents’ advanced age (Steinhauser et al., 2001). In their study of EOL preferences, Steunhauser et al. (2001) showed that as individuals age, their preferences shift away from resuscitative care and toward comfort care for EOL.

Second, is prior experience, either of their own declining health or experiencing the death of a loved one. In their study, Fried et al. (2009) also found that prior experience was highly impactful on current perceptions of ACP. Third, ACP readiness appeared to be impacted by the fact that a large life transition, namely moving out of independent living and to SL, had already been made. This loss of independence may have been a catalyst for the realization that EOL is nearing, making planning for future care more relevant. Finally, residents were also motivated to engage in ACP in order to ease stress and burden on their family. This is a known facilitator of engagement (Malcomson & Bisbee, 2009).

Family member readiness appeared to be most significantly impacted by previous experience. Through prior decision-making experiences, family members had gained an appreciation of negative outcomes that resulted from a lack of planning as well as the positive outcomes that can result from appropriate engagement in planning. A recent study by Amjad, Towl and Fried (2014) similarly found that having had experiences with others with regard to EOL care or decision-making was associated with an increased readiness to participate in ACP. The significant number of prior experiences that family members shared might be unique to the SL context, where this living transition is often precipitated by either a deterioration in health, requiring significant decision-making or the death of one spouse, leaving the other unable to live independently.
Clinician comfort with ACP discussions was impacted by beliefs about planning in the SL setting. In particular, clinicians expressed feeling conflicted around making treatment determinations for patients with dementia. The knowledge that patients with dementia are not at imminent risk of death but do have a diminished quality of life, seemed to make it difficult to generate a guide to plan for medical action. The complexity associated with the application of ACP to dementia patients has been documented in the literature. Mitchell, Kiely and Hamel (2004) looked at the chart documentation of 1609 patients with dementia in nursing homes and found that these patients are generally not perceived by physicians as having a terminal illness. If physicians do not see patients with dementia as being terminally ill, the complexity of having to determine goals of care for someone who is not cognitively adept but also not terminal becomes very challenging. Consequently, this challenge may lead to increased discomfort in ACP engagement with these patients and their families. Despite expressed concerns around engaging dementia patients in ACP, clinicians did not mention struggling with having to make determinations of incompetence and subsequent enactment of ACP documentation. This finding might be accounted for by the fact that many SL residents are already incompetent and thus, as was mentioned by one physician, a decision-maker has already been appointed.

**What to include in ACP interventions**

Understanding what to include in ACP interventions to make them appropriate and effective was also vital to achieving the overall purpose of this study. Based upon the stated barriers and facilitators to ACP engagement from the perspectives of residents, family and clinicians, suggestions for meaningful intervention components have been generated. First, based upon the finding that residents do not have a clear understanding of ACP terminology and process, interventions can continue to focus on improving communication between clinicians and
patients or family/decision makers. This is especially important due to the fact that GCD forms are difficult to understand, meaning that if residents associate only these forms with the totality of ACP, it makes sense that their recollection of ACP conversations on GCD is limited. Second, improving explanations of ACP documentation terminology would also help family members better understand the medical interventions options presented to their loved one. The GCD form is difficult for family members to understand, meaning that it may be necessary for this form to be used exclusively as a physician’s order, while family members and residents are presented with information pertaining to treatment/intervention in a simpler, more values-based format. Third, in order to provide information and support in an optimal fashion, clinicians (non-physician) must be better informed to provide explanations around GCD terminology, as they do not currently feel sufficiently equipped to do this. Alternatively, if interventions shift away from presenting GCD forms to patients as a template from which to make medical decisions, then clinicians must be better prepared to explain and involve residents and their families in a values-focused process involving each component ACP activity. Finally, ACP interventions should include an evaluation component such that issues arising that pertain to the delivery of and engagement in ACP for all stakeholders can be addressed and improved upon.

**Understanding of ACP Readiness**

The overall purpose of this study was to explore the perspectives and experiences of SL residents, families and HCP in order to better understand ACP readiness which was defined as a willingness to engage in ongoing discussions of underlying values and wishes for end-of-life care with family and HCP. Exploring each of the three research questions using an Interpretive Descriptive methodology provided an enhanced understanding from multiple perspectives of readiness to engage in ACP in the SL context, factors impacting readiness to engage, and
considerations when developing appropriate and effective ACP interventions. This increased understanding has implications for future practice, policy, research and theory. These are discussed in detail below.

**Implications for practice, policy, research and theory.**

**Practice.** One of the main findings of this study was the importance of previous experience in determining perceptions and readiness on ACP engagement from both the perspectives of residents and family members. In order to capitalize on the impact of experience, clinicians can take the approach of inquiring about experience and asking patients and their families to share their prior decision-making or EOL experiences. These experiences can then be used to emphasize the utility and benefit of ACP engagement. Encouraging ACP engagement through the elicitation of past experiences was a key theme in a recent qualitative study of surrogate experiences with decision-making (McMahan, Knight, Fried & Sudore, 2013). Capitalizing on experience becomes challenging for those who lack prior experience. In these situations, clinicians can take an approach to substitute personal experience with experience of others in similar circumstances. Clinicians can relay stories and experiences of patients who have found themselves in similar circumstances. Even more effective is a visual demonstration, as has been suggested by Volantes et al. (2007) in their study comparing the impact of verbal story telling and video story telling on ACP completion for patients with early dementia. They found that the video was significantly more effective in promoting ACP engagement and impacting preferences than a verbal exchange.

Another practice implication that can come from this study is increased role clarification for clinicians in SL. A lack of clarity in roles, as well as uncertainty as to who is most appropriate to initiate ACP conversations with patients and families was a main theme that emerged from the
data. Uncertainty might also contribute to discomfort with ACP conversations as the clinician is unsure whether they should be responsible for engaging patients on this topic. In order to improve clinician confidence and ease the burden of uncertainty, it is important for AHS to design and implement a comprehensive guide for how (and by whom) ACP should be ideally conducted in the SL setting. According to a number of clinicians in this study, social workers might be the best candidate to introduce ACP to patients and families and to support them through the decision-making process. This is supported in the literature by the suggestion that social workers have a unique role in advocacy as well as a focus on process that makes them the ideal clinician to guide the dialogue on ACP (Stein & Fineberg, 2013; Tulsky, 2005). As a member of the health care team, social workers can also use their unique position as advocates to confirm that patient wishes are known and respected in team-based decisions around ACP. In addition, social workers can advocate on behalf of and with patients during ACP discussions at annual meetings in SL, in order to ensure that patients and families/decision-makers understand what is being said and feel that their wishes and concerns are being addressed. Furthermore, social workers, as guided by the ACSW and CASW are well positioned to recognize and explore ethical issues pertaining to the respect for personal choice and dignity in the ACP process. They are knowledgeable in culturally competent practice and are thus equipped to advocate for specialized attention toward residents of various backgrounds and beliefs when it comes to engaging in sensitive EOL issues. Although social worker have the potential to take on a significant and impactful role in the ACP process, further exploration on this topic is needed. Research and literature to increase knowledge and clarification of the ideal social work role in ACP will help to guide clinical practice and policy in this field.
Role clarification can be further elucidated, not just within stakeholder groups, but between them. The findings from this study suggest that there is a tendency to expect residents to complete ACP documentation, including GCD forms, even though resident or patient completion of these forms is voluntary. A number of clinicians indicated that residents can be pushed to complete these documents even when they may not wish to do so. Although completion of these documents eases the burden of responsibility on clinicians, forcing residents to complete voluntary documentation overrides respect for their autonomy and dignity. Coupled with the fact that residents and families do not readily understand the terminology or complexity of GCD forms, it might be the case that overemphasizing resident involvement in this type of documentation undermines the roles of residents and clinicians in the ACP process. Optimal care and respect for resident dignity and autonomy might instead involve a shift in clinician focus, away from documentation as a primary goal, and towards increased discussions around the area of resident or patient expertise. Patients are the authority and expert on their goals, values, wishes and preferences (Gillick, 2009). Exploration of values and goals can include inquiring about whether or not patients wish to enter hospital if they were to fall ill, whether they believe in sustaining life at all costs or whether interventions should be measured against quality of life, whether patients want to spend as much time as possible with their families or if they feel like they have lived a full life and are comfortable with allowing nature to take its course. The clinicians’ ideal role then might be to use their authority as a medical expert to translate these stated goals and preferences, to the GCD and other medical order forms, rather than expecting patients and residents to be the authority in determining their medical goals of care.

Policy. Related to the previous point on practice implications, an important potential policy implication that can materialize from the findings of this study is a requirement that
clinicians rely on GCD forms only as a physician’s order, similar to order for tests, in which patients are not responsible for selecting the appropriate option. Instead, ACP with patients and family/decision makers could shift toward increased conversation to elucidate and clarify values and quality of life preferences. This shift can be supported on the basis that residents displayed low literacy around ACP and GCD terminology, they had low recollection of these discussions with clinicians, family members had difficulty understanding GCD terminology and content, and some clinicians criticized the practice of annual ACP discussions in SL consisting of a brief reference to GCD at the end of the meeting. To fit with the AHS ACP policy roll-out, perhaps it is a timely opportunity to enact such a shift, prior to ACP procedures becoming rigid and habitual.

Another policy implication based on the findings from this study is around the transfer of GCD when residents experience care transitions. Although participants indicated that this process has improved, they still face challenges when residents are transferred from hospital to SL. Improving or clarifying policy requirements around documentation transfer will help to simplify ACP engagement, prevent duplicity of documentation and improve congruence of care for SL residents.

**Research.** The findings from this study will be cross contextually analyzed with findings from other clinical settings as part of the larger ACP study program. First, this analysis will compare how the AHS ACP roll-out has transpired in various clinical contexts. In this capacity, variability in readiness, barriers, facilitators and the implementation of ACP in the SL setting will be compared with those in the out-patient renal, heart failure and cancer contexts. This analysis will be instrumental in helping ACP researchers understand unique ACP needs in each clinical
context in order to facilitate evidence-based interventions tailored to readiness in order to maximize ACP engagement in each setting and thus across AHS.

Although the findings from this study on readiness, coupled with what is already known about barriers and facilitators to ACP engagement are sufficient to inform the design and implementation of interventions in SL, there is nevertheless a scarcity of knowledge on ACP from the perspectives of residents with moderate cognitive impairment. For the current study, researchers were unable to access this population, due to perceived risks and resident vulnerability, but since those suffering from a more advanced impairment might face greater urgency to have their wishes known, it would be useful to know whether this group is as ready and engaged as those who have mild impairment or suffer only from physical frailty. Finally, it would also be helpful to speak to residents who have declined to engage in ACP in order to better understand their unique perspective. It would be difficult to access this population as well since they might not be willing to discuss their wishes if they refuse to engage in ACP. Still this type of exploration might help improve understanding of how readiness is reached and how interventions would be best designed to fit the variability of residents in SL.

Another area for future research could be how ACP readiness fits within the larger EOL advanced care process. For example, this study did not focus on determinations of incompetence and subsequent enactment, however, research exploring the full cycle of the advanced care process could provide a more holistic understanding of the significance of readiness, and its integration with other key process elements.

The main limitations of this study were around sampling and recruitment. First, ID suggests that because researchers may not know the actual variations in a population, it is ideal to use iterative sampling and analysis, in order to ensure that theoretical sampling is achieved.
Unfortunately, this was not possible in the SL setting, where access to patients was restricted by nurses due to vulnerability and possible cognitive decline. The fact that recruitment was limited to the discretion of NPs may also have biased the participant sample to those individuals who had had a positive ACP experience. An additional sampling limitation in the SL setting was the disproportionate number of female participants. This was mainly a reflection of the fact that more women than men are in SL due to female longevity coupled with the fact that the men living in SL are disproportionately cognitively incapacitated. Consequently, only one male resident was interviewed. However, this participant’s perspectives were not different from those of the remaining participants, indicating that more male participation may not have altered the findings. Similarly, all family member participants were female. Again this is likely a reflection of the fact that caregivers tend to be disproportionately female. Still, this meant that the male caregiver voice was not captured in this study. A final limitation pertaining to diversity in the participant population was a lack of cultural diversity. This was partly due to the fact that the researchers were only able to engage English-speaking participants due to budget restrictions and also that Caucasian residents are overrepresented in SL facilities. These factors may have prevented a full understanding of potential cultural variation in readiness for ACP engagement.

**Theory.** The findings from this paper affirm the theoretical-based expectations on patient behavior change. Although it is difficult to evaluate the process of achieving readiness since residents expressed already feeling ready and having engaged in ACP, they discussed attributes and perceptions that fit with the predictions of the two theoretical models discussed in this paper. In support of the TTM, residents described their engagement in ACP as a process rather than a single event. They disclosed thinking about their wishes, discussing their wishes and documenting their wishes on separate occasions. In addition, residents conveyed experiences that
can be likened to the strategies purported by the TTM to increase readiness. Dramatic relief consisted of the impact and influence of prior health, decision-making and EOL experiences that helped to strengthen the relevance of ACP for residents. They also described having engaged in environmental re-evaluation, particularly as a result of an encounter with the healthcare system and transition to SL. These types of experiences appeared to reinforce the belief that health was declining and therefore, ACP was important for future quality of life. Residents further described having engaged in a self-re-evaluation when considering their values and wishes around care, both medical and personal. Finally, social liberation could be perceived through residents’ expressed acceptance of their aging, gradual loss of independence and future health decline.

The findings from this study also lend further support to the relevance of the Health Belief Model in capturing the process of ACP engagement. Residents demonstrated an awareness of their susceptibility to negative outcomes if they failed to engage in ACP, they were aware of the potential severity of these outcomes, they also believed that their action could reduce the chance of experiencing the negative outcome and they felt ACP engagement was feasible. They were both motivated to engage in ACP and although they were unsure of how much clinicians would follow their wishes in hospital, they were confident that they had done what they could and that their family would follow their wishes.

**Conclusion**

This was a unique study in its exploration of ACP perspectives on readiness and associated factors from the perspectives of residents, family/decision makers and HCPs. The questions that this study sought to explore were: How do these groups perceive their readiness? What factors impact readiness? What should be included in interventions? In answering these questions, this study has provided an understanding of how these three stakeholder groups
engage in the ACP process. This study has helped to provide understanding related to the fact that readiness in residents and family/decision makers does not necessarily translate to equal readiness on the part of clinicians. Despite patient and family readiness, all three groups continue to face barriers related to comprehension. For patients and family/decision makers, these pertain to the content of medical documentation, while for clinicians, the main barrier is around lack of role clarity. This study has provided insight on the importance of prior experience with ACP, EOL and decision making that can be used by clinicians to promote and engage patients in ACP. This study has also provided future implications for practice, policy and research, while also helping to affirm proposed theoretical underpinnings of ACP engagement. Through its potential to inform future academic and clinical work, this study can help to improve understanding through ACP and ideally reduce unnecessary and unwanted interventions at EOL especially for those who may no longer be able to self-advocate and voice their wishes.
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Appendix 1

Advance Care Planning: Barriers, Facilitators and Readiness

Patient Interview Guide

Readiness Questions:

1. What do you know about Advance Care Planning? *(If participant does not know about ACP, read the participant the explanation provided)*

   *If the concept seems like it was difficult for them to grasp, ask how they would describe it to someone else in a way that is understandable*

2. Given the explanation you have now heard about Advance Care Planning, what kinds of experiences have you had with this type of process?

3. What are your feelings about doctors and nurses asking people to participate in this process? *(i.e., is it something they should be asking?)*

4. Have you participated in Advance Care Planning by either thinking about, talking about, or writing down your wishes for future care?

   *If yes, what did you do?*

   *If no, have you thought about this [Advance Care Planning] for yourself?*

5. How likely do you think it is that your family or someone else will need to make a treatment decision for you down the road because you would not be able to make the decision for yourself?

6. What kind of planning do you think you should be doing to prepare for the possibility of developing a serious illness?

7. What would you hope to achieve if you were to begin Advance Care Planning, either now or at a future time?

   a. How concerned are you that your wishes for how you would want to be taken care of if you were to become seriously ill might not be followed?

8. Do you feel (emotionally, mentally?) ready to think about ACP/have conversations regarding ACP/or complete forms related to ACP?

   *How did you come to feel ready?*
9. If not ready: Do you think there is something that could make you feel ready?
   a. (If they say they ‘don’t know’: Are there any reasons why you might want to engage in ACP in the future?
   b. If they are TOO HEALTHY: What are some reasons that make you want to wait until you are sick?
      i. Can you see any value in this activity for you, while you are well?

Barrier and Facilitator Questions:

Provide transition for participant – e.g., “We’ve discussed your readiness to take part in ACP; now I’m going to ask you some questions about thinking, talking, and writing down your wishes.”

1. Thinking

   1.1 Have you thought about your treatment options, just in case there is a change in your health?

   1.2 How did thinking about this make you feel? (E.g., relief, worry, sadness)

   1.3 Is there something that makes this thought process difficult for you?

   1.4 Is there something that would make this thought process easier for you?

2. Talking

   2.1 Have you talked to loved ones about your wishes for treatment, just in case there is a change in your health?

      2.1.1 If yes, with who?

      2.1.2 How did talking about your wishes make you feel? (E.g., relief, worry, sadness)

      2.1.3 Is there something that makes talking about your wishes difficult for you?

      2.1.4 Is there something that would make talking about it easier for you?
Advance Care Planning: Barriers, Facilitators and Readiness

2.2 Have you talked to a doctor or a nurse about your preferences for health care just in case your health worsens? Or have they ever talked to you about the kind of treatments that could or could not be used if your health worsens?

2.2.1 If yes, with whom?

2.2.2 How did you feel while having these discussions? (E.g., relief, worry, sadness)

2.2.3 Is there something makes talking to a nurse or doctor about your wishes difficult for you?

2.2.4 Is there something that would talking to a nurse or doctor about your wishes easier for you?

3. Writing

Say to participate — “Sometimes people choose someone who they trust to make decisions for them if they are ever unable to make healthcare decisions for themselves.”

3.1 Do you have somebody that you have selected for this purpose?

3.1.1 If yes, who is it, and what (processes/decisions/events) motivated you to choose them?

3.1.2 If no, how would you feel about choosing someone you trust to do this?

Say to participants — “Sometimes people write down who they choose to make decisions for them just in case they cannot. In Alberta, this legal document is called a personal directive.”

3.2 Do you have a personal directive?

3.2.1 If yes, what motivates you to have one?

3.2.2 If no, how would you feel about having one?

3.2.3 Does something stop you from having your wishes written down?
Advance Care Planning: Barriers, Facilitators and Readiness

3.3 Do you have your wishes/treatment decisions documented on any paper? If so, do you revisit these decisions regularly?

3.3.1 If yes, what makes you want to read over or think about these wishes on a regular basis?

3.3.2 If no, what makes it difficult to read over or think about these wishes? (e.g., lack of time, don’t want to think about it, forget, etc.)

3.3.3 If no, what would make it easier for you to read over or think about these wishes regularly?

3.4 Is ACP something you would recommend to other people? Why or why not?
Appendix 2

Advance Care Planning: Barriers, Facilitators and Readiness

Family Interview Guide

Readiness Questions:

1. What do you know about Advance Care Planning? *(If participant does not know about ACP, read the participant the explanation provided)*

   *If the concept seems like it was difficult for them to grasp, ask how they would describe it to someone else in a way that is understandable*

2. Given the explanation you have now heard about Advance Care Planning, what kinds of experiences have you had with your loved one with this type of process?

3. What are your feelings about doctors and nurses asking people to participate in this process? (i.e., is it something they should be asking?)

4. Have you participated in Advance Care Planning with your loved one by either talking about or writing down their wishes for future care?

   If yes, what did you do? How did you come to participate?

   If no, have you thought about this Advance Care Planning for your loved one?

   If no, do you feel (emotionally, mentally?) ready to participate in ACP with your loved one?

5. What would you hope to achieve if you were to begin Advance Care Planning with your loved one, either now or at a future time?

6. If not ready: Do you think there is something that could change how you feel?
Advance Care Planning: Barriers, Facilitators and Readiness

Barrier and Facilitator Questions:

Provide transition for participant – e.g., “We’ve discussed your readiness to take part in ACP; now I’m going to ask you some questions about thinking, talking, and writing down your wishes.”

1. Thinking

1.1 Have you thought about your loved one’s treatment options, just in case there is a change in their health?

1.2 How did thinking about this make you feel? (E.g., relief, worry, sadness)

1.3 Is there something that makes this thought process difficult for you?

1.4 Is there something that would make this thought process easier for you?

2. Talking

2.1 Have you talked to loved one about their wishes for treatment, just in case there is a change in their health?

2.1.1 If yes, who initiated the conversation, them or you?

2.1.2 How did talking about their wishes make you feel? (E.g., relief, worry, sadness)

2.1.3 Is there something that makes talking about their wishes difficult for you?

2.1.4 Is there something that would make talking about it easier for you?

2.2 Has your loved one talked to a doctor or a nurse about their preferences for health care just in case their health worsens?

2.2.1 If yes, with whom did they speak?

2.2.2 How did you feel about your loved one having these discussions? (E.g., relief, worry, sadness)
Advance Care Planning: Barriers, Facilitators and Readiness

3. Writing

Say to participate – “Sometimes people choose someone who they trust to make decisions for them if they are ever unable to make healthcare decisions for themselves.”

3.1 Has your loved one selected someone to speak for them?

3.1.1 If yes, who is it, and what (processes/decisions/events) motivated them to choose that person?

3.1.2 If no, how would you feel about your loved one selecting you to speak for them?

Say to participants – “Sometimes people write down who they choose to make decisions for them just in case they cannot. In Alberta, this legal document is called a personal directive.”

3.2 Does your loved one have a personal directive?

3.2.1 If yes, what motivated them to have one?

3.2.2 If no, how would you feel about them having one?

3.2.3 Does something them from having your wishes written down?

3.3 Does your loved ones have their wishes or decisions written down anywhere (even unofficially)? If so, do you revisit these decisions regularly together?

3.3.1 If yes, what makes you want to read over or think about these wishes on a regular basis?

3.3.2 If no, what makes it difficult to read over or think about these whishes? (e.g., lack of time, don’t want to think about it, forget, etc.)

3.3.3 If no, what would make it easier for you to read over or think about these wishes regularly with your loved one?

3.4 Is ACP something you would recommend to other people? Why or why not?
Appendix 3

Advance Care Planning: Barriers, Facilitators and Readiness

Clinician Interview Guide

Physical Site (hospital): ______________________________

Disease site: ______________________________

Professional designation: ______________________________

Readiness Questions:

1. *Elicit feedback regarding what ACP means to them* – “I’ve got some information here about Advance Care Planning, but I want to know what the term means to you.”

2. What do you think about the healthcare system asking people to participate in ACP?

3. Please describe how you see your role in the Advance Care Planning process.
   
   3.1 If no perceived role: Is there anything that you do to direct patients to participate in ACP? (I.e., refer to a colleague)

4. How do patients in *(clinic name)* come to these conversations surrounding ACP and their wishes?
   
   4.1 Tell me more about *when* these conversations occur for these patients.

   4.2 How do you know what a patient is ready to have these conversations?

   4.2.1 What do you do when they are *not* ready?

5. What is your opinion regarding how these conversations go overall?
Advance Care Planning: Barriers, Facilitators and Readiness

Barrier and Facilitator Questions:

*Provide transition for clinician* – e.g., “We’ve discussed your readiness to take part in ACP; now I’m going to ask you some questions about thinking, talking, and writing down your wishes.”

1. How comfortable are you initiating or revisiting discussions regarding ACP with patients and their families? (May include the following topics):
   
   - End-of-life wishes
   - Treatment options
   - Prognosis

2. What patient and family factors facilitate or hinder you in initiating this discussion? (language, age, length of your relationship, culture of patient)

3. Would you please share your thoughts on how you think the healthcare system is currently set up to facilitate end-of-life discussions between clinicians and patients/families. (May include the following topics):
   
   - Integration of information systems
   - Time allowed for conversations
   - Clarity of accountability

4. Is there anything that would help you do this work with your patients better?

5. Please describe your level of satisfaction with the amount of support and knowledge you obtain from current recourses (e.g., GCD training web-based module and Conversations Matter) to initiate Advance Care Planning discussions with patients and families.