

AN ANALYSIS OF THE COMPLEXITIES OF  
ADVANCE CARE PLANNING IMPLEMENTATION:  
INSIGHTS GAINED FROM A REVIEW OF THE LITERATURE

by

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## Abstract

**Background:** Advance care planning (ACP) is a process for patients and families to engage in discussions around future wishes for health care. It offers a means to increase dialogue about end of life care and has the potential to improve patient outcomes. Despite the benefits demonstrated in literature, there are still many challenges to ACP implementation. This thesis investigated why ACP is so difficult to implement by reflecting on the following stakeholders: patients and families of older adults and individuals living with chronic illnesses, health care providers, and health care organizations. Particular examples are drawn from the context in British Columbia, Canada.

**Methods:** A purposeful search strategy modifying the rapid evidence assessment approach was used to synthesize the literature. Research studies, summary reports, and policy documents were used to build a balanced picture of perspectives for policy makers. Bryant's (2009) Policy Change Model and critical theoretical perspectives shaped this analysis and highlighted the complexities and ideologies behind public, professional, and organizational sentiment.

**Findings:** The analysis of literature on patient and provider perspectives shows the biomedical dominance in health care culture and the disinclination to discuss end of life issues. A shift is needed where recognition and prioritization of ACP implementation is supported by leaders in health organizations. Organization-wide multi-component ACP efforts combined with goals of care documentation have been shown to be most successful in improving patient outcomes, but organizational commitment to development of processes and policies is necessary. There is opportunity for nursing leadership and research to move ACP efforts forward in organizations.

**Conclusion:** The analysis presented in this thesis maps evidence for policy makers, stakeholders, and nursing leaders interested in promoting strategic ACP implementation and future ACP research. Process and policy changes are needed to support public and provider engagement.

## **Preface**

This thesis is original, unpublished, independent work by the author, J. Wong.

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## **Chapter 1: Introduction**

### **Background and context**

In Canada, chronically ill and older adult patient populations tend to be poorly informed about their life limiting illnesses, options around end of life (EOL) planning, and are unprepared to make decisions regarding critical and EOL care (Heyland et al., 2010). Much of hospital care is focused on disease management and medical and surgical interventions, with very little planning around the possibility of complications and deterioration in health status (Bryant, 2009). Poles and Bousso (2011) write, “Advances have created previously unimaginable situations and given rise to a painful juxtaposition of life prolongation and death prolongation” (p. 694). With improvements in medicine and technology, the survival time for many patient conditions previously considered fatal has increased. Unfortunately, this at times leads to additional suffering for patients and families (Westphal & McKee, 2009).

Life saving and life prolonging measures can be aggressive, invasive, and visibly painful. Patients frequently have minimal chance of survival, without consideration of long-term debilitating disabilities (Poles & Bousso, 2011). There is strong evidence suggesting patients need realistic, achievable goals of care and better understanding of their medical condition (Barclay, Momen, Case-Upton, Kuhn & Smith, 2011). Decisions about life sustaining treatment are difficult, made especially challenging when the patients’ preferences have not been discussed or documented with family or health care providers (Douglas & Brown, 2002).

The amount of intervention a capable adult wants, or does not want, should be identified and documented at the point of primary care or hospital admission, before the onset of distress and incapability, and regardless of their health status (BC Ministry of Health, 2012). While this may be held out as an ideal, the issues related to EOL planning are complex. As I argue in this

thesis, more attention and focus on conversations should be given to a patient's goals of health care, particularly in patient populations with chronic illnesses and those followed by health care teams in both acute and community care.

Advance care planning (ACP) is a strategy demonstrated to create a supportive context for the patient and family to begin engaging in discussions around future wishes for health care (Grant et al., 2008; Kirsner, 2008). While there is increasing literature on the benefits of ACP, there are still many challenges to implementation, including the need for strategies to address the range of complexities surrounding EOL care. This includes social and cultural considerations, the pervasive ideologies surrounding life and death, and the health care system's tendency to prioritize tangible interventions.

The topic of this paper arose from my experiences as an intensive care nurse, where I often see unprepared patients and families who have not had conversations about EOL, or considered health care goals. The majority of families have no idea what their loved ones would want in a health crisis situation and are ill-equipped for decision making when the patient is not able to speak for themselves. I believe that having conversations with chronically ill or elderly patients and families can lead to better understanding of patient wishes and help us refocus our interventions on quality of life and appropriate treatment plans. The importance of the ACP process is highlighted by a literature review demonstrating a lack of congruence between older adult care preferences and health care provider knowledge of wishes (Sessanna & Jezewski, 2008). Heyland et al. (2013) report more than two thirds of patients' preferences are documented incorrectly or not documented at all in a patient's medical record. Looking at an aging, chronically ill population, Heyland et al. (2013) demonstrated disconnect between what patients and/or families identify as their preferred goals of care, and the information translated in

the medical record documenting patient preference. Besides arguing for patient autonomy and patient centered care, there is strong evidence to view ACP through the lens of patient safety and quality improvement.

A recent editorial commentary in the *Journal of the American Medical Association* by Allison and Sudore (2013) highlighted the disregard of patient preferences as a medical error when treatment goals did not match the patient or family's wishes. The health care community has largely ignored the safety issues involving life or death decisions and the documentation of code status discussions. Unfortunately, we do an inadequate job of communicating patient wishes and preferences, and this is reflected in the differences between documented and actual preferences in care settings.

My clinical experience has heightened my concern about resource allocation issues, where money is readily spent in the intensive care unit (ICU) and acute care on life prolonging treatments, without enough attention on conversations and care that do not traditionally fall within the treatment and cure 'paradigm'. Many patients who enter the ICU have no idea what intubation or ICU care entails, despite being hospitalized or being ill for months. When critically ill, individuals are rarely able to actively participate in decision-making. They are subjected to invasive life support treatments when a health crisis occurs, despite the lack of realistic hope for returning to their previous health status, and potential for severe cognitive or physical disability (Gill, Fukushima, Abu-Laban, & Sweet, 2012). Silveira, Kim, and Langa (2010) demonstrated in a longitudinal study that patients who prepare ACP tend to prefer comfort care or limitations on interventions, and those who had advance care plans received care strongly compliant with their preferences. Unnecessary suffering occurs because our health care system does not prioritize discussions around goals of care despite our ageing, chronically ill populations. This thesis

highlights the importance of having and normalizing conversations around patient and family understanding of illnesses early, and developing structures, policies and procedures to guide patients through the ACP process with trained clinicians.

Evidence shows ACP increases patient satisfaction and improves patient outcomes such as care adhering to patient wishes, patient and substitute decision maker satisfaction, comfort, and understanding (Engelhardt et al., 2006; Harle et al, 2008; Heyland et al, 2009; Horne, Seymour, & Shepherd, 2006; Kass-Bartelmes & Hughes, 2004; Rabow, Dibble, Pantilat, & McPhee, 2004; Tierney et al., 2001). Policy and guidelines from various health organizations and government mandates recommend EOL discussions (Clayton, 2007; Dunbrack, 2006). However, in practice, these conversations are rare. In a report by Con (2007), key informants agreed ACP is necessary, but the promotion of discussions around end of life decision making, death and dying were found to be unappealing. Organizations continue to face challenges in embedding ACP into practice. This literature review gleans insights from the experiences of selected health care organizations and provides recommendations for implementation.

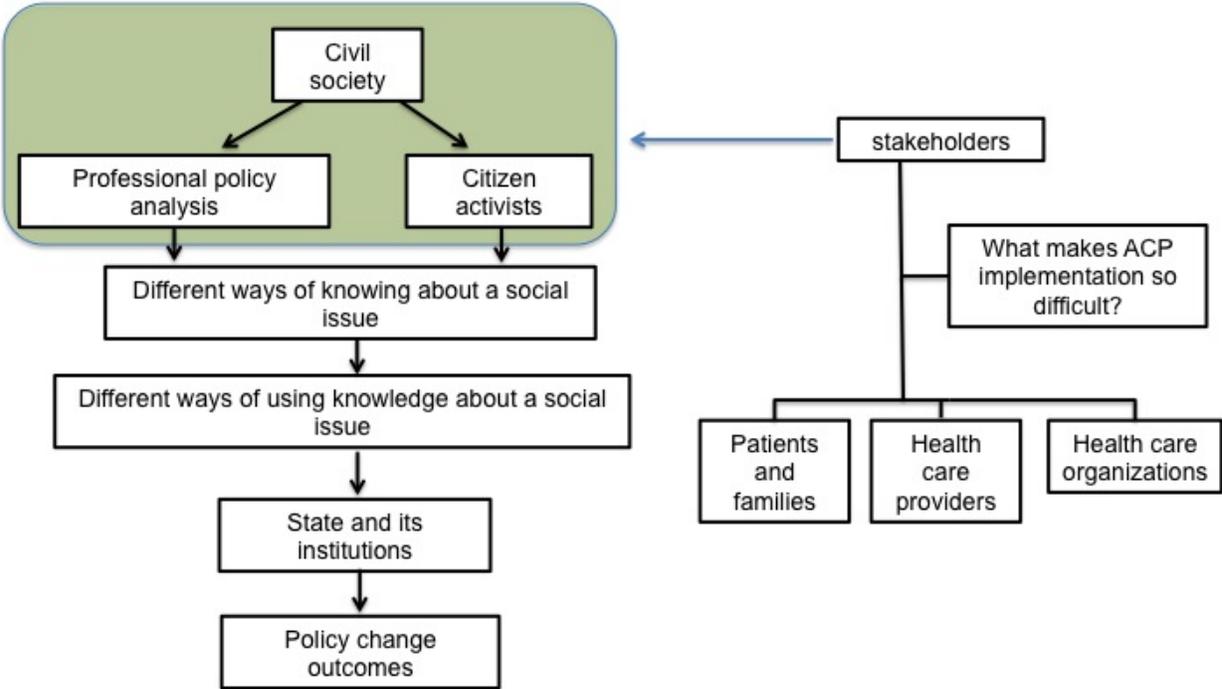
I want to understand how nurse-leaders can strategically work towards preparing our patients and families for health care decision-making, and how we can accurately document and support patient preferences. A few health care organizations have been successful in the implementation of ACP and this paper investigates the investment, rationale, accomplishments, and costs. Despite the complexities, the structures and processes an organization chooses to put in place to facilitate ACP can lead to remarkable achievements in knowing patient wishes and acting and providing care in congruence with preferences.

## **Problem statement and purpose**

The purpose of this thesis is to critically and systematically explore the literature on strategies and difficulties related to ACP implementation within health care organizations, and implications for nursing and nursing-leadership in relation to this important area of clinical practice. After reviewing the broader literature, this thesis then focuses on organizations in large urban health authorities in British Columbia, and the policies, resources, and evidence currently used to implement ACP. The goal is to generate insights about how organizational structures and policies impact the decision-making process regarding ACP, and how nursing can help shape ACP with patients and families. In particular, I want to understand patients' decisions to take action, or not take action, on their right to make decisions in advance for health and how nursing can support this process. My interest is in exploring whether ACP is a feasible strategy to engage in with patients and families, specifically in older adult populations with chronic illnesses. Furthermore, I investigate what implementation strategies best impact ACP communication between patients and health care teams. Implications from this analysis leads to insights and recommendations that may better support implementation of ACP in health care organizations across acute, community, and long term care settings. I believe nursing has broad opportunity to expand its role as leaders and facilitators to help initiate and support ACP discussions. Engagement, education, and honest conversations about choices in advanced illness among patients, families, and health care teams appear intuitive and should be a priority.

Informed by a critical theoretical perspective, the following Figure 1 adapts Bryant's Model Informing the Policy Change Process (2009, p.86), and is used to guide this analysis in relation to the complexities of ACP implementation with regards to various stakeholders. I have used this model to develop guiding questions for the literature synthesis. This model helps

understand the layers and intrinsic values of civil society, focusing attention on the intricacies from three stakeholder groups: patients and families, health care providers, and health care organizations.



**Figure 1: Bryant’s model informing the policy change process with ACP stakeholders**

In practice, ACP and EOL conversations are rare for patients, and conversations focus mostly on disease management, even in the older adult, chronically ill populations (Barclay, et al., 2011). While the general public tends to be mostly supportive (60-90%) of ACP, only 10 to 20% of the public in the US, Canada, and Australia have completed an ACP document (CHPCA, 2010; Con, 2007; Schiff, Bulpitt, & Chakravarthi, 2000). When EOL discussions do take place, it is often late in the course of illness and during acute hospital care (Mack et al., 2012). Recent studies describe considerable dissatisfaction and opportunities for improvement around conversations on health care trajectories in older adult populations (Heyland et al., 2010). The

overarching questions are, despite research, why is ACP so difficult to implement in health care organizations? And what is essential for ACP implementation to be successful and integrated into care?

This thesis discusses ACP implementation as the creation of infrastructure in health care organizations to facilitate the engagement and education of health care professionals and the general public (CHPCA, 2010). These mechanisms include: ensuring communication and documentation of patient wishes, awareness of health care providers and substitute decision makers to these wishes, portability of care wishes through health care settings, visibility of documents in patients' homes and charts, electronic health care records, and goals of care (GOC) designations (CHPCA, 2010; Fairbank, 2011; Rhee, Zwar, & Kemp, 2012; VCH Client Relations, 2013).

## **Objectives**

In this thesis, I explore what can be accomplished, what can facilitate ACP completion, the supports needed for implementation, and nursing implications. The specific objectives are:

1. To consider why it is so complex and difficult to implement ACP in acute and community care settings, especially in chronically ill and older adult populations.
2. To gain insights from the lessons learned by select health care organizations that have tried to implement more systematic ways of addressing EOL care.
3. To reflect on feasibility and make recommendations for ACP implementation in health care organizations and in nursing practice.

The focus of this literature synthesis is on ACP particularly in relation to older adults or those with chronic illnesses, health care provider perspectives, and organizational processes. This study explores an important opportunity for knowledge translation given that patient populations

and health care teams are not particularly well informed about the research evidence on ACP. The recommendations consider the ways in which ACP would need to be tailored to particular contexts and settings if it were to be effective, and a vision for an expanded nursing role in facilitation and public engagement. In this paper, I analyze selected literature to explore the feasibility of implementation of ACP in health care organizations.

### **Key questions guiding the synthesis of literature**

There has been over twenty years of research into the benefits and challenges of ACP and advance directives, and communication around EOL and decision-making. I believe the evidence supports the view that health care organizations are structures that have a momentous role in endorsing ACP and in prioritizing knowing and supporting patient wishes. There ought to be processes, practices, and policies to assist providers and families to consider and act on patient preferences. Significant knowledge gaps continue to exist detailing the intricacies of ACP and supports required to increase the opportunity for ACP knowledge translation in health care organizations.

The framework shown in Figure 1, combined with a critical lens, helps guide the review and includes the following questions:

1. Regarding patients (older adults and adults with chronic illnesses) and families
  - a. What are some of the pervasive societal assumptions around ACP?
  - b. How do various ideologies and discourses shape societal assumptions around ACP?
2. Regarding health care providers
  - a. How does the dominant culture of health care and provider perspectives impact ACP implementation?

- b. What are the implications for the discipline of nursing in relation to ACP within healthcare organizations?
3. Regarding health care organizations
  - a. How is ACP currently addressed (or not) in health care organizations? If not, why has ACP not been addressed?
  - b. How can the current praxis between theory and practice of ACP be improved?

Ultimately, this analysis of the literature considers the direction and evidence base for ACP as a health policy initiative, and seeks to be useful as a basis for stakeholders' discussions in relation to the development of ACP programs.

**Key definitions: Understanding the components of advance care planning (ACP)**

There are many variations in terminology to discuss ACP and EOL care in different jurisdictions. In Canada, ACP is a process where capable adults reflect on and communicate their decisions about accepting or refusing future health care interventions. This enhances discussion around issues such as life sustaining technology, and preservation of patient autonomy (BC Ministry of Health, 2012). ACP emphasizes ongoing conversations with family, friends, and health care providers around what health care treatment one would want if incapable of expressing decisions. Additionally, ACP encompasses clarification of GOC when deterioration in patient condition is anticipated (Baughman et al., 2012; Boyd et al., 2010). ACP can include appointing a proxy decision maker, and these plans should be reviewed periodically, with any life changing event, hospitalization, or new diagnosis. Discussions may include understanding of illness, concerns of health and care, preferences of types and place of care, decisions around cardiopulmonary resuscitation, and documentation with legally binding agreements (Boyd et al).

ACP provides mechanisms to ensure individual autonomy and support patient centered care during health crisis (CHPCA, 2010). Ideally, it is a comprehensive planning process involving reflection and ongoing discussions to improve quality of care (Emanuel, Danis, Pearlman, & Singer, 1995). ACP includes dialogue around values, beliefs regarding life and death, what makes life meaningful, and circumstances where the burdens of treatment would outweigh benefits of life prolongation or quality of life (Grant et al., 2008). ACP strives to help patients' support systems and health care providers understand and establish treatment plans that are consistent with patient wishes and values (Gillick, 2004; McCarthy et al., 2008).

If a patient has a completed ACP, it is the health care team's responsibility to know what to do with the documentation. Besides encouraging ACP with chronically ill and older adult patient populations, the receipt and management of legal documentation in a health organization is crucial to eliminate medical error and facilitate congruence between preferences and care provided. This proves to be difficult in practice, and the challenges are discussed in this paper.

The United States has a federal mandate for ACP from the Patient Self Determination Act (1991). Canada does not have such an initiative or federal legislation. Provinces adopted their own statutes between 1990 and 2000, regulating the use of advance care plans differently and adding to the confusion with varying definitions (Garrett, Tuokko, Stajduhar, Lindsay, & Buehler, 2008). While legislation is functionally similar, the language is a challenge, stemming from the fact laws around ACP are not harmonized, and diverse requirements are found across the various provinces and territories (CHPCA, 2010). In this paper, the definitions and terms reflect the language used in British Columbia. The following terminology is from the BC Ministry of Health (2012) *My Voice: Expressing Wishes for Future Health Care* advance care

planning guide and workbook, and also found in Appendix A: *My Voice Advance Care Planning Guide Quick Tips* unless indicated otherwise.

**Basic Advance Care Plan:** Written beliefs, values, and wishes for future health care treatments. These are useful to guide substitute decision makers if a health care decision is needed and the patient is unable to speak for themselves (VCH Client Relations, 2013).

**Temporary Substitute Decision Maker:** Proxy by default, a person who becomes the decision maker who has no appointed agent. The order of this list is legislated (spouse, parents, children, etc). This term is commonly used and understood as anyone making care decisions for the patient when the patient is unable to make own decisions about care (BC Ministry of Health, 2012). It should not be assumed this is the primary carer (Blackford & Street, 2012).

**Representation Agreement (RA) 7:** Agreement in British Columbia allows an adult with a lower level of capacity to name a person they trust to make their routine personal care and health care decisions, and routine financial management decisions. This does not allow the representative to make decisions around life support or life prolonging medical interventions. This person would be considered the substitute decision maker, or proxy.

**RA 9:** Agreement allows capable adults to name a representative to make personal care and health care decisions, including the ability to accept or refuse life support. This does not allow for financial or legal decisions. This person would be considered the substitute decision maker, or proxy, in the event of incapacity.

**Advance Directive (AD):** A written health care directive and tool allowing a capable adult to state decisions about accepting or refusing specific health care treatments. This must be followed if the AD addresses the health care decision needed. No one else will be asked to make this

health care decision unless otherwise specified, as the document speaks directly to the health care team. The AD can give direction through the Representative if there is a RA 9.

***Enduring Power of Attorney (POA):*** A proxy for financial and legal decisions if an adult becomes incapable. A POA is most often confused with an RA. A person who has POA in British Columbia does not have medical health care decision-making capabilities.

***Living Will:*** An easily recognizable term, although not a legal term in British Columbia. Perceived to state what a patient wants or does not want for health care, similar to a basic advance care plan which expresses a patient's wish of any kind.

***Capacity to make a health care decision:*** The ability to understand benefits, risks, and alternatives to proposed health care and communicate a decision. Health care professions must obtain consent to treatment from a capable person (Dunbrack, 2006). Basic advance care plans, RAs, and ADs are only in effect if and when a person becomes incapable.

***Do not resuscitate (DNR) order:*** A physician's order written in a patient's chart indicating cardiopulmonary resuscitation (CPR) should not be attempted in event of a cardiac or respiratory arrest.

***Life sustaining treatment:*** Medical procedures to support or replace essential function of the body. This includes CPR, intubation and mechanical ventilation (supports or replaces function of the lungs), enteral feeding for nutrition and intravenous therapy for hydration, dialysis, etc. (Dunbrack, 2006).

***Palliative care:*** Comprehensive approach to treating chronic illness focusing on physical, psychological, and spiritual needs of patients. Goal is oriented towards quality of life by controlling suffering, pain, and symptoms of serious illness (Dunbrack, 2006; Stajduhar, 2011).

***Goals of Care (GOC) designation/ Levels of Care forms:*** Medical orders to elicit patient care preferences and translating them into medical orders addressing high probability interventions. These forms address DNR, as well as levels of medical care and interventions, resuscitation and intensive care, and medical care and interventions focused on comfort (Alberta Health Services, 2010).

***Greensleeve:*** An important feature of ACP implementation where documentation ensuring a person's choices and wishes for future health care are known and communicated. This is a green plastic pocket at the front of the patient chart containing copies of completed ACP and goals of care documents, along with a discussion record and parties who participated in ACP conversation (Fairbank, 2011).

### **Organization of the thesis**

This research paper synthesizes literature on ACP, and examines the current social and political context of ACP in British Columbia as a case in point. Chapter 1 introduced ACP and terminology, and posed the primary question of why ACP is so difficult to implement. Objectives, guiding questions, and Bryant's conceptual framework to guide analysis have been presented.

Chapter 2 explains the methodology of this focused systematic review, and provides an overview of the theoretical perspectives that inform the analysis. The exploration of the literature is undertaken using a modified rapid evidence assessment (REA) approach. I use components of a REA aiming to purposefully summarize literature and various forms of evidence, and map evidence by having specific questions of the literature (Kangura, Konnyu, Cushman, Grimshaw, & Moher, 2012). A table to display a synthesis of research is introduced.

Chapter 3 highlights the findings of this modified REA. It looks at cultural notions of death and changes in EOL care. It discusses the complexities of ACP implementation with regards to stakeholders, and reflects on current initiatives by the government and health authorities, and actions which may modify an individual's likelihood to engage in ACP.

Chapter 4 concludes this thesis with a summary, discussion, and recommendations for health organizations and nurse leaders for ACP implementation efforts to be successful.

## Chapter 2: Methods and Approaches of Literature Synthesis

This chapter provides an overview of the methods used to organize the synthesis of the literature, which draws on techniques used in a REA. Selection criteria and tools are presented. Limitations are discussed.

### **Modifying approaches used in this rapid evidence assessment**

A modified rapid evidence assessment (REA) process was used to investigate the overarching questions as previously discussed: What makes ACP implementation so difficult? What is essential for ACP implementation to be successful?

A REA is a streamlined literature review using methods to accelerate traditional systematic review processes, and is purposeful, with its results targeting policy makers, healthcare organizations, and patient associations (Ganann, Ciliska, & Thomas, 2010). I drew on specific methods and approaches used in REAs to guide my review and analysis, as the guiding principle is to provide quick summaries of current research to “inform system and policy response... Conclusions often focus on federal, regional, or local jurisdictional contexts” (Ganann et al, Background, para. 1). While traditional systematic reviews are considered the gold standard in knowledge synthesis, they often focus on a narrow clinical question, and require lengthy timelines and resources. REAs are an attractive alternative as they succinctly address a broader scope of evidence and methodically synthesize contextual resources with a focus on usability (Kangura, Konnyu, Cushman, Grimshaw, & Moher, 2012).

Traditional REAs score literature based on the continuum of hard evidence, usually ranking research according to the Maryland Scale (Appendix 2), which classifies the strength of studies and weighs evidence according to its quality and relevance. Gough (2007) defines three main dimensions when considering the quality and relevance of studies: the methodological

quality of the study considered, relevance of the study design for answering the question, and the relevance of the study focus.

From a critical perspective, the notion of hard evidence is problematic in its concern with methodological quality and rigor (Bryant, 2009; Reimer Kirkham et al., 2009). What counts as “hard” evidence itself is subjective, depending on disciplinary perspectives, methodological approaches, and different views of epistemology; the notion of evidence therefore holds different meanings depending on the reader, and what is assumed to be hard evidence. For example, as noted in the United Kingdom Civil Service *Rapid Evidence Assessment Toolkit on How to do a REA*, “Appraising the quality of qualitative research is a contested field, not least because there is little agreement as to the difference the use of different methods make and whether the nature of qualitative enquiry is itself amenable to rigid quality framework” (United Kingdom Civil Service, 2010, Resources for Appraising Quantitative Studies, para. 8). In many cases, there is gravitation towards the exclusion of reports, papers, and grey literature because it is not considered ‘hard,’ or strong enough in methodological quality.

A critical theoretical lens prompts questions about the status quo, the ideological underpinnings that shape dominant practices, and the potential for transformation. For this review, I have chosen to use a modified approach to the REA process by focusing on answering the non-impact question around implementation of policy: What is required to make it work? I did not score the literature based on the continuum of methodology; instead, there was purposeful searching with a critical lens, focusing on literature that would highlight contextual opportunities and strategies that impact ACP implementation. This focused search strategy included grey literature and reports that helped cumulate knowledge and appraise what is known about ACP policy, internationally, nationally, and specifically in British Columbia. I looked at

dominant ideologies in civil society, dominant practices in health care. I also reflected on the values of the medical and nursing professions, and the opportunities for the emergence of different models of care incorporating ACP.

This review focused on the literature relevant to answering the questions and study objectives. Using components of a REA helped guide the assessment of what is known about ACP policy. An REA carries a stipulation that conclusions may be revised once a more systematic review has been completed, but ultimately seeks to provide an overview of what the evidence is reporting, as well as the overall direction of literature (Davies, 2004); therefore, the analysis presented in this paper maps evidence to direct strategic ACP implementation needs and future ACP research.

### **Conceptual and theoretical underpinnings**

This study uses a critical lens as a theoretical framework because of my interest in uncovering the layers of ideology and culture at work in the health care system, and the structures and processes in place that impact our decisions and actions. Critical social theory is interested in uncovering social structures, discourses, epistemologies, and ideologies maintaining status quo and contributing to inequalities (Kincheloe & McLaren, 2005). Concerned with issues of power and economy, class, and education, a critical lens fosters understanding of how the health care system privileges certain issues over others (Bryant, Raphael, & Rioux, 2010). Using this conceptual approach, I identify and challenge structural and process barriers to ACP. Attention is given to how socioeconomic status, age, education level, expertise, and position affect health and the ability to influence issues. I also critique how society and processes influence ability to change. The aim of research utilizing this paradigm is to recognize structures and paradigms that control knowledge and ideas. From this perspective, one goal of research is

to transform practice and effect social change (Bryant, 2009). It draws from Freire's (1972) understanding of praxis: "reflection and action upon the world in order to transform it" (p.28).

Reimer-Kirkham et al. (2009) write, "The nature of knowledge produced by critical inquiry is socially organized, meaning it is contextual, perspectival, political, and historical" (p.157). I look at the layers of knowledge and have organized this literature review first by discussing context and ideology from different stakeholders, before moving forward to recommendations. My research is informed by the notion of an evolving criticality, "perpetually searching for new and interconnected ways of understanding power and oppression and the ways they shape everyday life and human experience" (Kincheloe & McLaren, 2005, p.306). Funding inequities, medical priorities, and ideologies shape the issues around ACP, and the inability for these discussions to take root despite evidence demonstrating their benefit. This lens enables me to confront "practices that regulate what is considered reasonable and true" (Kincheloe & McLaren, p. 305).

Critical theoretical perspectives are useful for drawing attention to the biomedical paradigm of health care delivery, and the tendency to focus on symptom and disease management, access to health care professionals, treatment by specialists, and tangible, concrete interventions (Bryant, 2009). This creates separation between medical and social issues, and disparities in access to care (Bryant). A critical lens helps to understand ideologies and implicit values, and can help us gain knowledge around patient priorities regarding EOL planning, as well as understand structures in place that limit the initiation of ACP discussions.

An individual's perceived susceptibility and fragility and perceived severity of disease may influence their attitudes towards ACP. Socio-demographic variables, modifying factors, along with cues to action, all need to be taken into consideration as health organizations move

towards implementing ACP in care processes such as questions on nursing admission assessment forms and education sessions (Grant et al., 2008; Kirsner, 2008).

Thorne (2009) writes that situating within the tradition of critically oriented knowledge generation invites us “to consider the intellectual tensions that become visible when a conviction for the inherent value of considering complex problems like social justice and equity enters into a dialogue with an organizational culture committed to the rule structures derived from previous success in the handling of simple problems” (p.150, 151). With this in mind, Bryant’s (2009) Model Informing the Policy Change Process frames the findings of this analysis to help us understand the dominant paradigms of health care, and the assumptions and beliefs held by various stakeholders. From this, I move forward with pragmatic recommendations.

### **Inclusion criteria for literature reviewed**

Perspectives from stakeholder populations, as reflected in the literature, were explored in this literature assessment. Studies on ACP focusing on patients and families, especially the older adult population or those with chronic illnesses, were examined, along with research on health care provider culture and beliefs, and structural organizational considerations and processes. Ideally, broad implementation moving ACP beyond older adults or those with chronic illnesses, to include individuals of all ages could help normalize the conversations around planning in advance. ACP conversations can build connectedness in families and communities, and health status can change rapidly at all ages. Furthermore, practitioners are beginning to recognize planning at age 65 may be too late, as many populations have early onset of major health conditions (Carr, 2012). However, the majority of research around ACP focuses on older adults or those with chronic, life limiting illnesses, and thus this literature review focuses on these populations.

Studies addressing ACP approaches, practices, and outcomes within a variety of organizations were included, as I wanted to understand the impact of strategies in different organizational contexts and regions, and their outcomes of ACP completion. Health organizations in developed, Western countries were prioritized. Research was searched from 1990 with the landmark ‘Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment’ (SUPPORT) on EOL care and the strategies that were largely ineffective in ACP completion (SUPPORT Investigators, 1995). The SUPPORT study was a \$28 million Robert Wood Johnson Foundation project which took place from 1989 to 1994 in multiple sites across the USA, which documented a failure to prevent adverse or negative EOL experiences for seriously ill, hospitalized patients, and where ACP intervention efforts were largely ineffective in improving communication of preferences of EOL care to physicians (Schwartz et al., 2002). From this project, researchers have embarked on learning from the failure of these ACP interventions, and sought to address the discrepancy between patient wishes and actual care at EOL.

As this is a modified REA, summary reports were considered eligible if they were evidence based, with reported literature details and references, including recommendations and guidelines. Standards or policy documents were also eligible for this literature review. Primary research related to ACP and with outcomes related to the research questions were included, such as randomized control trials, prospective comparative studies, and qualitative studies. In the literature I reviewed, the interventions, outcomes, and measures used across the studies were variable; quantitative data was not pooled in the synthesis of evidence.

## **Search strategy**

REA search strategies are intended to be “principled, planned, rigorous, taken with care and checked, explicitly reported, and grounded in the research question” (United Kingdom Civil Service, 2010). The aim is not exhaustive searching; rather, a purposive strategy used to build a balanced picture of different perspectives. This is a pragmatic approach to providing evidence to policy makers. The following databases were used: Ebsco, Academic Search Complete, AgeLine, CINAHL, Education Research Complete, Education Full Text, MEDLINE with Full Text, PsycArticles, and Social Work Abstracts. Search terms used included: advance care planning, advance directives, resuscitation orders, EOL care, palliative care, caregivers, family, proxy, decision making, communication, goals, incapacity, surrogate, and autonomy. Reference lists of relevant papers were also searched for additional citations.

Experts on ACP were consulted and literature recommended. A snowball effect occurred from grey literature and conference proceedings, resulting in useful information from health organizations and special interest groups to provide rich insight into structures and processes. Current guidelines, standards, policies, and position statements documents were included. The potential for missing important studies was recognized as decisions were made where sources were prioritized. Some bias is likely to have occurred, and perspectives limited as I focused on the phenomenon guided by the research questions and objectives. This strategy requires subject knowledge and informed decisions made on which sources to prioritize (United Kingdom Civil Service, 2010). As a critical care nurse with valuable work experience in ACP implementation and facilitation in a health organization, my knowledge of this subject is quite solid, and thus I feel I have the requisite knowledge to assess this information and critically analyze the literature. My knowledge based related to ACP and implications for nursing were greatly enhanced by the

thesis committee members who guided this work, one of whom is a nursing leader in EOL and ACP education and research.

### **Limitations**

Limitations in this modified REA approach include English language publications only, studies limited to those available in electronic format, and limited grey literature searching (United Kingdom Civil Service, 2010). This methodological approach introduces constraints at the literature searching and retrieval stage, and I acknowledge the risk of selection bias, publication bias, and language of publication bias that occurs with REAs (Butler, Deaton, Hodgkinson, Holmes, & Marshall, 2005). Other implications to be considered include the “limited ability to follow up with authors and industry contacts to clarify information presented” (Ganann et al., 2010, Methodological Approaches, para. 2). Searching was less comprehensive with time limitations, and thus had the potential to be bias. Using only electronic databases and only newer studies risked missing evidence contained in other sources.

### Chapter 3: Findings from the Literature

The first objective of this thesis begins to consider the complexities and difficulties in implementing advance care planning (ACP) in health care organizations by looking at the pervasive societal assumptions, and various discourses from key stakeholders. I start with the Canadian context, noting the changing demographics and technology, and the ideologies underpinning end of life (EOL) care before focusing on patient and provider perspectives. The second objective focuses on lessons by specific health organizations who have been successful, or not, in implementing ACP, and analyzes health care processes and structures.

#### **Civil society and end of life care: The Canadian context**

Bryant's (2009) Model Informing the Policy Change Process begins with an examination of civil society, which encapsulates the values and beliefs of stakeholders, as well as institutions and traditions. This provides context for policy analysis, specifically ACP implementation. Societally, our western notions of health have firm biomedical priorities, where the organization and delivery of health services emphasize detection of illness and treatment by health care professionals (Bryant, 2009). Our health care system operates within an acute care, cure-focused ideology (Stajduhar, 2011; Thorne, 2008).

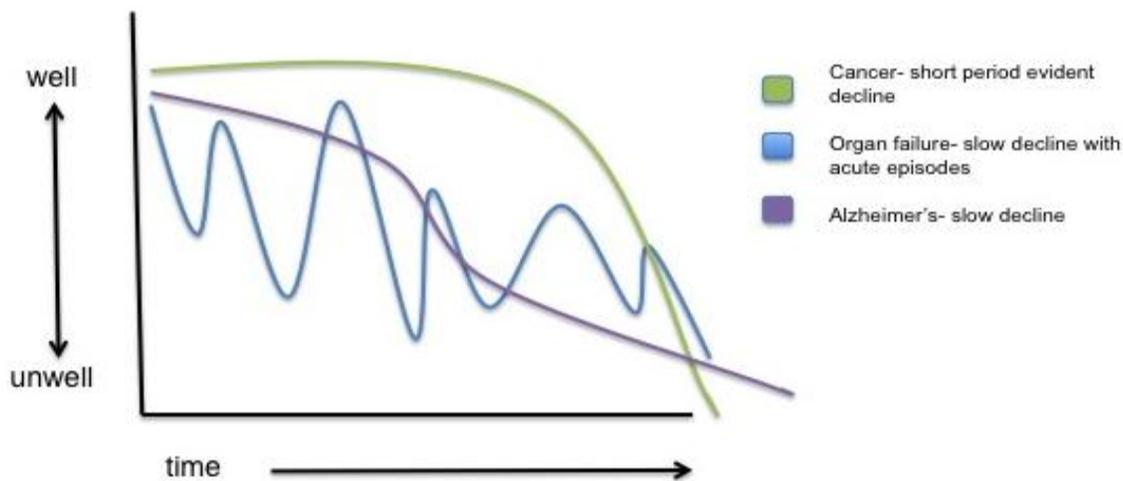
Historically, people generally 'got sick and died,' from childbirth, occupational hazards, periodic epidemics, and heart attacks; Sir William Osler's (1901) *Principles and Practice of Medicine* indicated adults hospitalized with diabetes died within a month. Now, our health care system helps us grow old and accumulate diseases. Lynn (2005) has argued, "the great success of modern medicine has been to transform acute causes of death into chronic illnesses" (p.14). Subsequently, EOL care planning is beginning to receive greater attention as changing

demographics and circumstances amplify the need for approaches outside the cure focused paradigm.

The majority of deaths are caused by chronic conditions, exacerbations of chronic illness, or acute illness compounded with an underlying chronic disease (Winzelberg, Patrick, Rhodes, & Deyo, 2005). The trajectory of life threatening, non-malignant disease makes determination of palliative status and transition to EOL care difficult (Coventry, Grande, Richards, & Todd, 2005). There is a variable trajectory of illness involving episodic, acute exacerbation, hospitalization, stabilization, and steady decline (Lynn, 2005). This presents challenges around lack of prognostic certainty and subsequent discomfort with initiating EOL conversations (Schonfeld, Stevens, Lampman, & Lyons, 2012).

Many patients have a unique treatment course filled with complex decision-making opportunities around life sustaining treatment choices, such as the use of ventilators, resuscitation, and dialysis.

Figure 2 shows the periods of wellness and slow decline associated with chronic illness. Trends of chronic illness lack prognostic clarity in comparison to other illnesses with more defined trajectories.



**Figure 2: Possible trajectories of illness** (Adapted from Gaspard, 2012; Lynn, 2005).

EOL care planning for individuals with life limiting chronic illness is fundamental to a patient centered, well-managed health care system (Stajduhar, 2011). However, this is challenging to achieve for several key reasons: The acute to chronic shift means that dying trajectories are long and unpredictable, and people are faced with considerable decisions along the health care continuum but are not prompted to plan for EOL. Additionally, large multidisciplinary specialty teams do not always know patients well and have considerable discomfort with initiating EOL conversations.

Heyland et al. (2000) documented over 70% of Canadians die in hospitals, and the majority was elderly patients dying from causes unrelated to cancer, and without a clear course of illness. In British Columbia, about 50% of deaths occur in hospital (BC Vital Statistics Agency, 2011). With increasing health care costs and tendencies to prolong life in chronically and critically ill adults, there has been extensive discourse around health care planning, decision-making and quality of care (Con, 2007; Heyland et al., 2006, 2010, 2013). Increasingly, frail older adults suffering from degenerative chronic illnesses are being kept alive in hospitals through use of medication and technology and have a longer illness trajectory, resulting in questions around treatment goals and quality of life (McPherson & Wister, 2008; Seale, 2005).

The last few decades have shown emerging interest in ethical dilemmas involving the concept of dignified death and critique of the 'life and cure at any cost' paradigm (Poles & Rousso, 2011). In 2000, the report *Quality EOL Care: The Right of Every Canadian* was released by the Standing Senate Committee on Social Affairs, Science, and Technology. The Quality EOL Care Coalition was subsequently formed and Health Canada's Secretariat on Palliative and EOL Care was established in 2001. This coalition worked to develop and implement strategies addressing palliative EOL care, and identified barriers impeding quality

care and resources. The most pertinent barrier found by the coalition was that death persistently prevailed as a ‘taboo’ topic (PIAWG, 2006). There has been an evident lack of social discourse on death and dying (Lynn, 2005).

Despite this, McPherson & Wister (2008) point out, “Social values, beliefs, and practices concerning death and dying are changing. There is more open discussion about and acceptance of death... There is more emphasis on dying a good death with as little pain and suffering as possible” (p.388, 396). Demographic, technological, ethical, and legal considerations have led to a need to refocus goals for quality care rather than accepting curative aggressive treatments as status quo. Attention is beginning to be called to resources spent and interventions provided when it is not congruent with patient wishes, or medically appropriate in face of debilitating and worsening chronic illness. Problems around communication and decision-making have led to a need for system response to these changes; the findings from this paper are grounded in the assumption that ACP and EOL planning is fundamental to good care.

### **ACP: Overview of planning and legislation in British Columbia**

To better understand the context guiding the work to be done in health care organizations and by nurse leaders, it is important to be familiar with relevant legislation. In 2011, the Government of British Columbia made changes to the Health Care (Consent) and Care Facility (Admission) Act, allowing for more choices to facilitate ease of ACP and documentation (Clelland, 2012). Health authority guidelines encourage clinicians to incorporate ACP into health care practice and remind providers of the benefits of planning for future care (Kopetsky & Day, 2013; Porterfield & Robinson, 2013). In British Columbia, ACP starts with conversations around beliefs, values, and wishes for future health care (BC Ministry of Health, 2012). These

preferences should be written down as a basic ACP, as health care providers are legally obliged to take these wishes into consideration.

The BC Ministry of Health encourages every capable adult to reflect on who would be making health care decisions on their behalf if they were unable to speak for themselves. As noted in Chapter 1, the Ministry published *My Voice: Expressing Wishes for Future Health Care* as a workbook to assist adults in understanding ACP, identifying who their temporary substitute decision maker would be, and offering templates for basic advance care plans, Representation Agreements (RAs), and Advance Directive (AD). The Ministry of Health's *My Voice Advance Care Planning Guide Quick Tips* (Appendix 1) summarizes the options for capable adults.

Legally, there is a hierarchy of decision makers under the *Health Care Consent Act*. If an individual does not agree with the list of temporary substitute decision makers, a Representation Agreement (RA) should be filled out, and any capable adult is able to assign a representative to make health decisions on their behalf. As of 2011, these documents are now legally binding with two witnesses, or one lawyer or notary, to increase accessibility for the general population. It should be noted that a RA differs from a Power of Attorney (POA). There are frequent misconceptions around the terms and these can vary between provinces. In British Columbia, a RA is only for health care decisions, while a POA is solely for financial and legal decision-making.

If a capable adult has a clear trajectory of illness or has a very good idea of what health interventions he or she wants or does not want, these instructions can be written down as an AD. In British Columbia, an AD is a specific legal document addressing future health care goals, and an ACP tool that requires only two witnesses, or one lawyer or notary. In other jurisdictions, the definition of AD is less specific and may encompass other aspects of ACP (Grant et al., 2008).

Dunbrack (2006) points to the diverse legal recognition for this tool: Ontario has ‘power of attorney for personal care’, Alberta has ‘personal directives’, and Nova Scotia has ‘written authorizations’.

As shown above, the context of ACP implementation and EOL planning can be challenging and confusing, from ideology to political reality. Trends in health care policy and advances in chronic disease management have led to new realities where a commitment to quality EOL care is necessary. At the very least, health care providers and organizations have to understand the legal implications of ACP documentation. The following sections further demonstrate the complex landscape of stakeholders.

### **Stakeholders: patients, families, providers, and organizations**

Bryant (2009) discusses the many groups that act on the system to influence public policy. Stakeholders include experts, policy analysts, and citizen activists. These groups affect knowledge creation, but Bryant points to the inequity in the capacity of the groups to influence change and processes. This thesis reviews research, policy, and expert literature regarding the three main groups influencing the complexities of ACP implementation: patients (older populations or those with chronic illness) and families, health care providers, and health organizations. I have organized the literature in a table highlighting key findings around ACP perspectives, attitudes, and interventions according to these groups (see Appendix 3). The table reflects the structure from the questions guiding the synthesis of literature, as introduced in Chapter 1.

This analysis is framed by Bryant’s (2009) policy change process and discusses three types of knowledge: instrumental, interactive, and critical. Each way represents a different approach to understanding the ACP phenomenon, and all are demonstrated in Appendix 3.

Instrumental knowledge is exemplified by the biomedical and positivist-rationalist approach of evidence, in randomized control and intervention trials, and associated with expert knowledge. Interactive knowledge is found from perceptions and understanding of the concept, and reflected in qualitative research trying to understand patient and provider perspectives of ACP. Critical knowledge takes a closer look at the structures in place and the awareness of power the health organization holds with its funding, policies and processes.

As a modified REA, this table synthesizes these different types of knowledge and literature without scoring for methodology, instead concentrating on findings and experiences helping to answer my guiding questions and objectives. The following sections consider the difficulties and challenges behind ACP implementation, and cumulate insight from health organizations that have successful EOL planning models.

### **ACP implementation: Complexities shaping patient and family engagement**

To comprehend why older adults or those living with chronic illness have difficulty engaging in ACP or EOL planning, I look at the widespread societal assumptions around ACP and EOL. Historically, very small percentages of the adult population have completed advance directives (ASPE, 2008; Con, 2007). Locally, in British Columbia, in a study of elderly patients attending an urban emergency department, only thirty five percent of participants knew what ACP was, nineteen percent said they had a completed ACP, and only five percent brought it to the hospital (Gill, Fukushima, Abu-Laban & Sweet, 2012).

There are ambivalent views on conversations on EOL care and dying; the majority of patients are unwilling to acknowledge prognosis or anticipate death, believing they are too healthy, and disregarding EOL issues as irrelevant. Many consider ill health simply as a part of growing old, content with assuming family and providers know their wishes and preferences

(Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011; Gott et al., 2009; Mathie et al., 2011; Schickedanz et al., 2009).

Even in older adult populations with limited life expectancy residing in care homes, where dying is not an unexpected outcome, death is still not readily acknowledged. Mathie et al. (2011) found that living in a care facility, observing other residents dying, and experiencing episodes of acutely ill health did not shape residents' priorities for discussions around EOL. A minority of participants was able to anticipate death or express explicit plans and wishes; most felt they had limited control, and were unconvinced they could plan for the future or that planning would be helpful.

Due to efforts in a number of health authorities across Canada, the ongoing multisite Canadian ACCEPT study looking at elderly patients at high risk of dying in the next six months has found steadily rising numbers for ACP completion; 76% of patients had thought about EOL care, and 48% had completed an ACP (Heyland et al., 2013). Despite this, only 30% had discussed wishes with a family physician, and only 55% discussed wishes with a member of the health care team. While many elderly patients have thought about and expressed care preferences, communication and documentation remain insufficient. Two qualitative themes have emerged from investigating this noticeable gap from thinking about, to discussing wishes with the health care team: 'Not Yet,' not ready to engage with issues of mortality, life expectancy, or prognosis and treatment decisions, and 'Just Ask,' as they are ready and welcome the opportunity to discuss fears and make plans, but are reluctant to initiate the conversation (Simon, Porterfield, Raffin, & Heyland, 2013 in print). Generally, older adults or adults living with chronic illness tended not to have shared with their health care providers their wishes should they become seriously ill or injured, and unable to speak for themselves (Heyland, 2013).

Despite society's mixed and hesitant views around EOL discussions, recent studies show many older adults welcome ACP, and want health care professionals to 'Just Ask.' Patients and families have the expectation that health professionals initiate discussions (Barclay et al., 2011; Knauff, Nielson, Engelberg, Patrick, & Curtis, 2005). The literature listed in Appendix 3 displays diverse patient attitudes towards ACP. Research demonstrates patients ultimately want sensitive, honest conversations with repeated opportunities to talk, build relationships, and clarify understanding (Heyland et al., 2010). In spite of chronic illness and its uncertain prognosis and frequent occurrence of unexpected declines, many patients do not realize the seriousness of their condition and do not wish to engage in EOL discussions (Barclay et al., 2011; Patel, Janessen, & Curtis, 2011). There remain considerable opportunities for improvement with regards to patient understanding, information sharing, and decision-making.

A more current view of discussing ACP with patients and families stems from research showing ACP as a multistage process grounded in communication and understanding of values, which offers invaluable assistance to family members and surrogates at EOL. Wright et al. (2008) showed EOL discussions are not associated with higher rates of depression or worry, and in fact are associated with lower rates of ventilation, resuscitation, ICU admission, and earlier hospice enrollment. Wright et al. (2010) emphasized the suffering with aggressive care; patients who died in the ICU or hospital experienced more physical and emotional distress and worse quality of life, while family members had heightened risk for post traumatic stress disorder and prolonged grief. Detering, Hancock, Reade, & Silvester (2010) demonstrated in a randomized control trial the increased patient and family satisfaction with ACP intervention, and significantly less stress, anxiety, and depression in family members of patients who passed away after involvement in decision making.

Locally, the Vancouver Coastal Health (VCH) Community Engagement mandate is to “enhance patient and public involvement in health service planning and decision making” (Cuddington, 2013, p.2). Forums have been held annually with organizational executives, frontline staff, and the public to discuss issues, and the most recent workshop discussed quality. Two major themes arose as most important: communication of complex health information, and dialogue around care options. The consumer public demonstrated they want health services to be tailored to the needs, preferences, and cultural values of the patient and families. As one participant concisely noted, “Patients should know the possible pitfalls of the proposed treatment and providers need to clearly explain the risks” (Cuddington, p.6). Despite uncertainty around discussing future health care, patients and families have established they appreciate knowledge and support in the capacity to participate in decision making in health care. ACP helps facilitate good care and decision-making.

Literature showed small numbers of consumers participating in ACP without guidance from the health care team. Patients and families assume health care providers should lead conversations (Barclay et al., 2011; Alano et al., 2010; Heyland et al., 2010). Unmistakably, patients and families need more encouragement to engage in the ACP process with their health care team. When efforts to introduce ACP occur, literature validated increased patient and provider satisfaction with quality of care (Detering et al., 2010).

### **ACP implementation: Ideologies and demographics shaping patients’ assumptions**

The conceptualization of ACP has its origins in ethical and legal debates and controversies over EOL medical treatment. Tensions arose from the medical professional’s principle of non-maleficence, or “do no harm”, which was “uniformly taken to mean that life should be prolonged at all costs” (Johnstone & Kanitsaki, 2009, p.407). Court decisions started

to favor the patient's right to refusal of unwanted treatment, paving the way for legislative reform. Traditional ACP is built on core Western values of patient autonomy, informed decision making, truth telling, and control over the dying process (Johnstone & Kanitsaki).

Factors associated with greater participation in the ACP process include older age, greater disease burden, Caucasian race, higher socioeconomic status, knowledge about EOL treatment options, a long standing relationship with a primary care provider, and a positive attitude towards EOL discussions (Barclay et al., 2011; Douglas & Brown, 2001; Freer, Eubanks, Parker, & Hershey, 2006; Garrett, Tuokko, Stajduhar, Lindsay, & Buehler, 2008; Lovera et al., 1999). Access to care and trust in health clinicians are crucial (Bigby, 2003; Con, 2007). It cannot be ignored that structured ACP and discussions around death and dying are incompatible with some cultural traditions and beliefs (Castillo et al., 2011; Carr, 2012; Crawley et al., 2000; Johnstone & Kanitsaki, 2009; McAdam, Stotts, Padilla, & Puntillo, 2005; Newman-Giger, Davidhizar, & Fordham, 2006). Con (2007) writes,

ACP may be culturally incongruent for some patients, therefore, health care professionals should identify appropriate alternatives for health planning and decision making... All cultures felt that if health care professionals could take the time to understand the individual, this would be the most respectful way to provide a dignified death (p. vi).

The notion of surrogate decision maker is one that is appropriate regardless of culture and should be introduced when care is commenced, beginning the process of reflection and planning in a non-threatening manner (Porterfield & Robinson, 2013).

Socio-demographic factors are predictive of EOL plans; this includes race, marital status, and age (Kahana, Dan, Kahana, & Kercher, 2004). Studies looking at racial differences in healthcare experiences and religious orientations confirmed these findings, where certain groups

are found to be distrustful of institutions, and fear poor medical care would result from formal documentation of not wishing life-prolonging treatments (Crawley et al., 2000). In certain religious faiths, some view the passage to death to be endured, rather than medically determined (Con, 2007; Johnstone & Kanitsaki, 2009; Waters, 2001).

Other concerns about ACP expressed by families revolve around the fact that patient preferences may change over the course of illness, and ongoing discussion is needed. There is a fear that ACP documents are not reviewed regularly by physicians, or modified to reflect the evolution of preferences (Castillo et al., 2011; Heyland et al. 2010). There is also an issue of portability, with consumers lacking faith that documents would transfer from the various health care settings near the EOL (Allison & Sudore, 2013; Freer et al., 2006; Lynn & Goldstein, 2003; Rhee, Zwar, & Kemp, 2012). Despite the legal language behind ACP, there is a common perception among patients and families that clinicians might not follow ACP documentation, and thus questions of utility arise from the uncertainty that care may not conform to their documented wishes (Freer et al., 2006; Singer et al., 1998; Teno et al., 1997; SUPPORT, 1995).

Older adults who are less preoccupied with the future were found to be more open and able to discuss plans and preferences for EOL care, where their key concerns revolved around their family members' well-being (Mathie et al., 2011). Beyond the traditional understanding of benefits of ACP such as respect for autonomy and preparation for future incapability, patients perceived benefits associated with ACP such as preparation for EOL and death, avoidance of the prolongation of dying, relieving burden on family, and strengthening personal relationships (Singer et al., 1998). The conceptualization of ACP must be fluid and flexible to “culturally diverse worldviews and meanings associated with health, illness, life, and death... broadening understanding of the principles of autonomy, informed consent, truth telling, cultural liberty, and

the role of families and family love in EOL decision making and care” (Johnstone & Kanitsaki, 2009, p.412).

Patients and families hold legitimate concerns when discussing ACP or legal documentation. These add to the difficulty in conversations around planning for future health care and EOL. The literature in Appendix 3 shows various concerns that must be addressed for ACP implementation in acute and community settings in older adult and chronically ill populations.

### **ACP implementation: Difficulties arising from health care provider perspectives**

When contemplating the struggles in implementing ACP, health care provider perspectives must be considered. Despite potential advantages, and research supporting EOL care planning as improving patient outcomes, there is considerable clinician discomfort with the broad issues of EOL and dying. Health care providers are influential with their perspectives, and their prevailing attitudes contribute to a tendency to prolong life, and an inclination to view death as a failure (Rhee et al., 2012; Schonfeld et al., 2012). There is a distinct focus on medical management rather than addressing uncertain prognosis and risk of sudden death. This results in a prioritizing of the curative expert-driven paradigm where “health can be maintained through medical interventions and by individuals following the recommendations of physicians, [and] public health educators” (Bryant, 2009, p.41).

Health care providers have difficulty finding ethical balance with autonomy, beneficence, and non-maleficence. All clinicians agree patients have the right to be informed of prognosis, but struggle with the need to avoid giving bad news, often underplaying the severity of the patient’s condition (Barclay et al., 2011; Boyd et al, 2010). Further, health care professionals tend to

miscalculate patient need for information, and overestimate understanding and awareness (Hancock et al., 2006).

The literature synthesis displays the tensions surrounding ACP implementation efforts, the lack of attention, and unsubstantiated concerns paid to ACP by health care professionals. Kahana et al. (2004) found physicians generally do not discuss EOL plans with their patients. In their study examining facilitators or deterrents to EOL planning in community dwelling older adults, almost three-quarters of physicians did not know their patients had completed ACP documents. Older adults' health status, or the length of doctor-patient relationship, did not relate to the tendency of ACP completion or influence physician knowledge of patient wishes. Wright et al. (2008) found more than 60% of dying patients did not recall having ACP conversations with their physicians, and providers often avoided EOL planning, were overly optimistic, or delayed discussions until health crisis, when patients were close to death. There is false belief that ACP causes depression and anxiety, and that patients would not want treatment limitations (Knauf et al., 2005). Clinicians tend to fear EOL discussions might cause alarm, destroy hope and positive coping strategies, create anxiety, and cause patients to give up on fight for life (Barclay et al., 2011; Boyd et al., 2010).

Provider perspectives impact ACP implementation. When clinicians tend not to lead ACP discussions, these conversations ultimately do not occur. Kahana et al. (2004) write:

Physicians are ultimately responsible for ensuring that their patients' wishes are respected, and many patients expect physicians to initiate ACP dialogue. Thus, the perspectives of physicians and caregivers likely affect not only whether older adults plan for EOL needs, but also the types of preparations they make (p.1164).

Research documents the paternalistic tendencies of providers, believing the best care is care that prolongs life. Literature also looks at clinician discomfort with the inherent uncertainty involved in planning for the uncertain future (Rhee et al., 2012). Physicians are shown to rely on patient prompts for ACP conversations to occur, and feel they should not have to take responsibility for initiating discussions (Patel et al., 2012). Unfortunately, this inevitably leads to missed opportunities for ACP and communication of health care wishes between patients and providers.

### **ACP implementation: Complexities arising from the dominant culture of health care**

The preoccupation with technological and interventional advances has led to a deficiency in communication and understanding of ACP and documentation. Health care provider ambivalence towards the positive outcomes of ACP, and difficulty with ACP terminology has led to an aversion to the topic of ACP (Boyd et al., 2010). In one study, provider reluctance is documented despite computer-generated prompts, readily accessible materials, and time, where extended lengths of appointment for preventative focused visits were implemented to encourage ACP conversations (Wissow et al., 2004). There are trepidations with externally imposed legal systems, and shortage of interest and understanding around legal validity and interpretation of formal documentation (Rhee et al., 2012). Compounded with feeling that lengthy explanations of ACP goes beyond physician responsibility, there are also concerns around the absence of technology, or standardized electronic medical records allowing for timely retrieval of ACP documents, leading to diminished interest in investing time and efforts into ACP completion (Rhee et al.; Wissow et al.).

Providers may lack skills related to ACP and EOL, leading to the feelings of discomfort when leading these discussions (Schonfeld et al., 2012; Rhee et al., 2012; Livingston et al., 2011; Boyd et al., 2010). Con (2007) writes, “The need for professional ACP education across

disciplines have been well documented by many studies conducted during the 1990s yet this area has shown little improvement”(p.vi.). In Con’s key informant interviews, level of training was a key theme for provider uneasiness with instigating conversations. Health care professionals noted they had to look for additional specialized training in palliative and psychosocial care.

Literature indicates the increasing awareness that there needs to be more training for clinicians. Ho and Taylor (2013) shared preliminary results from an ongoing study on decision making called *We are the Biggest Barriers: Healthcare Providers’ View on Their Own Challenges in EOL Discussions*. Health organizations are slowly beginning to take notice. Education efforts for health care professionals about the importance of ACP are improving, and imperative, especially to improve compliance with patient wishes. “A true partnership means not only that older adults should be making plans with their health providers and caregivers, but also that physicians and family members should be proactive in initiating discussions about care wishes” (Kahana et al., 2004, p. 1167). The goal is to shift provider ambivalence to one where ACP benefits are acknowledged and ACP process routinely practiced.

Moving from the general support of ethical principles of autonomy and individualized patient centered care, randomized intervention trials have shown that clinician awareness of patient barriers to ACP can open communication around EOL (Au et al., 2011). With clinician training and facilitation, there is demonstrated higher quality EOL, and higher concordance between patient wishes and received medical treatment (Au et al.; Morrison, Morrison, & Glickman, 2004). Briggs et al. (2004) found ACP lead to greater satisfaction with the decision making process for both patients and providers, and can help alleviate decisional conflict in patients and families. Fairbank (2011) writes,

Doctors and nurses all want to hope for the best, but hoping for the best while preparing for potential death need not be mutually exclusive... Health professionals do not need to fully share a patient's hopes or fears to respect, learn about, and respond to them... with a combination of optimism (let's hope) and realism (let's prepare)" (p. 256).

Evaluation of health care professionals' satisfaction when involved in ACP implementation has been largely positive, where ACP consultants feel they are improving care, better involving families, helping prepare for the future, and giving people opportunities to die with dignity (Fairbank, 2011).

There is no consensus on who should conduct ACP. Literature supports physician led conversations, but this observation was not congruent with key informant views (Con, 2007). There has been limited attention paid to the unique position of nursing in relation to ACP. Most research interest and funding has centered on physician perspectives or interventions. As shown in the literature synthesis, nurses have not been the main focus in research around provider perspectives (Appendix 3). Commentary on the need for interdisciplinary health care research and clarity around the perceived role of nurses in communicating patient preferences and EOL decision making has been noted, but little has been followed up on (Con, 2007; Oddi & Cassidy, 1998).

Nurses are in a position to initiate ACP conversations, clarify issues, and assist with formal documentation within the setting of established, trusting patient- provider relationships. Recent action research in Australia involving nurses and nurse managers in community palliative care programs has been largely successful in enabling nurses to monitor, evaluate, and plan quality improvement of an ACP model to improve EOL care (Blackford & Street, 2012). More

research supporting nursing and multidisciplinary interventions in ACP implementation would be appropriate as nursing informally contributes to patient understanding and decision-making.

### **ACP implementation: Insights gained from health care organizations**

A goal of this paper is to pursue insights from the literature regarding the successes and challenges of instigating ACP in health care organizations. This section looks at current ACP efforts and various organizational experiences with ACP initiatives. Various health care organizations have shown promise in promoting ACP completion with multicomponent intervention. I reflect on the feasibility of such implementation.

Specific communities have been quite effective in systematically implementing ACP into care. In La Crosse, Wisconsin, USA, the *Respecting Choices* intervention is an intensive, community wide, multicomponent, longitudinal approach demonstrating collaborative ACP mechanisms with positive effects. Patient and provider education, changes in documentation practices, and alterations in community expectations and standards of care were shown to increase ACP completion six fold and demonstrate congruency between treatments received and patient wishes. (Hammes & Rooney, 1998). Detering et al. (2010) write, “Models of advance care planning such as the Respecting Choices<sup>®</sup> programme have shown that a coordinated, systematic, patient centered approach to ACP by trained non-medical facilitators can improve outcomes for patients” (p.1).

‘Living and Dying in Style’ is a program based in rural southern Australia aiming to encourage ACP in palliative care programs and residential care facilities (Fairbank, 2011). ACP consultants are given a training course with an overview of ACP, legal considerations and documents, and hands on practice and completion of forms. Role playing, the ability to assess mental capacity, and discussion of ethics, resuscitation, and life prolonging treatments highlight

controversial issues and the importance of beginning the conversation. Protocol begins by asking a simple question using local terminology, “Have you appointed anyone to have Medical Enduring Power of Attorney?” The fact that this question is asked of every patient is underlined, and ACP is introduced in a non-threatening manner to respect wishes around healing, versus the culture of curing (Fairbank).

The Respecting Patients Choices<sup>®</sup> model by Austin Health in Australia has four major elements: organizational system changes, ACP education and training, implementation, and quality improvement. All four components require support from organizational executive, management and staff. It has been a cultural shift and a change in clinical practice including prominent filing of ACP in Greensleeves, a visible green plastic folder at the front of a patient chart meant to ensure documentation is known and communicated, and transfer of these documents between facilities. Moving beyond simple policy, it is considered unacceptable for a patient to have a completed ACP, only to have these preferences ignored because it was ‘lost in the system’ (Clayton, Hancock, Butow, Tatterall, & Curow, 2007; Mitchell & Fairbank, 2006; Lee et al., 2003). A randomized control trial by Detering et al. (2010) found that when elderly patients received formal ACP from a trained facilitator in coordination with treating doctors who ensured patients understood their illness, treatment options, and likely prognosis, patients were more much more likely to have their EOL wishes known (86% to 30%), and have increased family and patient satisfaction. From a resource allocation perspective, Malloy et al. (2000) found use of ACP reduced health care utilization without reducing patient or family satisfaction with care.

Moving forward with attention to sustainability, a nursing led Respecting Patients Choices<sup>®</sup> evaluation tool has been developed to provide information to assist nurses to embed

ACP into usual care and measure performance and quality over time. This tool enables nurse managers to have a clear outline of service progress, achievement, and direction for future changes (Blackford & Street, 2012). The ability to monitor, evaluate, and plan to improve EOL care with their ACP model provides information for quality improvement, and moves beyond the traditional measure of success by completion rates of advance care plans.

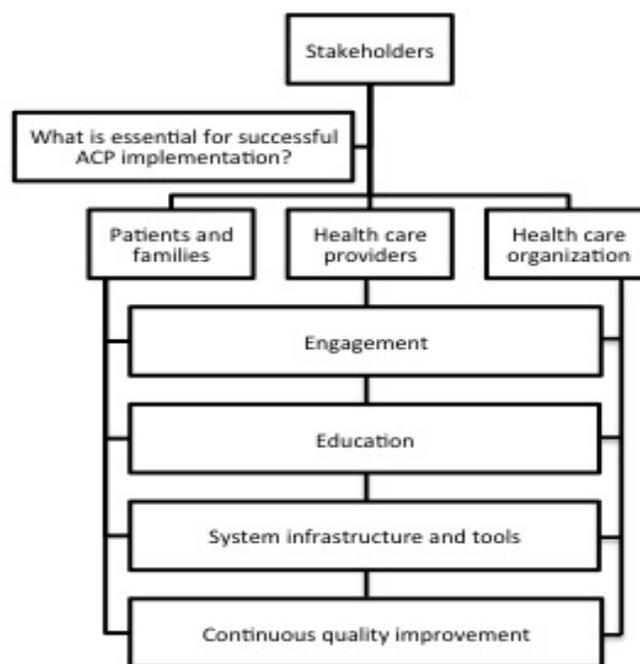
Five key elements have been identified for models crucial to successful ACP implementation: trained facilitators, involvement of family in conversations, patient centered discussions, correctly filed documents, and systematic education of doctors (Briggs, Kirchhoff, Hammes, Song, & Colvin, 2004; Hammes & Rooney, 1998; Prendergast, 2001). Part of the focus of ACP discourse is on realistic, achievable goals of care, and improving patient and family understanding of the medical situation (Detering et al., 2010). Patients may vary their decision making when faced with likelihood and severity of choices, but the emphasis of planning is on goals, values, beliefs, and what it means to live well, rather than specific treatments in particular circumstances.

In a grounded theory qualitative study of key informants around the success of the Respecting Choices<sup>®</sup> program, major themes to building effective coalitions to systematically integrate ACP in care included commitment to leadership, recruitment of members and funding, paid support staff, education, and cohesiveness where disparate groups collaborate with shared perspective and common vision (Marchand, Fowler, & Kokanovic, 2006). Coalitions need defined short, intermediate, and long term goals with measurable outcomes and evaluation related to the process of ACP.

These key elements for effective ACP discourse differs from the failure of the SUPPORT study, which relied on a research nurse to verbally relay information to the treating doctor about

a patient's preference for CPR, but did not facilitate patient centered care or discussions, did not involve the patient's surrogate or family, and did not ensure the treating doctor was aware of the patient's ACP (SUPPORT Investigators, 1995). The remarkable inability of the study intervention to improve patient outcomes suggests that systems level changes are crucial, where processes and structures need to be addressed.

In Canada, two health authorities have had successful ACP initiatives based on developing structures and processes for ACP. Through these experiences, the former Calgary Health Region (now Alberta Health Services) and Fraser Health Authority collaborated and led the development of a framework with four basic building blocks (CHPCA, 2010): Engagement, Education, System Infrastructure and Tools, and Continuous Quality Improvement.



**Figure 3: Multicomponent ACP implementation framework** (Adapted from the Framework for Advance Care Planning in Canada, CHPCA, 2010).

Multicomponent ACP efforts are needed for any systematic change and must impact all stakeholders. All components are essential and must function together to be effective. The challenge is to embed quality improvement activities and education in system infrastructure and engage all disciplines in the process, while continually demonstrating ACP as a worthwhile investment for organizations.

### **ACP implementation: Improving the current praxis between theory and practice**

In Canada, Alberta Health Services and Fraser Health Authority in British Columbia have been leaders with their streamlined ACP and goals of care (GOC) documentation. Building on experience from the Physician Order for Life Sustaining Treatment (POLST) program in Oregon, USA, these two health authorities have adopted mechanisms for providers to elicit patient preferences, and translate them into a set of medical orders addressing high probability interventions. Documentation on highly visible forms ensures the portability across care settings. Completion and correct, prominent filing of ACP assists health care professionals with EOL decision-making (Wasylenko, 2012; Detering et al., 2010).

The following image (Figure 4) adapted from a Vancouver Coastal Health presentation helps illustrate how ACP can be influenced by each care episode or as health conditions change, as well as how ACP can help guide GOC discussions.



**Figure 4: ACP versus GOC** (Adapted from Kopetsky & Day, 2013)

GOC documents are seen as health care professional and organizational directed forms supporting health care decision-making. These include medical orders around code status and EOL care. Successful implementation of ACP in various health care organizations has coincided with implementation of GOC documentation and the expectation of medical staff explaining goals of care designations to patients. “ACP and GOC designations are fundamental clinical practices that support good care and decision making... The architecture and process tools are critical [as] we can improve our chances of having ‘best available information’ and therefore, making the correct decisions with people” (Wasylenko, 2012, p.5,6). While ACP conversations guide decisions, a GOC designation guides the health care team in times of medical emergency to provide care best reflecting a patient’s health condition in the context of their health circumstances, wishes, and values (Alberta Health Services, 2012).

There is clear disconnect between knowledge regarding the benefits of ACP and implementation of this process in practice. Without organizational support and processes in place to support ACP practice, health care providers are unable or unwilling to engage in ACP with patients and families. The literature indicates that while many older adults are interested in

engaging in ACP, there are often few opportunities to do so (Mathie et al., 2011). ACP has been widely regarded as an attractive ideal, but implementation is shown to be a difficult endeavor. An entire set of barriers to ACP implementation arises from a lack of accountability as no specific part of the health care system is responsible for initiating discussions around future health care. ASPE (2008) write, “An added complication has been fractured continuity across the system and the lack of ACP portability” (p.xiv). Structural organizational changes and processes are necessary to support health care professionals to engage in ACP with families. GOC documentation is a crucial component where organization support and provincial leadership is required.

Alberta Health Services has shown change is possible (Health Canada, 2008). A chart audit prior to ACP/GOC implementation showed 8% of charts populated with ACP documents. After development of a clinically relevant set of GOC designations to guide time sensitive decisions around interventions and directions of care, a subsequent chart audit showed vast improvements (Wasylenko, 2012). A process for conversation that focused on goals, addressing patient values and preferences within the context of medically appropriate options was established. A Greensleeve housing these documents at the front of the chart were also implemented for visibility and portability (Health Canada, 2008). This allowed for inter-provider, rapid and reliable communication with summary tracking sheets indicating most recent decisions and participants of conversation. Eighteen months after the policy ‘go live’ date, 90% charts in long term care/ assisted living (LTC/AL) and 78% charts in emergency/ acute care (ED/AC) contained Greensleeves. 97% charts from LTC/AL and 84% charts in ED/AC contained GOC designations and appropriate documentation (Wasylenko).

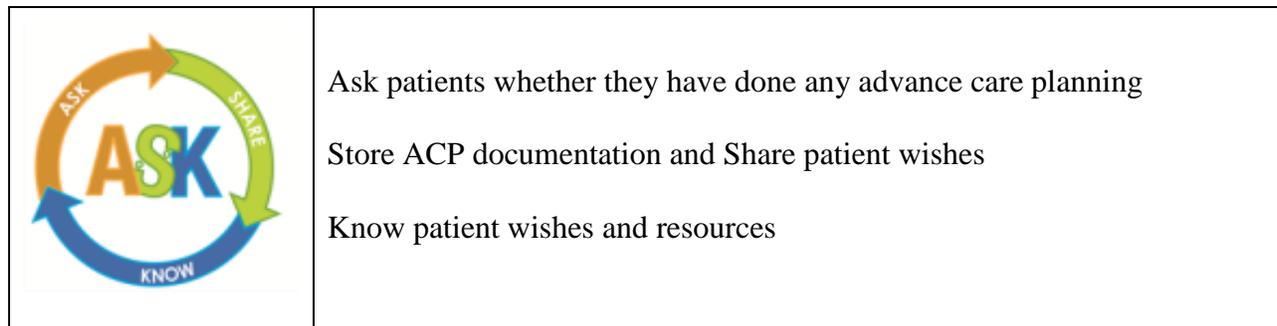
In British Columbia, the Ministry of Health has published a *Provincial End-of-Life Care Action Plan for British Columbia*. It outlines priorities and actions to guide health authorities in planning services focusing on “an individual’s quality of life to ensure the patient’s symptoms and goals of care are identified and addressed appropriately” (Ministry of Health, 2013, p.4). Unfortunately, this mandate has not led to funded positions, or leadership towards provincial standards for goals of care documentation. Without policy and strong working relationships between health authorities, different goals of care documentation and pilot projects have emerged and added to confusion around terminology. Providence Health Care uses Options for Care, Fraser Health has developed Medical Orders for Scope of Treatment, Richmond Hospital is adapting the Calgary Model of Goals of Care, and various residential care facilities use differing versions of Levels of Intervention. Tensions have arisen from provincial initiatives without adequate funding, and much of ACP implementation work has been left to health authorities (Kopetsky & Day, 2013). The lack of funded positions and unstructured provincial policy approach has led to different outcomes across the province.

There are current struggles with the financing of resources (people, time, and money) despite policies in place supporting ACP. Implementation has been a challenge and the case continues to be built by pointing out benefits to patient safety and quality, and potential for reducing over-treatment, unwanted, or inappropriate medical care. Support from senior management is critical, although this has been proven difficult to obtain as GOC documentation competes with many priorities. Finding champions able to succinctly demonstrate ACP benefits and engage organizational leaders, along with securing a group of clinicians willing to move GOC documentation forward, are the necessary steps at any health organization. At Fraser Health, ACP/ Medical Orders for Scope of Treatment (MOST) is part of the established,

successful EOL program populated by a Director who is also a registered nurse, a supportive Medical Director, and engaged physician consultants working with a group of clinical nurse specialist leaders. The health organization operates on a program management model, and the EOL program worked with each program to identify program leaders for ACP implementation. The leaders of ACP deliver comprehensive training with a full time team, and were able to find a voice at patient safety, risk management, and professional practice tables, and this was essential to its success (Health Canada, 2008).

There are positive changes where literature and research have helped stakeholders push for policy changes in health care organizations. All health authorities have had some degree of ACP initiatives, especially for staff education and provider engagement. In British Columbia, the Ministry of Health collaborating with the General Practice Support Committee (GPSC) developed learning modules as part of the Practice Support Program on End of Life Care (GPSC, 2013). Accreditation Canada has encouraged national comprehensive health services standards to embed quality improvement and patient safety initiatives into operations (Accreditation Canada, 2013). At Vancouver Coastal Health, sections to introduce ACP to the inpatient population have been incorporated into new Nursing Admission Assessment Forms as a result of Accreditation standards related to facilitating compliance with wishes (Kopetsky & Day, 2013). With external funding from the Integrated Primary and Community Care initiative, a four month Advance Care Planning Acceleration Project endeavored to support health care providers in engaging with patients to consider their wishes for future health care (VCH Client Relations). The Physician Stream contained education sessions to familiarize physicians with BC legislative framework for ACP, and ACP tools and resources including the *My Voice* workbook. The

clinician stream supported the Ask/ Share/ Know- ASK strategy for health care providers (www.vch.ca/acp; VCH Client Relations):



**Figure 5: ASK strategy**

Greensleeves Guidelines were updated, and education efforts for clinicians received positive feedback (VCH Client Relations, 2013). Currently, the challenges are to normalize ACP and EOL conversations, to engage leadership and provide resources, and to develop care processes incorporating ACP and GOC documentation.

This shift in culture is not easy, and political and organizational setbacks occur. In the United States, President Obama’s administration recently reversed its decision to revise Medicare regulation to pay physicians to discuss ACP with patients (Medical Ethics Advisor, 2011). Locally, Vancouver Coastal Health’s senior management has not allocated ACP or GOC any monetary support for the calendar year. Despite policy changes and sporadic educational efforts with regards to ACP since 2010, there has been limited implementation. At one acute care hospital, an informal chart audit conducted in early 2013 showed only one Greensleeve in over a three-month period of patient discharges and chart disassembly in Health Records (D. Ridley, Health Records Manager, personal communication, March, 30, 2013). With terminology around ‘fiscal crisis’ and ‘economic uncertainty’ permeating internal emails in health organizations, strong leadership and advocates for ACP are needed for effective ACP

implementation. It appears it is a difficult argument for administrators to fund ACP and appreciate the long-term reduction in patients entering the emergency department and intensive care units. Without support and engagement from leadership, patient and provider reluctance to discuss EOL plans and widespread indifference of ACP remain standard practice.

## Chapter 4: Discussion, Recommendations and Conclusions

Chapter 4 provides a summary of this thesis, and highlights main points from the study findings. I offer recommendations for advance care planning (ACP) work in chronically ill and older adult populations. The position of nursing is examined. Implications for practice, research, patient and provider engagement, and organizational policy and processes are discussed.

### Discussion

This analysis of literature is drawn from critical perspectives as I attempt to understand the complexities behind what makes ACP implementation so difficult. I am “examining the conditions and assumptions upon which something exists... and, following deconstruction, envisioning a renewed or reconstructed way” (Reimer-Kirkham et al., 2009, p.161). The attention to context, and privileging of certain types of knowledge and ideologies, help uncover the complications of ACP implementation.

This research paper began with the assumption that ACP should be the gold standard. Studies show ACP conversations between patients and physicians were associated with fewer life sustaining procedures and decreased rates of intensive care admissions, and that the absence of ACP and documentation led to worse ratings of quality of life at end of life (EOL) and decreased satisfaction by the family (Wright et al., 2008). Literature highlighted in Appendix 3 may help policy makers appreciate the literature showing patient perspectives, and the challenges with successful ACP implementation and quality care when patients are unable to speak or participate in decision-making. Trials of the *Respecting Patient Choices*<sup>®</sup> model of ACP in community settings with older adults, palliative care, and residential aged facilities showed improved quality of EOL care of patients, increased patient and family satisfaction, and reduced likelihood of residents in care facilities being transferred to hospital to die (Mitchell & Fairbank,

2006; Lee, Heland, Romios, Naksook, & Silvester, 2003). In the elderly population, a randomized control trial of this model of ACP demonstrated improved quality of care, patient and family satisfaction, quality of EOL care, and a reduction of depression, anxiety, and post traumatic stress in surviving family populations (Fairbank, 2011).

Research on patient and provider perspectives shows the biomedical dominance in ideology and the absence of priority placed on ACP by the majority of leaders in health organizations. While complex family discussions around decision-making should not be disregarded, literature showed the natural gravitation to the quick fix, and easily accessible, tangible, concrete medical achievements and technologies. Lynn and Goldstein (2003) point to the tendency of health care teams to offer routine treatments in response to health problems rather than treatment choices based on planning incorporating the patient situation and preference. There is still difficulty in appreciating that “discussions about goals of care and code status constitute a medical procedure every bit as important to patient safety as a central line placement or a surgical procedure” (Allison and Sudore, 2013, p.E2). The vivid challenge is encapsulated by the culture of health care that values intervention over conversation. This difficulty is compounded by patients’ preference to allow providers to take the lead on any discourse on planning for future health care, and provider disinclination to have these conversations.

Successful implementation requires ACP to be a priority in daily practice, and part of routine care, where health care providers believe the time taken to discuss patient wishes is well spent (Detering, Hancock, Reade, & Silvester, 2010). Mechanisms need to be in place to ensure ACP is offered to patients, that plans are readily available and correctly documented, and for care to reflect the patient’s wishes. Executive teams need to support policy changes, and clinical

leaders to promote ACP, support ACP consultants, and raise awareness in communities: health care professionals, agencies, and the public. Funding to acknowledge the time, knowledge, and skills required to implement ACP should be sustainable (Fairbank, 2011). Literature suggests health services and organizations need to take responsibility for assisting patients with ACP. It should not be an excuse that clinicians are improperly trained or have limited knowledge in having ACP conversations. ACP needs to be an institutional priority, and part of the panel of quality indicators used by administrators in formal assessments of center or provider performance (Wissow et al., 2004).

In British Columbia, the discourse reflected in *My Voice Workbook* and Ministry of Health's *End of Life Action Plan* has been to expect the public to adopt ACP, and for health care providers to discuss goals of care. Where there has been success, there has been strong provider engagement. Much of this work was left to the health authorities. As there is no clear consensus on who should conduct ACP or when these conversations should take place, health organizations should be cognizant of the need for processes to encourage ACP implementation across the continuum of care. As these changes have been slow to occur, the government perhaps needs to take a stronger leadership role and mandate working groups for provincial guidelines and policies. The findings from this literature analysis suggest that without leadership, funding, and resources, ACP implementation and goals of care (GOC) documentation remain fragmented.

### **Feasibility of ACP implementation in health care organizations**

This thesis outlines the system-wide considerations that must be taken into account with ACP implementation: community and public awareness, health professional involvement, and organizational concerns. Perceptions around decision making for future unpredictable health situations, dismissive attitudes of health professionals, and accessing and understanding ACP

documents throughout health care settings all need to be addressed to impact delivery of EOL care. Engagement of health care professionals and the public are a priority for any viable solutions putting ACP into practice, as is investment into time and human resources and involvement of community leaders. In British Columbia, where there are several health authorities with one pioneering successful ACP and EOL programs, collaboration is necessary to streamline processes, diminish confusion around terminology, and provide cohesive care based on patient goals wherever they live. Health authorities and the Ministry of Health should take a stronger leadership position and provide adequate resources to support ACP implementation and GOC documentation.

Wright et al. (2008) show there can be adverse outcomes associated with not having ACP discussions. The same study also demonstrated EOL conversations do not contribute to negative attitudes from patients and families. There is a lack of excuse to avoid dialogue, and a well-defined need to increase the frequency of EOL planning. Clinicians need to acknowledge death is inevitable, and not a failing of the medical system. The focus should be on clarifying patient priorities, and knowing patient wishes. This does not mean an absence of care, or giving up on treatment, but rather, finding congruence between patient wishes and care provided. Health care professionals are not averse to aggressive care and thrive on medical technology, and tend to treat more than not, but should be sure that the treatment provided is the care an individual or family wishes. Proactive roles need to be taken by all stakeholders to facilitate partnerships where the health care team is informed of patient preferences for health care.

Public awareness of CPR as well as its futile applications and expected outcomes should be emphasized, as death prolonging technology and aggressive treatment are commonly employed without thought (Butterworth, 2003). Our health culture is steeped in the power of

technology, and curative interventions and tendency to deny death (Bryant, 2009). Lynn et al. (2000) suggest our culture of medicine is antithetical to quality care at the EOL; Butterworth writes, “Financial incentives and the curative focus of continuing medical education pressure provision of invasive interventions, while [complex and] palliative care is not significantly compensated” (p.42). Normalizing the discussions of death and dying may be unappealing, but necessary to deal with the increasing prevalence of chronic illnesses and aging population. Access to care incorporating ACP processes and quality end of life experiences have been shown to be feasible in sites across Canada, the United States, and Australia. This requires a shift towards recognizing the value of ACP and the time and resources required to do this work in health care organizations. It may be an easier transition with encouragement and strong policy leadership by the government.

ACP information management is a future area of study involving the transfer of information between health service systems. This includes support and education of clerical staff, to a system of alerts, to understanding the challenges in the transfer of electronic information with vastly different technology and record keeping systems that exist between services. A major reason for ACP not being reviewed and followed by health care professionals can be attributed to failures in the transfer of documents and the location of documents, which can render the documents inaccessible in a health crisis situation (Bricker, Lambing, & Markey, 2003). Health organizations can do better and work towards technology to streamline transfer of documentation.

### **Policy recommendations**

Proponents of ACP need to adopt strategies to convince organizational leadership and policy makers to make policy changes. In British Columbia, professional policy analysts and

citizens were able to lobby government and changes were made to ACP legislation in 2011. Tools such as the *My Voice Workbook* were produced to encourage accessibility and completion of ACP documents. However, since this policy has emerged, uptake and understanding of documentation and process has been slow. Much of the public and clinician engagement efforts have been left to the health authorities, which have differing priorities. Quality EOL care with ACP and GOC imbedded into processes is variable across the province. A more persuasive policy voice from the Ministry of Health with adequate funding of resources towards engagement, education, and leadership could alleviate some of the tensions associated with this provincial initiative.

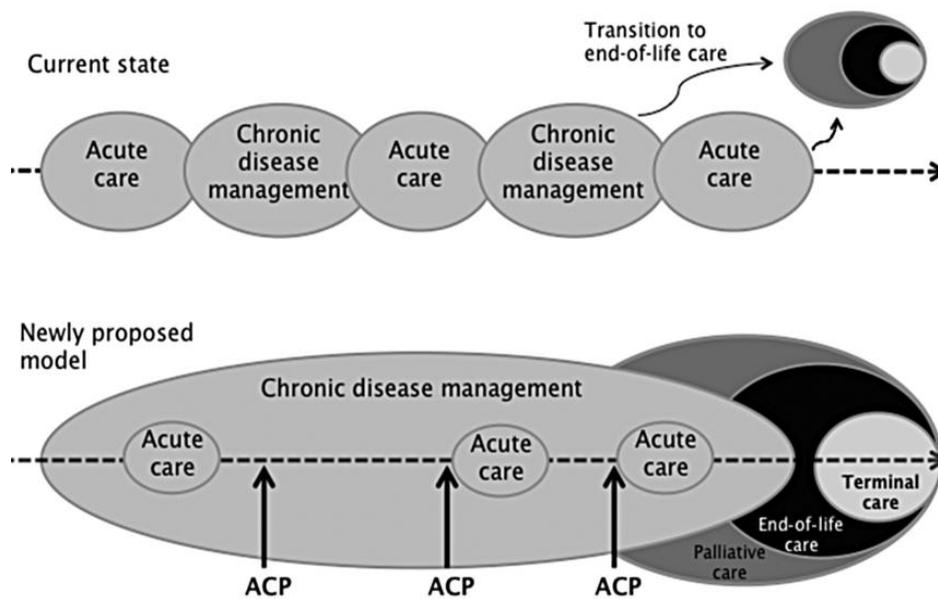
Efforts need to be directed to the Ministry of Health to encourage ACP engagement and consistent GOC documentation across the province. Health organizations, which have the responsibility of receipt and management of documents, also need to fully support the ACP process. Health care providers need to be engaged, should know the legislation and resources available, and understand the fundamental components and underpinnings of ACP. Varying approaches and strategic pressures will be needed to present information to senior management in organizations and government to influence ACP policy.

The lack of ACP can be harmful for patients near the end of life; system redesign and attention on quality improvement should occur. Health care organizations should make it objectionable and unacceptable for clinicians to fail to plan ahead for care when patients are diagnosed with fatal chronic illness. There should be mechanisms and processes in place for reporting the failure to plan for future and complex care needs. Each health care provider should be concerned about having the best available information to assist with appropriate clinical

decision making and to reduce the risk of inappropriate care decisions (Wasylenko, 2012).

Correct, reliable documentation is a challenge.

In the United States, Patel, Jansen, and Curtis (2012, p. 74) propose a model of chronic disease management (Figure 5) where ACP is successfully integrated into health care. This is an ideal of how health care organizations, nurse leaders, and health care teams can support health care decision-making.



**Figure 6: Model of chronic disease management**

ACP should begin at the onset of diagnosis, and reviewed at every stage, normalizing the conversation and ensuring patients goals are reflected and are compatible with the patient's health status.

ACP implementation is a slow process requiring a shift in cultural expectations and an acceptance of discussions around EOL care and the palliative approach. Based on the insights gained from the process of reviewing the literature, I am optimistic of the strides that can be taken. Health care organizations have the power to successfully implement ACP when

stakeholders are engaged and resources committed to the shift in health care culture to prioritizing knowing patient wishes.

### **Recommendation for institutions and health care organizations**

Since the 1980s, federal and provincial governments “have attempted to reduce the role of government in health care and related health policy areas. Few governments appear willing to address inequities in health outcomes” (Bryant, 2009, p.93). Despite successes in nearby health authorities and jurisdictions, governments are less inclined to spend resources and take responsibility to achieve ACP objectives and outcomes. This needs to change, as it is essential for care to shift to better suit patients with chronic disease and complex care needs.

Bravo, Dubois, & Wagneur (2008) showed clinician involvement, education, and training were most effective in patients’ increasing uptake of ACP. This requires organizational support and resources, and shared responsibility for high quality, safe, patient care. As Kirsner (2008) succinctly writes, ACP implementation:

Requires a commitment to quality and safety by the board and management of a health service organization. A culture of openness, mutual respect and teamwork promulgated by the management are also important elements... Clarifying roles and responsibilities are further elements of the process [recognizing] the value of health service user involvement and decision-making (p.91-2).

Organizations need to recognize the benefits of ACP and be committed to creating and establishing ongoing education and training, practice change, and evaluation.

In order to be relevant and important to patients, families, and providers, ACP resources must be user-friendly, affordable, and accessible (Dunbrack, 2006). Health care organizations need to recognize the common complaint of readability around ACP documents. They are

difficult to understand, and the nuances between the different documents confusing. Writing what one wants in formal documents is an unrealistic expectation for many patients and families who are unable to understand the legal templates. Readability especially impacts vulnerable populations (Castillo et al., 2011).

In British Columbia, the *My Voice Workbook* is generally considered to be fifty pages of perplexing language that can be difficult for use by the consumer public (Porterfield & Robinson, 2013). The Institute of Medicare in the United States recommends health materials be written at a 6<sup>th</sup> grade reading level or lower, while most ACP language and mandated legal language are written above a 12<sup>th</sup> grade level (Castillo et al., 2011). Besides patients and their families, physicians and other health care professionals also have had difficulty deciphering these documents. Supports to assist stakeholders in legal understanding are a requirement for ACP engagement to be successful.

Health care organizations should be cognizant of policy trends and research evidence and allocate resources accordingly. GOC documentation should be a solution taken up by health organizations in response to issues of readability and confusing legal terminology as they translate patient wishes to concise medical orders. Documentation should be clear, readable, and readily accessible in the medical chart, to be reviewed with any health change.

The importance of ACP and GOCs is significant when looking at both patient care outcomes and quality of care. GOC designations and documentation are perhaps the companion to make ACP feasible, and the vehicle to normalize conversations between health care providers, patients, and families. To help avoid confusion, leadership at the health organization and government levels should engage stakeholders and begin a working group with the goal towards standard, evidence-based GOC documentation.

## **Implications for nursing**

The nursing profession, and nurse-leaders, can have a strategic role in ACP implementation. Nurses are an important resource and distinct group of stakeholders invested in ensuring patient wishes are implemented. It is an ethical responsibility, according to the Canadian Nurses Association (CNA) Code of Ethics, to be accountable and promote and respect informed decision-making. Nurses are well positioned to exercise leadership in clinical care, and initiate, complete, and revisit ACP with patients. With the privilege of nursing knowledge, clinicians should encourage EOL planning and view ACP as an integral part of chronic disease management. From clinical experience and research, it is recognized planning is least effective in a health crisis or when clear evidence of death or short prognosis occurs (Boyd et al., 2010). Nurses can help find opportunities to assist patients articulate and understand their goals for health care, and appreciate that appropriate care does not limit treatment, but rather reflects the goals of patients.

Literature shows the inclination of health care providers to simply avoid ACP conversations and mistakenly believe it is the responsibility of patients or other health care colleagues to broach the conversation. Nurses must recognize ACP is the responsibility of each individual involved in patient care. Individual nurses in practice are in a position to build relationships and document dialogue and preferences and support patients and families when decisions are to be made. As a guiding principle for nurses who are interested in advocating for greater attention to ACP on their units, Mathie et al. (2011) write:

Within an environment where there is continuity of contact, the opportunity to build relationships and conversations over time, discussion and documenting EOL care preferences can and should be threaded through conversations about what is important...

Advance care planning that documents an ongoing dialogue may be more helpful at the time of decision-making (p.742).

Nurses pride themselves on being patient advocates, and accordingly must recognize the significance of ACP to patients, families, and quality of care. Once staff perceptions shift, nurses can engage, educate, and communicate ACP through proper documentation. Knowing patient priorities and helping convey these preferences should become routine care, and part of “providing safe, compassionate, competent, and ethical care” (CNA, 2008, p.3).

All nurses have the ability to engage stakeholders in the journey towards successful ACP implementation. The following Box 1 highlights actions nurses can take to move towards prioritizing knowing patients’ wishes.

#### Nurses in clinical practice:

- Recognize that Advance Care Planning (ACP) is a legitimate, evidence-based practice, and a way for capable adults to communicate their wishes about future health care decisions.
- Understand legislation around health care consent, ACP and the terminology used, ie. Representation Agreements, advance care plans, Advance Directives, Power of Attorney.
- Ask for continuing education and resources for ACP from educators, leadership, and management. Know where to find ACP resources for patients, families, and health care providers.
- Ask older adult patients, or those with chronic illnesses, if they have thought about who their substitute decision maker would be if they could not speak for themselves and if health care decisions have to be made.
- Encourage patients to think about their wishes before a health crisis and to share these wishes with their families/ substitute decisions makers and health care providers.
- If patients have documents or plans, share these plans with the health care team and store appropriately.
- Advocate for goals of care (GOC) documentation if not in place in the organization.

#### Unit managers and educators:

- Recognize ACP and clarification of GOC as essential to the process of providing patient care.
- Be appreciative of the skill, time and resources it takes to have ACP conversations.
- Help develop guidelines and interdisciplinary team processes for ACP and GOC conversations and documentation.
- Support staff with education and engagement opportunities related to ACP and GOC.
- Monitor and evaluate ACP efforts; outcomes can lead to recommendations and changes to protocols and policies.

#### Nurse leaders

- Engage stakeholders within health care organizations, or within health authorities, in developing ACP policy, resources, tools, and processes, and GOC documentation.
- Call attention to research, literature, and reports about ACP, and advocate for funding for ACP implementation.
- Encourage sustainability through development of quality improvement measures and outcome indicators.

#### Nurse educators and researchers

- Ensure ACP is part of nursing curriculum.
- Consider ACP and quality EOL care as important as newest medical technologies.
- Lead action-oriented research to demonstrate how ACP can be embedded into the care process and develop outcome measures for ACP.

**Figure 7: Recommendations for nursing**

Unit managers should be cognizant of the time and resources needed for ACP to succeed and support staff with education and engagement opportunities. ACP should be encouraged, and efforts recognized and evaluated. The example noted earlier from Australia can serve as a successful model for managers to emulate, with the implementation of the Respecting Patients Choices<sup>®</sup> evaluation tool to provide information for assessment of EOL care achievements and ACP sustainability (Blackford and Street, 2012). Implementing, monitoring, and evaluating ACP practices and outcomes can lead to recommendations and changes to institutional protocols and policies to better support ACP practices (Kirsner, 2008).

Nursing leadership and ownership is likely to be necessary for ACP to move forward. Nurses are involved in patient education and advocacy, holding roles of educator, initiator, facilitator, and liaison with the family unit and health care team (Hinders, 2012). Nurse leaders in at the organizational level can help coordinate multidisciplinary efforts for engagement and development of system infrastructure and tools to facilitate ACP. These leaders have the opportunity to call attention to research and strategies to improve communication between adults, family members, and health care professionals, and advocate for funding and resources. They can engage care settings and coordinate interdisciplinary approaches to focus on patient and family decision-making processes. Current efforts to develop cohesive, evidence-based goals of care documentation to supplement ACP implementation can benefit greatly from nursing leadership. Nurse leaders are able to lead efforts towards policy development and an ACP/ GOC process built into the organizational system. As seen in health authorities with successful ACP/ GOC implementation, nursing can be influential in helping shape, establish and evaluate these system wide approaches.

Nurses involved in education must ensure ACP knowledge is built into the nursing curriculum. As part of the shift in health culture, ACP and quality EOL care needs to be considered a skill as important as learning the newest medical technologies. For example, in British Columbia, educational institutions are beginning to add components of the palliative approach in the curriculum (iPanel, 2013); continuing education opportunities around effective ACP strategies and research should also be explored and pursued.

More nursing specific research should be encouraged around ACP implementation work at the systems level, and focus on where ACP work may be most effectual and resources best utilized. Our care systems are episodic, and investment and investigation into ACP implementation projects would be valuable to discern the most effective way to embed ACP into care processes. The most effective ACP implementation will be system wide, but perhaps the first steps are for nurse leaders to focus on smaller site-specific prototype projects able to show measurable outcomes used to persuade leadership for funding and resources. Further action-oriented research can help explore this knowledge gap around how nursing can best encourage ACP conversations, how to most effectively initiate these conversations to facilitate informed decision making, and evaluate program outcomes.

## **Conclusion**

This thesis illustrates the profound difficulties and numerous components of health care that must be impacted before changes related to ACP can be made in a health organization. Dialogue needs to occur and involve health, legal, and social, public sectors. Successful ACP models and approaches include awareness of quality improvement activities and depend on system wide consumer participation to improve the processes of care.

Nursing has the opportunity to become specialists in this field, and to move ACP and palliative care upstream from acute and EOL health crisis situations. Nurses have the expertise in patient and family centered care, and have the capacity to be leaders in multidisciplinary efforts to improve care for patients with life limiting illnesses. As clinicians committed to tailoring care to meeting peoples' priorities and health needs, it is time to recognize ACP and GOC documents as a necessary standard of care. I echo the sentiments of Lynn & Goldstein (2003):

Ultimately, addressing the errors in [EOL] care does not falter for lack of creative possibilities, but rather from lack of recognition across systems that the care was inappropriate, that the errors harmed the patient and family, and that ensuring patient safety through reliable advance care planning is a priority... The fundamental element needed is commitment to the enterprise (p. 817).

Our critical knowledge originates from reflection and action. This literature synthesis may be useful in helping engage policy makers and stakeholders to appreciate the transformative difference ACP and GOC documentation can make to patient care, and challenge existing policies to value discourse around EOL care.

More current research moves beyond prevalence of ACP completion to patient and family preferences to how to support conversations through illness and prognosis. Similar strides are occurring with literature on professional experience, values, and dynamics within health organizations. Future research needs to further evaluate effective programs, incorporate multidisciplinary perspectives, and continue to demonstrate patient outcomes.

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## Appendix 1: ‘My Voice’ Advance Care Planning Guide Quick Tips (Summary of Legal Terminology in British Columbia)

### My Voice Advance Care Planning Guide Quick Tips

#### Basic Steps for Capable Adults

- 1 Access the My Voice advance care planning guide online at [www.gov.bc.ca/advancecare](http://www.gov.bc.ca/advancecare). If you need help finding the guide online, call HealthLink BC at 8-1-1.
- 2 Think about your beliefs, values and wishes for future health care treatment. Have conversations with family/friends, physicians, and health care providers.
- 3 Write down your beliefs, values and wishes for future health care treatment. Decide what health care treatments you will or won't accept.
- 4 Write down the contact information for the people who could be individually asked to be your temporary substitute decision maker (TSDM) if a health care decision is needed for you.

**Note:** To name a specific person to make decisions on your behalf, see representation agreements below.

#### You have the option of including the following item(s) in your advance care plan:

##### Standard Representation Agreement: Section 7

Allows an adult with lower level of capability to name a representative to make their routine financial management decisions, personal care decisions and some health care decisions. Does not allow the representative to refuse life support or life prolonging medical interventions.

##### Enhanced Representation Agreement: Section 9

Allows you to name a representative to make your personal care decisions and some health care decisions, including decisions to accept or refuse life support or life-prolonging medical interventions. Does not allow the representative to make financial or legal decisions on your behalf (see enduring power of attorney).

##### Advance Directive

Allows you to state your decisions about accepting or refusing health care treatments directly to a health care provider. The advance directive must be followed when it addresses the health care decision needed at the time. No one will be asked to make a decision for you (see exceptions in My Voice guide).

##### Enduring Power of Attorney

Allows you to appoint someone to make financial and legal decisions on your behalf if you become incapable.

(<http://www2.gov.bc.ca/assets/gov/topic/2038E757D68E49D5DC8C3CD0061E8E1B/pdf/advancecareplanningquicktips.pdf>)

## Appendix 2: Methodological Quality According to Sherman's (1997) Maryland Scale, Used in Traditional REAs

Level 1	Observed correlation between an intervention and outcomes at a single point in time. A study that only measured the impact of the service using a questionnaire at the end of the intervention would fall into this level.
Level 2	Temporal sequence between the intervention and the outcome clearly observed; or the presence of a comparison group that cannot be demonstrated to be comparable. A study that measured the outcomes of people who used a service before it was set up and after it finished would fit into this level.
Level 3	A comparison between two or more comparable units of analysis, one with and one without the intervention. A matched-area design using two locations in the UK would fit into this category if the individuals in the research and the areas themselves were comparable.
Level 4	Comparison between multiple units with and without the intervention, controlling for other factors or using comparison units that evidence only minor differences. A method such as propensity score matching, that used statistical techniques to ensure that the program and comparison groups were similar would fall into this category.
Level 5	Random assignment and analysis of comparable units to intervention and control groups. A well-conducted Randomized Controlled Trial fits into this category.

(<http://www.civilservice.gov.uk/networks/gsr/resources-and-guidance/rapid-evidence-assessment/how-to-do-a-rea>)

Addendum: Typical REAs score literature based on the continuum of hard evidence, ranking research by the strength and quality of study. From a critical perspective, this notion is problematic with its concern of quality and rigor. This scoring system leads to gravitation towards excluding qualitative studies, reports and grey literature, as it is not considered strong enough in methodological quality. This literature analysis modifies this process by focusing on systematically answering the questions around ACP implementation, and does not score literature based on the continuum of methodology.

### Appendix 3: A Selection of Literature Reviewed According to Stakeholders

**Table 1: Literature on patients and families**

Author	Year	Methodology	Population	Key findings
Heyland et al	2013	Multisite, prospective study (n= 278 pts, 225 family members)	Elderly patients at high risk of dying in next 6 months and their family members	76% patients (pts) thought about EOL care 12% preferred life prolonging care 48% had completed an ACP 73% had formally named a surrogate decision maker for health care only 30% discussed with family physician only 55% discussed with any member of the health care team -many elderly patients have thought about dying and expressed preferences, but communication and documentation remain inadequate
Patel et al.	2011	Narrative review	Patients with COPD	-due to uncertain prognosis and frequent occurrence of unexpected declines, ACP must be a part of regular care.
Castillo et al.	2011	Critical content analysis	Review of statutes, articles, and legal proceedings	legal barriers to completion -inadequate readability, grade 12 level -unavailable in patients languages -standardization does not allow for alternate religious, cultural, social beliefs -unintended negative consequences and legal restrictions prevent patients, especially vulnerable ones, from communicating EOL wishes -recommendation to eliminate notary/witness requirements

Author	Year	Methodology	Population	Key findings
Mathie et al.	2011	prospective qualitative interviews (n=63)	experiences and expectations of older adults in care homes with limited life expectancy	<p>ability to engage in ACP correlates:</p> <ul style="list-style-type: none"> <li>- with patient's acceptance of being in a care home,</li> <li>- involvement of their family members in making decisions</li> <li>- extent of belief that they can influence decision making within their everyday lives</li> </ul> <p>Findings did not support assumption that living in a care home and observing other residents dying would shape how residents talked about their priorities for EOL care</p> <ul style="list-style-type: none"> <li>-entry to a care facility not a trigger to engage with issues of mortality, life expectancy, and refusal of treatments/ minority of residents able to anticipate their death and talked of explicit plans/ wishes</li> <li>-previous health care knowledge, hospital experience, previous experience of death (friend/ family) associated with being able to articulate what they want to happen at EOL</li> </ul>
Barclay et al.	2011	systematic review and narrative synthesis	adult patients with heart failure	<p>many adult patients with heart failure do not realize the seriousness of their condition or do not wish to discuss EOL issues.</p> <p>Literature shows diverse attitudes towards EOL discussions</p> <ul style="list-style-type: none"> <li>- welcome information, opportunity to discuss fears/ make plans/ put affairs in order reassuring</li> <li>-others rarely think about death/ prognosis/ do not regard EOL issues as relevant/ ill health 'part of growing old'/ prefer professionals to make medical decisions/ enjoy present/ view self as incapable of understanding illness, accept low level knowledge/ avoid subject</li> <li>-mixed and ambivalent views, some awareness but not willing to acknowledge or discuss poor prognosis</li> <li>-patients want conversations- sensitive, honest, with repeated opportunities to talk</li> </ul> <p>fears: may not be able to process information, reluctant to put doctors in uncomfortable positions, will not be given full information</p>

Author	Year	Methodology	Population	Key findings
Alano et al.	2010	Interviews with multiple logistic regression (n=200)	Hospitalized and community dwelling cognitively intact patients >65 years	-barriers to completion: lack education, no one has ever spoken to the patient, patient would rather have health care decisions made for them, procrastination -probability of completing ADs related to requests by health care providers, educational level, exposure to ACP media campaigns
Silvera et al.	2010	Data in the Health and Retirement Study (n=3746)	Adults 60 and older who had died between 2000-2006	Patients who have prepared ADs received care strongly associated with their preferences -subjects with living wills less likely to receive all care possible -subjects with proxies less likely to die in hospital or receive all care possible -critical health care decisions must be made for 43% of older adults around time of death -70% of these pts cannot participate in making these decisions -30% of elderly Americans cannot decide what care they do or do not want at EOL -ACP has significant effect on outcomes on decision making
Heyland et al.	2010	Multicenter cross sectional survey (n=363 pts, n=193 family)	Hospitalized patients with advanced life limiting illnesses and caregivers	EOL care priorities: psychological and spiritual care, planning of care and enhanced relationships with physicians, especially in aspects related to communication and decision making (should be targeted for improvement) areas needing improvement: -feelings of peace -assessment and treatment of emotional problems -physician availability and communication -timely information about patient condition and discussions about use of EOL technology -better planning of care, especially in relation to communication and decision making

Author	Year	Methodology	Population	Key findings
Wright et al.	2010	prospective, longitudinal, multisite study (n=342)	patients with cancer and caregivers	-pts who died in ICU or hospital experienced more physical and emotional distress and worse quality of life -ICU deaths associated with heightened risk for PTSD and prolonged grief disorder for caregivers
Schickedanz et al.	2009	descriptive study, self report measured with open and closed ended questions using quantitative and qualitative analyses (n=143)	adults aged 50 or older	ACP as process: discrete steps of contemplation, discussion, documentation- interventions must address barriers and advance to next ACP step 84% “too healthy” “irrelevant” “leave it in god’s hands/ fate” “hadn’t given it much thought” -assume family and providers know wishes “don’t want to think about death” “am too busy with work or family other barriers: relationship concerns, information needs, problems with forms
Johnstone et al.	2009	Narrative review	People of minority ethnic backgrounds, core principles of ACP	Cross cultural implications and considerations: -choices at EOL decision making more related to ethnicity and culture than age, education, socioeconomic status -culture has profound influence on how pts perceive, experience, practice health -ACP completed less frequently in minority cultural and linguistic populations -prefer family/group decision making and regard ADs as intrusive legal mechanisms interfering with their responsibilities as family members to care for loved ones -family centered model of decision making less likely to believe patient should be told about the diagnosis, family to make decisions around EOL care -less trusting of health care policies and system -cultures have strict taboos surrounding what is and is not appropriate to discuss- illness as punishment/ plans for EOL care a portent of death

Author	Year	Methodology	Population	Key findings
Garrett et al.	2008	Multicenter longitudinal study (n=2564)	Adults aged 65 or older with cognitive impairment	Relationship between demographic and health predictors and three outcomes: thought about, discussed, or formalized eol preferences. -ACP execution a multistage process.
Wright et al.	2008	Prospective, longitudinal cohort study (n=332)	Patients with advanced cancer and their informal caregivers	- EOL discussions not associated with higher rates of depression or worry - EOL discussions associated with lower rates of ventilation, resuscitation, ICU admission, and earlier hospice enrollment -more aggressive medical care associated with worse patient quality of life and higher risk of depressive disorder in caregivers, worse bereavement adjustment
McCarthy et al.	2008	prospective, observational cohort study (n=220)	community dwelling very elderly adult ages 84-100	-69% discussed wishes for medical care with someone -17% discussed wishes with a physician or health care provider -2/3 had proxy -55% living will -41% had both -vast majority prefer comfort measures -many willing to enduring specific life prolonging interventions and distressing health states to avoid death
Newman-Giger et al.	2006	Narrative review	Assumptions of values related to EOL care	cultural taboos surrounding what is and is not acceptable to speak about -illness // punishment; discussions around diagnosis and prognosis forbidden -illness // test of faith and aggressive treatment and care indicated -ethnic minorities have different values and ideas about health care and dying process Ethics: do not harm// life prolonged at all costs vs. autonomy and rights to refuse treatment -core values of ACP and Patient Self Determination Act: autonomy, informed decision making, truth telling, control over dying process

Author	Year	Methodology	Population	Key findings
Heyland et al.	2006	multi site questionnaire (n=440 patients, 160 family)	hospitalized older patients with advanced cancer and chronic end stage medical disease	key elements of quality EOL care: -trust in treating physician -avoidance of unwanted life support -effective communication -continuity of care -life completion variation in perception indicates need for individualized approaches
Freer et al.	2006	prospective study (n=508)	adult ambulatory patients at internal medicine clinical sites	- 86% unfamiliar with term AD -93% familiar with specific kind of AD -43% claimed to have AD -25% thought provider had copy -documents often not in chart and of little help if needed -correlation of AD completion varied with educational level and literacy (those with limited education likely to feel vulnerable and disadvantaged with terminology)
Knauff et al.	2005	Cross sectional study (n=115)	Patients with oxygen dependent COPD	Patient related barriers -assume clinicians will initiate ACP when needed -lack education -assume deterioration normal part of ageing vs disease deterioration -poor medical literacy
McAdam et al.	2005	descriptive, correlational, cross sectional study with convenience sample (n=22 pts, 22 family)	critically ill Filipino Americans	-more education had more positive attitudes -only 28% had prior knowledge of ACP -Filipinos may view illness as inevitable, the will of God, and follow the advice of an authoritarian person or head of family -strong filial piety, obligation of family members to care for the sick -pts assume passive role and expect family assistance

Author	Year	Methodology	Population	Key findings
Azoulay et al.	2005	longitudinal study, interviews (n=284)	family member with decision making role of ICU pt	-higher rates of PTSD found in family members who felt information incomplete, who shared in decision making, and whose relative died in the ICU, whose relative died after EOL decisions -33% family members of ICU pts showed post traumatic stress reaction -goal of family centered care to reduce the risk of stress reactions to the traumatic ICU experience
Coventry et al.	2005	systematic review	older adults with non-malignant life threatening disease	-strong evidence of unmet symptom control, psychosocial and family support, informed and open communication and choice at EOL -determining prognosis/ palliative status/ need for ACP more complicated in life threatening non malignant disease without clear trajectory -attempts to predict survival and identify patients appropriate for palliative care impractical and unrealistic -difficult to accurately predict <6 month survival in non cancer patients
Briggs et al.	2004	Experimental design (n=27 patient-surrogate pairs)	Patients in heart failure, renal, and cardiovascular surgery clinics	-1 hour patient care ACP interview indicated that congruence in decision making for future medical treatment in patient-surrogate pairs in intervention group significantly higher than control group -greater satisfaction with decision making process -less decisional conflict demonstrated in treatment group
Kahana et al.	2004	Longitudinal study, interviews (n=231 patients/ 99 physicians/ 127 caregivers)	Community dwelling older adults age 65-99	-fewer than half had executed AD and discussed wishes -characteristics associated with EOL planning: Caucasian, unmarried, younger adults -health status did not related to tendency to have ACP -families much more likely to report knowledge of ACP than physicians -most physicians not informed about older pts ACP -not having intimate partner encourage // more likely to initiate EOL discussions with other family members -younger individuals more likely to be proactive consumers

Author	Year	Methodology	Population	Key findings
Schwartz et al.	2002	Quantitative-pilot trial (n=61)	Ambulatory geriatric	ACP with trained facilitator= - Higher congruence between agents and patients in understanding of patients' EOL care preferences - greater increase in patient knowledge about ACP -patients less willing to undergo life sustaining treatments for new serious medical problems - more willing to undergo treatments for incurable progressive disease - less willing to tolerate poor health states
Douglas & Brown	2001	convenience sample (n=30)	hospitalized patients	-moderately positive attitudes about ACP -attitudes do not determine who will and will not complete ACP. Most who have completed have specific reasons for doing so demographics for completion: Caucasian, female, over 65, had less than a high school education, perceived health as poor
Crawley et al.	2000	Narrative review	African American community	-distrust of health care institutions and fear documenting they do not want life prolonging medical treatments result in poor medical care -passage to death something to be endured, consistent with faith, rather than something technologically and medically determined
Lovera et al	1999	Prospective cross sectional study (n= 476)	Tertiary care academic medical center emergency department	77% pts did not have ADs Frequent reasons for not having AD: never thought about it, preferred family to make decisions, procrastination Factors predictive of having AD: older age, having a specialist, having a life threatening medical problem, not being catholic Patients who had ADs only discussed with primary care physicians 5% of the time

Author	Year	Methodology	Population	Key findings
Hammes & Rooney	1998	Retrospective (n=540)	Community based	Community educational outreach and facilitated discussion Completed ACP increased from 15% to 85%. -96% documents readily available in medical record -98% patients wishes followed -ACP to be revisited periodically
Singer et al.	1998	Qualitative interviews (n=48)	Patients undergoing hemodialysis	-traditional academic assumptions around autonomy not as supported by patient perceptions -benefits of ACP include preparation for EOL care, avoidance of prolongation of dying, strengthening of personal relationships, relieving burdens placed on family, informal communication of future wishes, social process -ACP does not occur solely within the context of physician patient relationship, but also within relationships of loved ones
Nolan & Bruder	1997	descriptive study (n=34)	medical inpatients , 18 years and older	-positive perception of ACP as opportunity for treatment choices -majority indicated families would want them to have an advance directive and prevent costly medical expenses and prevent guilt over treatment decisions -96% believe ACP should be discussed when patient is healthy
Teno et al. (SUPPORT)	1997	Observational cohort study (n=9105)	Seriously ill patients, multisite hospitals	Patient education and documentation, nurse facilitated communication -no evidence intervention enhances effect of AD on measures of resuscitation decision making -AD did not substantially enhance patient-provider communication or decision making -patterns indicate increasing frequency of AD unlikely to be substantial element in improving care of seriously ill patients

**Table 2: Literature on health care providers**

Author	Year	Methodology	Population	Key findings
Schonfeld et al.	2012	pilot qualitative study with focus groups (n=32)	physicians experiences in conducting EOL conversations with elderly patients suffering from multiple comorbidities	<p>themes:</p> <ul style="list-style-type: none"> <li>-discomfort to have EOL conversations with pts with MCM vs. those with single, terminal diagnosis</li> <li>-rely on pt prompts (physical or social) yet lack of clear threshold or prompting event</li> <li>-lack of good communication tools contributes to physician discomfort</li> </ul>
Rhee et al.	2012	qualitative descriptive interviews (n=23)	key informants, expert clinicians, and representatives of key stakeholder organizations	<ul style="list-style-type: none"> <li>-prevailing attitude where prolongation of life valued, and death a failure</li> <li>barriers to ACP implementation</li> <li>-lack of continuity of care</li> <li>-paternalistic attitudes</li> <li>-absence of standardized electronic medical records system allowing timely retrieval of ACP documents and medical information</li> <li>-lack of understanding legal validity and difficulties interpreting documents</li> <li>-inherent uncertainty involved in planning for future- uncertain, unpredictable, complex health care</li> <li>-access to ACP documents</li> <li>-unclear or nonspecific documents</li> </ul>

Author	Year	Methodology	Population	Key findings
Livingston et al.	2011	qualitative study (n=58)	staff at a nursing care home	<ul style="list-style-type: none"> <li>-care staff, nurses and doctors not a cohesive team</li> <li>-unaware of or had concerns about validity of advance care plans</li> <li>-lack of knowledge and belief in advance plans, vague, contradictory answers</li> <li>-fear blame and ACP can be invalidated</li> <li>-feel they would be blamed for message, and vulnerable in a foreign society</li> <li>-avoided conversations to protect residents from upset</li> <li>-death as taboo</li> <li>-feelings of inappropriateness to talk with residents about dying</li> <li>-worries about accuracy of information relayed to relatives</li> <li>-education and support about discussing and implementing plans around care at EOL and cultural issues required</li> </ul>
Au et al.	2011	questionnaires, cluster-randomized (n=92 clinicians, 376 pts)	clinicians and patients	<ul style="list-style-type: none"> <li>-clinician awareness of patient barriers can improve communication around EOL care</li> <li>-higher quality EOL communication in intervention arm</li> </ul>
Barclay et al.	2011	systematic review	healthcare professionals	<ul style="list-style-type: none"> <li>clinicians unsure how to discuss uncertain prognosis and risk of sudden death</li> <li>-fear causing premature alarm/ destroy hope/creating anxiety and depression, causing patients to give up fight for life</li> <li>-prediction of time of death almost impossible, confounding prognostic models/ uncertain disease trajectory</li> <li>-clinicians wait for cues from pts/ reluctant to address EOL issues; consequently conversations do not take place</li> <li>-doctors focus on medical management rather than future/ approach illness as problem to be fixed vs. terminal illness</li> <li>-all agree pts have right to be informed of prognosis, yet want to avoid giving bad news- struggle balancing frightening pts with underplaying condition</li> <li>-ethical balance between beneficence and non-maleficence, autonomy</li> <li>-discomfort with broad issues of death and dying disrupts communication</li> <li>-interventionist culture, danger that issues of EOL care only considered too late in illness</li> </ul>

Author	Year	Methodology	Population	Key findings
Boyd et al.	2010	mixed methods evaluation of a pilot educational intervention implementing ACP (n=28)	GPs, community nurses (central role in offering ACP to larger numbers of community dwelling adults)	<ul style="list-style-type: none"> <li>-general support of principles of autonomy and individualized prognosis</li> <li>-clinicians have limited understanding of ACP as defined in policies</li> <li>-clinicians do not practice ACP components in a structured way, unable to articulate components of ACP in cohesive or consistent way</li> <li>-barriers: prognostic uncertainty, limited liaison with hospital/specialty services, experience of hospitals focusing on treatment even with pt deterioration</li> <li>-hard to introduce ACP with “inappropriate positive messages from the hospital” (p.e452)</li> <li>-fear of destroying positive coping strategies</li> <li>-ambivalent about ACP benefits</li> <li>-written documentation “tick box”</li> <li>-do not routinely practice or document ACP process</li> <li>-difficulty with terminology, related activities and formal processes</li> <li>-concern of dangers of externally imposed, monitored system</li> <li>-common perception ACP irrelevant to current personal circumstances</li> <li>-difficulty contemplating serious illness/ fears about premature treatment withdrawal</li> </ul>
Hancock et al.	2006	systematic review	adults in advanced stages of life limiting illness	<p>EOL prognostic/communication</p> <ul style="list-style-type: none"> <li>-health care professionals tend to underestimate pt and carer information needs and overestimate understanding and awareness</li> </ul>
Knauf et al.	2005	Focus groups in cross sectional study (n=115)	patients with oxygen dependent COPD and their physicians	<p>Barriers to ACP</p> <ul style="list-style-type: none"> <li>-unique disease trajectory with obscure transitions to EOL</li> <li>- poor recognition ACP should begin early</li> <li>- false belief patients with advanced COPD would not want treatment limitations</li> <li>- false belief ACP leads to anxiety, depression, and take away hope</li> <li>-ICU/ inpatient poor environment for ACP</li> <li>-inadequate clinician training</li> </ul>

Author	Year	Methodology	Population	Key findings
Morrison et al.	2005	Intervention study, controlled clinical trial (n=139)	Long term care residents	<p>Multicomponent ACP intervention directed at social workers</p> <ul style="list-style-type: none"> <li>-intervention residents more likely to have preferences regarding resuscitation, nutrition, and hospitalization documented on the chart</li> <li>-higher concordance between pts wishes and treatments received</li> </ul> <p>barriers: physician lack of understanding, erroneous beliefs about appropriateness, discomfort with the patient, time constraint, compensation concerns in fee for service system discouraging lengthy office visits</p>
Wissow et al.	2004	prospective quasi-experimental trial with ACP intervention (n=2120)	individuals 65 and older with a health maintenance visit with primary care provider/ provider follow up survey	<p>provider reluctance despite reminders, access to materials, and focus on extended length, preventive focused visits:</p> <ul style="list-style-type: none"> <li>-passive exposure to materials not sufficient, active modeling and practice of new skills required</li> <li>-lacked time to discuss ACP, despite availability of extended health maintenance visits</li> <li>-need to provide guidance to pts who had difficulty understanding, and questions around who in the health care system best suited to discuss</li> <li>-low literacy pts, or not familiar with concepts needed more than simply explanation</li> <li>-elaborate explanations went beyond responsibility</li> <li>-responsibility of patients/ organization/ clinic management to raise subject</li> <li>-lack skills related to talking about ACP</li> </ul>

**Table 3: Literature on health care organizations**

Author	Year	Methodology	Population	Key findings
Heyland et al	2013	Multisite, prospective study (n= 278 pts, 225 family members)	Elderly patients at high risk of dying in next 6 months and their family members	-agreement between patients' expressed preferences for EOL care and documentation in medical record: 30.2%
Blackford & Street	2012	multisite action research approach	community palliative care programs	ACP service evaluation tool - useful for nurse managers with clear outline of service progress, level of achievements, and direction for planning changes -enable nurses to monitor, evaluate, and plan quality improvement of ACP model to improve EOL care -domains for establishment, consolidation, and sustainability: governance, documentation process, education, practice, quality processes, community engagement
Rhee et al.	2012	qualitative descriptive study (n=23)	key informants, expert clinicians, representatives of key stakeholder organizations with interest in eol care	-inadequate awareness -societal reluctance to discuss EOL issues -lack of health professionals' involvement in ACP -difficulties accessing ACP documents, interpreting written documents, making binding decisions for future unpredictable situations -paternalistic attitudes of health professionals -system wide implementation of multifaceted interventions and flexible pt centered approach -ACP as process by pts vs. discussions by health professionals to better understand pt values and goals for quality care

Author	Year	Methodology	Population	Key findings
Barclay et al.	2011	systematic review	adults with heart failure and clinicians- low levels of agreement	<ul style="list-style-type: none"> <li>-discrepancy between groups regarding perception of information exchanged/ reliability of clinician reports and adequacy of form and content in which providers discuss EOL care</li> <li>-growing tension between active management and need to communicate uncertain/ poor prognosis</li> <li>-conversations recommended to be offered at all stages of disease trajectory</li> <li>-beneficence and non maleficence vs. autonomy- recognizing right to make informed choices about care</li> <li>-palliative approach: philosophy vs. care delivery with specialists and hospices- approach to support pts through illness to EOL</li> </ul>
Detering et al.	2010	prospective RCT (n=309)	competent medical inpatients aged 80 or more	<ul style="list-style-type: none"> <li>primary outcome: -pt's EOL wishes known and respected (86% vs 30%)</li> <li>-family members of pts who died had significantly less stress, anxiety, and depression</li> <li>-ACP increased pt and family satisfaction</li> </ul>
Tamayo-Valazquez et al.	2010	systematic review	AD interventions	<ul style="list-style-type: none"> <li>-passive informative materials in isolation do not increase ACP</li> <li>-interactive informative interventions with multiple sessions between pts and health care providers most effective (combination of informative material and repeated conversations)</li> </ul>
Yung et al.	2010	structured interview and medical record data from previous studies- Assessing Care of Vulnerable Elders (n=245/ n = 566)	community dwelling adults age >65 with high risk death/ functional decline/ age > 75 with positive falls, incontinence, dementia	<ul style="list-style-type: none"> <li>-comprehensive assessment of continuity of ACP information through multiple healthcare settings.</li> <li>-community dwelling older adults preferences for EOL care not consistent with documentation in medical records</li> <li>-translation of EOL preferences into ACP documentation poor ?lack of discussion + failure to document</li> <li>-electronic health records and standardized data collection needed to ameliorate problems</li> </ul>

Author	Year	Methodology	Population	Key findings
Bravo et al.	2008	systematic review and multilevel analysis	older adults	health care professionals' involvement, education, and training most effective in increasing uptake of ACP vs. educational interventions at patients least effective
Marchland et al	2006	qualitative study, grounded theory (n=24)	key informant interviews in La Crosse	-elements of successful programs to promote completion and support meaningful discussions and honour ACP when executed: commitment (need for leadership, recruitment of key members and funding), cohesiveness (disparate groups collaborating towards common purpose), and outcomes/ evaluation process
Wissow et al.	2004	prospective quasi-experimental trial with ACP intervention (n=2120)	individuals 65 and older with a health maintenance visit with primary care provider	-intervention- physician education and prompts resulted in 20 fold increase in odds of creating a new advance directive (modest increase from <1% to 7.8%) -difficult to produce written material addressing wide range of literacy and knowledge needs -no measures of medical severity (admission to hospital, emergency visits, 3 chronic conditions) related to ACP completion
Lynn & Goldstein	2003	case study	ACP in patients with eventually fatal chronic illnesses	-failure to treat symptoms adequately at EOL a serious medical error -documented plans should be available and understood across settings -emergency care providers should regularly ask about ACP -enrolling or leaving any program of health care should routinely involve reviewing and documenting ACP -facilities should audit rates and work -payers could compensate at a higher level for those achieving goal -various programs do not communicate with each other, nor take responsibility for measuring and achieving excellent care across settings -proper course of care can save money and pt and family from "suffering and abrogation of self determination" (p816). -regulations, financing, and service delivery arrangements must improve

Author	Year	Methodology	Population	Key findings
Malloy et al.	2000	RCT (n=1292)	residents in nursing homes	Let Me Decide systematic implementation of program -educating staff, residents, and families re: range of health care choices -intervention groups reported fewer hospitalizations per resident, and less resource use -no change in satisfaction -increase use of ACP reduces health care utilization without affecting satisfaction or mortality
Dexter et al.	1998	RCT	patients 75 and older	Computer generated reminders resulted in 15% completion vs. 4% in control group with doctors who did not make reminders
Cugliari et al.	1995	quantitative (n=419)	patients who are admitted for a planned admission to tertiary care	meeting information needs by distribution of ACP resources prior to planned hospital admission increases completion of proxy forms
High	1993	Intervention study (n=293)	Community dwelling populations of older people	predominantly white, low income population -educational material, free legal assistance -knowledge and use associated with race and education levels -common reason for non-use: deferring to others, putting it off intervention strategies to increase use of ACP -printed materials alone did not promote creation of ACP -group meeting resulted in 25% participants making a living will