Person Focused Directives for End of Life Care in Long Term Care (PFD-LTC)

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Prepared by: S. Kathleen Bailey, M.A., (PhD Candidate)

Department of Psychology

Faculty of Health and Behavioural Sciences, Lakehead University

Thunder Bay, Ontario, Canada

Dissertation Supervisor: Gordon Hayman, Ph.D

Internal Second Reader: Michael Stones, Ph.D

Internal Reviewer: Mariette Brennan, Ph.D, Faculty of Law

External Reviewer: Trevor Smith, Ph.D, Nipissing University

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Helen “Shirley” Friday, 1925 - 2014

My grandma began every prayer with “Thank You.”

And her gratitude was contagious, not just because of how fun she was to be around or her smile, but because she delighted in sharing the things she was thankful for with her friends and family, and I think most importantly, because she told you that she was thankful, and she told you why.

Among the things my grandma was thankful for were her five grandchildren. She has a favourite grandson, Cameron, in the city of Washington, another favourite grandson, Graham, in Texas, a third favourite grandson, John, in Terrace, British Columbia, and then a favourite granddaughter, Friday, in Salmon Arm, British Columbia, and geography made me the luckiest favourite because I got to be the local favourite.

Proximity meant that I got to spend a lot of time learning about gratitude with grandma, especially over the last couple of years. We were thankful together on a number of occasions for prime rib with Yorkshire pudding, thankful for fish and chips with mushy peas, thankful for grilled cheese sandwiches; we were definitely thankful for a lot of ice cream and cookies, and thankful for the occasional glass of wine. Grandma never met a food she was not thankful for.

But even more than ice cream, my grandma valued kindness- it made her happy to give it and it made her even happier to see the people she loved display it. She was a productive, capable, and generous woman her whole life, and although she saw nothing remarkable about these characteristics in herself, it would be rare for her to miss an opportunity to point out how impressed she was by even the smallest displays of thoughtfulness or compassion in others. I cannot count the number of times she taught me kindness by telling me stories of the kindness and selflessness of others- be it her mother lending their telephone to a neighbour on Lark Street, or a couple here at Corpus Christi making space for her between them when she came for mass.

She was also a stickler for good grammar; I know all five of her favourite grandchildren are so thankful for that now that we are grown up. She wanted the best for us, and she wanted us to be able to communicate it effectively. She told us to take trips, which we all do, and to engage kindly with the world and all the people and pets in it, which we try our best to do.

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Table of Contents

List of Tables

List of Figures

Abstract

Dementias are age-related, neurodegenerative diseases, the cases of which are expected to rise exponentially as the population ages. To date there is no known cure or intervention that appreciably slows the progression of disease. One in ten Ontarians aged 65 and older is currently living with a dementia, and many of them will move into long term care (LTC) as the disease progresses. Advance care planning (ACP) can extend a person's wishes concerning health care decisions in the event they lose capacity. ACP is especially relevant for LTC residents with dementia because of the resulting cognitive decline, poor health outcomes, and eventual loss of the ability to communicate. To meet its intended goals, ACP needs to be informed and documented using unambiguous language. ACP documentation too often does not meet this standard, and can vary considerably between facilities. LTC residents dying with dementia may be particularly vulnerable to not having their wishes known or honoured. Little is known about how variability in ACP documentation can affect patient care at the end of life (EOL), or whether the presence or absence of dementia presents an added risk for having insufficient ACP.

Study One investigated variability in ACP documentation between facilities and compared existing local documents to best practice principles for documenting ACP. Study Two gathered information on the experiences and perceptions of care providers who work with older adults regarding ACP documents, and their opinions on introducing a common language to ACP documentation across facilities. Study Three utilised generalised linear mixed modeling (GLMM) to investigate whether ACP documentation would equate to differences in the EOL care received by residents of LTC across the province of Ontario, and whether the presence or absence of dementia would play a role in end of life decision making (i.e., place of death). Province-wide data from LTC residents who entered and died in LTC over one census year with

a thirteen month follow-up was analysed for relationships between place of death and documentation related to ACP.

Results from study one verified that ACP documents across settings were of low quality when compared to ACP best practices and often did not meet legal requirements in this jurisdiction. Additionally, ACP documents were identical across all participating LTC facilities and organisations. Study two demonstrated that there was some variation in the perceptions and experiences of health care workers. Information provided by workers with significant experience using ACP documents yielded the following themes: not speaking the same language, confusion/inconsistency, support for standardisation, and ACP documents as barriers to care. There was substantial local support for standardising the language of ACP across settings as a means of easing communication and providing appropriate patient care. Study Three demonstrated that ACP is uncommon in LTC according to the documentation available, but when present, ACP does appear to have an effect on place of death. Those with more advanced symptoms and impairment were more likely to have ACP-like orders in place and to die in the LTC home compared to outside of the LTC care home (e.g., acute care, emergency care). Despite advancements such as the Ontario Dementia Care Strategy, which emphasised the development of quality ACP practices in LTC, implementation of ACP remains elusive and poorly understood. Health care providers at all levels (e.g., directors, nurses) supported the need for change and improved ACP practices. Re-examining ACP-related legislation as well as improving access to ACP practices in LTC settings could improve EOL care for older adults living in LTC. Development of a Person-Focused Directive model for LTC (PFD-LTC) that meets the needs of LTC residents, their families, health care providers and institutions, law-makers, and the public is encouraged.

Person Focused Directives for End of Life Care in Long Term Care (PFD-LTC)

Introduction

Dementia is a significant cause of mortality (Todd, Barr, Roberts, & Passmore, 2013) and a leading cause of morbidity, disability, and healthcare spending (Luengo-Fernandez, Leal, & Gray, 2010). Dementias are age-related, neurodegenerative diseases, the cases of which are expected to rise exponentially as the population ages. In 2008, it was estimated that nearly half a million (500,000) Canadians were living with dementia. The population is rapidly ageing in Canada as elsewhere. Approximately 16% of Canadians are aged 65 and over (Statistics Canada, 2016), a number that is expected to rise to 25% by 2036. The Alzheimer's Society of Canada projected that over 1.1 million Canadians could have dementia by 2038 (2010). It is estimated that 228,000 Ontarians are currently living with dementia, rising to 255,000 over the next three years, and to 430,000 Ontarians by 2038 (Government of Ontario, 2016). Dementia has no cure and there are no treatments as of yet that appreciably slow the progression of disease (Rabins, Rovner, Rummans, Schneider, & Tariot, 2017). Death with dementia, therefore, does now and will continue to characterise the end of life (EOL) experiences of many patients, their caregivers and health care providers.

Nearly one quarter (24.4%) of Ontarians spend time in LTC as they approach the EOL (Tanuseputro, Wodchis, Fowler, Walker, Bai, Bronskill, et al., 2015). Dementia is the commonest factor precipitating a move to some form of assisted living or long term care (LTC), with recent Canadian studies showing the presence of dementia in between 60-90% of people entering these facilities (Brazil, Maitland, Walker, & Curtis, 2013; Rockwood, Richard, Garden, Hominick, Mitnitski, & Rockwood, 2014). Residents of LTC are therefore at increased risk for

dying with dementia compared to the general population. Advanced care planning (ACP), "the development and expression of wishes for the goals of medical treatment and the continuation and discontinuation of such treatment and care," (Canadian Hospice Palliative Care Association, 2012), can improve quality of life during dying by extending a person's wishes concerning EOL health care decisions beyond the time when they lose their capacity to express them. ACP is especially relevant for LTC residents with dementia because of the resulting cognitive decline, poor health outcomes, and eventual loss of the ability to communicate.

While issues of decision making competency can arise for anybody at any age, cognitive impairment is a defining symptom of dementing illnesses, making communicating wishes and preferences for EOL care all the more important. Having a documented and accessible advanced carepPlan that is easily and reliably interpretable by family and health care workers who were not involved in its preparation is an essential component of ACP (Alfonso, 2009; Detering, Hancock, Reade, & Silvester, 2010; Silvester, Parslow, Lewis, Fullam, Sjanta, Jackson, 2013). For people with a dementia and their care providers, effective ACP is a necessity for ensuring a person's wishes are carried forward and honoured at the EOL. While attempts to increase the use of ACP in LTC have been numerous, implementation has been imperfect, with evidence showing significant between- and within-facility differences in the quality of ACP documentation, when it exists at all (Sommer, Marckmann, Pentzek, Wegscheider, Abholz, & in der Schmitten, 2012; Silvester, Parslow, Lewis, Fullam, Sjanta, Jackson, et al. 2013; Gunter-Hunt, Mahoney, & Sieger, 2002). To date, no one has examined how institutional differences in ACP documentation in LTC has impacted clinical decision making at the EOL, and whether ACP documentation differentially impacts residents with a dementia.

Dementia Subtypes and Diagnosis

The clinical determinants of dementia are incompletely understood. Alzheimer's disease and vascular dementia are the two leading forms of dementia (Goodman, Lochner, Thambisetty, Wingo, Posner, & Ling, 2017), with the combination of these two pathologies (i.e., mixed dementia) also ranking very high for prevalence (Anor, O'Connow, Saund, Tang-Wai, Keren, & Tartaglia, 2017), particularly among the oldest old (Kawas, Kim, Sonnen, Bullain, Trieu, & Corrada, 2015). Other etiological subtypes of dementia included in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013; subsumed under Neurocognitive Disorders) are frontotemporal neurocognitive disorder, Lewy bodies, traumatic brain injury, Parkinson's disease, HIV infection, Huntington's disease, prion disease, another medical condition, and multiple aetiologies.

Studies examining the association between brain pathology and behaviour revealed that the relationship is not consistent across subtypes. For example, Alzheimer's disease often presents with greater memory impairment than executive functioning impairment, compared with equal amounts of cognitive impairment across domains (verbal memory, nonverbal memory, and executive function) commonly (but variably) seen in vascular dementia. This variability begs the question of whether executive impairment is actually a useful diagnostic marker for vascular dementia (Reed et al., 2007). A review of recent evidence demonstrated that Alzheimer's disease and vascular brain injury make additive, independent contributions to cognitive dysfunction in dementia, and it was argued that these diagnostic classifications are oversimplified (Chui & Ramirez-Gomez, 2015). Even the most advanced models currently available only predict around 40% of the variance in cognitive performance seen in people with dementia (Chui & Ramirez-Gomez, 2015; Launer, Hughes, & White, 2011).

Vascular dementias, in contrast with Alzheimer's disease, show considerable variability in its neuropsychological and neurophysiological profiles. Magnetic resonance imaging (MRI) and computerized tomography (CT) are currently the most reliable marker for vascular brain injury, however cognitive impairment is more closely related to the presence of microinfarcts in neuropathology (autopsy) studies, which are undetected from imaging (Chui & Ramirez-Gomez, 2015). Alzheimer's neuropathology is thought to be characterised by the presence of beta-amyloid plaques and tau-related neurofibrillary neurodegeneration (tangles), which spreads outward from the medial temporal lobe. Beta-amyloid imaging techniques can be used to increase the certainty of an Alzheimer's diagnosis, but is not diagnostic in isolation. Atrophy in the hippocampus is another known marker for Alzheimer's disease.

A multimodal approach, which includes repeated neuropsychological and cognitive testing in addition to imaging and fluid biomarkers (e.g., cerebral spinal fluid) is recommended for diagnosis of dementia and differentiating among subtypes and stages (Jack, Albert, Knopman, McKhann, Sperling, Carrillo, et al., 2011; McKHann, Knopman, Chertkow, Hyman, Jack, Kawas, et al. , 2011; Albert, DeKosky, Dickson, Dubois, Feldman, Fox, et.al., 2011; Martinez-Torteya, Trevino, & Tamez-Pena, 2015), however many clinicians do not have access to the training and technologies necessary to implement this approach. The most commonly used criteria for the clinical diagnosis of dementia were established more than 30 years ago (McKhann, Drachman, Folstein, Katzman, Price & Stadlan, 1984) and have been shown to have sensitivity and specificity that are less than ideal and may lead to misdiagnosis in up to 20% of cases (Blennow & Hample, 2003). Given the state of current diagnostic practices and knowledge, the literature review did not differentiate between dementia subtypes; however, subtyping was retained when specified in the reviewed literature.

Dying with Dementia

Dementia can be recorded on a death certificate as the sole cause of death, but is often listed as an underlying condition. The later stages of dementia are characterised by progressive memory loss; increased loss of physical abilities such as walking, eating, dressing, and continence; increased difficulty communicating, for example they may not understand what is said, lose their speech, or repeat the same vocalisations or even cry out words or sounds; and problems with eating and swallowing that can contribute to significant weight loss (e.g., apraxia for mastication and swallowing, loss of interest in food, loss of awareness of hunger). Frailty associated with late stage dementia increases susceptibility to infections and other physical problems so that the actual death of a person with dementia might be hastened or directly caused by another acute condition, commonly pneumonia (Brunnstrom & Englund, 2009; Russ, Starr, Stamatakis, Kivimaki, & Batty, 2015).

The number of deaths attributed to dementia on death certificates is rising, while other causes of death are declining. For example, between the years 2000 and 2010, the age-adjusted death rates for cancer, heart disease, and stroke in the United States each fell by between 30% and 36%, while the death rate for dementia rose by nearly 39%, (Tejada-Vera, 2013). In Australia, where Alzheimer's disease was the third leading cause of death in 2012, incidence rose by 142.5% over a decade (Australian Bureau of Statistics, 2014). In Canada, Alzheimer's disease was the seventh leading cause of death from 2000 to 2011 (Statistics Canada, 2012; Statistics Canada, 2014). Between 2000 and 2009, the number of deaths in Canada attributed to Alzheimer's disease increased by 25.4% (Statistics Canada, 2012). Beeri and Goldbourt's (2011) six-year study examined n=718 deaths in a cohort of N=1713 men who had participated in a longitudinal study and been evaluated for dementia. During follow up, 71.8% of those with

dementia and only 35.4% of those without dementia died, for a hazard ratio of 2.27 (95% CI: 1.92-2.68) for the men with dementia. Midlife sociodemographic (socioeconomic status) and cardiovascular (blood pressure, ever smoking, cholesterol) risk factors did not interact with the presence of dementia to affect mortality, leading the authors to conclude that dementia is an independent risk factor for death. There has been a disproportionate increase in morbidity from dementia and other neurological disorders compared with other age-related disorders globally over the last two decades (Pritchard & Rosenorn-Lanng, 2015).

Clinicians and family members often overlook dementia as a cause of death, and people who die with dementia infrequently receive adequate EOL care (Sachs, Shega, & Cox-Hayley, 2004). Clinical decisions made at the EOL, such as whether to initiate life-sustaining treatments like ventilation and feeding tubes, or to transition to comfort care and allow a natural death, have significant and lasting consequences for patients, families, clinicians, and all levels of the health care system. When treatment providers fail to recognise or communicate to substitute decision makers when a patient is dying, EOL decisions are not fully informed decisions. Several lines of evidence show that there is significant inconsistency in medical decision making. Variability in clinical decision making in EOL when a patient dies with dementia may in part stem from variability in recognising the dying patient and from systemic barriers to fully informed EOL decision making (e.g., Ramsbottom & Kelley, 2014), such as the preparation of effective ACP.

Individual Differences in Medical Decision Making

Variability in individual decision making results from decision makers' unique combinations of knowledge, experience, and values. Variation in medical decision making, that is, differences in clinical treatment decisions when faced with the same problem, is well documented but poorly understood (Reyna & Lloyd, 2006). Wennberg and colleagues in the

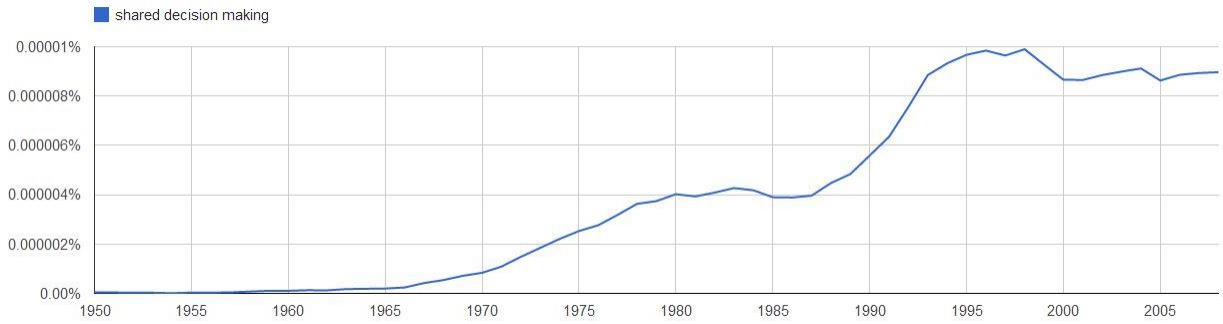
1970s and 80s documented variability in clinicians' decision making in several classic papers (e.g., Wennberg & Gittelsohn, 1973; McPherson, Wennberg, Hovind & Clifford, 1982; Wennberg, Freeman, & Culp, 1987). These researchers demonstrated regional differences in the incidence of medical procedures that could not be explained by characteristics of the population. Variability was exposed within neighbouring communities, between states, and across international borders. Wennberg, Barnes, and Zubkoff (1982) termed their explanation for practice variability the Professional Uncertainty Hypothesis (PUH). PUH stated that individual-level differences in clinicians' evaluation of patients (diagnosis) and their individually-held beliefs concerning the value of treatments for meeting patients' needs (therapy) accounted for variability in practice patterns above and beyond regional disparities in access to medical resources and specific patient characteristics such as age. Nightingale's quintessential studies examining physicians' personality characteristics as predictors of decision-making with hypothetical case scenarios further contributed to the empirical knowledge regarding variability in physician decision-making (1987a, 1987b, 1988). Variability in clinician decision making continues to be an important area of study with implications for patients and healthcare systems (e.g., Mutrie, Bailey, & Malik, 2009; Bailey, 2010; Wilkinson & Truog, 2013).

Patient-Centred Care

Since that time, there has been increasing attention focused on facilitating shared decision making (Figure 1) among professional care providers and patients (and families/substitute decision makers, SDMs). In 1988 the term "patient-centred care" was coined by the Picker Institute as they proposed to shift the focus of healthcare providers from disease to the patient and family (Gerteis, Edgman-Levitan, Daleu, & Delbanco, 1993). A patient-centred approach to care would emphasise the experience of the patient in a complex and often fragmented healthcare

system. A central tenet of patient-centred care is respect for individual patients' preferences, needs and values in all clinical decisions (National Research Council, 2001). shared decision making is most important when decisions have significant consequences and lasting implications for the patient (Barry & Edgman-Levitan, 2012). EOL decisions epitomise clinical decision making under Barry & Edgman-Levitan's description.

Figure 1: Google Ngram of "shared decision making," 1950 – 20081



SDM in clinical practice represents a "philosophical reorientation" (p.2, Watson, Thomson, & Murtagh, 2008) from the paternalistic physician-as-decision-maker model to one that honours the validity of input from patients as well as treatment providers. Under shared decision making, patients are experts in their own healthcare needs and play an active role in decision making regarding treatment. Patients deliberate jointly with their care providers and decisions are based on the best evidence regarding risks and benefits of all available

1 A Google Ngram is a graphical display of a statistical analysis of text demonstrating how often words or phrases have occurred in the corpus of (several million) Google Books over a selected time period. In this Ngram the texts analysed were written in the English language, from any country. The y-axis demonstrates what percentage of books contained "shared decision making." For more information see Michel, Shen, Aiden, Veres, Gray, Brockman, et al., (2010).

treatment/intervention options (Table 1). The process of sharing and dialoguing relevant information is more important than who makes the decision.

Multiple studies and systematic reviews demonstrated that a) patients desire more involvement in treatment decision making, (Salzberg Global Seminar, 2011; Say, Murtagh, Thomson, 2006) and b) shared decision making leads to better patient outcomes such as increased knowledge, reduced conflict in decision making, increased involvement in decision making, fewer patients remained undecided (O'Connor, Bennett, & Stacey, 2006). Communication and decision making about care is prioritized as the most important area underlying quality EOL for persons with dementia (Tilly, 2006).

Table 1: Components of Shared Decision Making

- Establishing context in which patients' views about treatment options are valued and deemed necessary
- Transferring technical information
- Making sure patients understand the information
- Helping the patient base their preferences on the best evidence
- Eliciting patients' preferences
- Sharing treatment recommendations
- Making explicit the component of uncertainty in the clinical decision making process

Note. From Elwyn, Edwards, & Kinnersley (1999)

Demographic variables such as younger age and female sex are often associated with a preference for more active involvement in medical decision making (Martin, 2002; Say,

Murtagh, Thomson, 2006), however, older cognitively intact adults do express treatment preferences when asked (Philippart, Vesin, Bruel, Kpodji, Durrand-Gasselin, et al., 2013). Unfortunately, patients' treatment preferences oftentimes do not closely match the treatment decisions of their physicians (Garrouste-Oregas, Tabah, Vesin, Philippart, Kpodji, et al., 2013). For example, the two-part ETHICA study obtained the preferences of cognitively intact, chronically ill octogenarians for receiving life sustaining treatments (part 1) and compared them with treatment decisions of physicians faced with the same clinical scenarios (part 2).

In part 1 of the study, ETHICA researchers employed professionally produced video scenarios with two possible outcomes to represent the inherent uncertainty of treatment decisions. Two video scenarios were constructed with the help of fourteen individuals aged 80+ and the films contained images of actual patients. One scenario entailed treatment with non-invasive ventilation for cardiogenic oedema that resulted in either resolution and discharge to a cardiac unit, or death. The other scenario demonstrated invasive mechanical ventilation following an acute respiratory failure resulting from bacterial pneumonia; outcomes were either prompt resolution and discharge to a pulmonary unit, or acute renal failure that required a prolonged admission and renal replacement therapy. Each video scenario was presented to the participants (N=115, 68% female; Philippart, Vesin, Bruel, Kpodji, Durrand-Gasselin, et al., 2013), and they were asked to choose from the following options: consent to treatment, refuse treatment, have no opinion, or let the physician decide. All participants had chronic illness and were either living in a care home (30%) or were recently discharged from a hospital stay and living independently (70%). Most were independent for instrumental activities (81%) and activities of daily living (71%). After watching the vignettes, over one quarter (27%) refused non-invasive ventilation, and nearly one half (43%) refused invasive mechanical ventilation.

Furthermore, 63% would refuse further invasive procedures if mechanical ventilation did not resolve their medical emergency. Loss of independence and quality of life was associated with a reluctance to undergo life-sustaining treatments.

In ETHICA part 2 (Garrouste-Oregas, Tabah, Vesin, Philippart, Kpodji, et al., 2013), researchers used clinical scenarios to investigate variability in French physicians' treatment decisions while manipulating patient and health system characteristics. Patient-level variables such as age, functional independence, and medical history were demonstrated to play a significant role in clinicians' medical decisions. Of the 100 participating physicians, the endorsement of non-invasive ventilation was 85.7%, invasive mechanical ventilation was 78%, and for renal replacement therapy after invasive mechanical ventilation was 62%. Treatment decisions to begin either type of ventilation were associated with patient age under 85 years, higher self-sufficiency in the patient, and bed availability. Patients who lived with a spouse were more likely to receive renal replacement therapy. Increasing the number of beds available in the unit by one resulted in increased admissions for treatment. Addition of a single bed resulted in a 38.6% increase for non-invasive ventilation and 13.6% increase for invasive mechanical ventilation. Overall, however, agreement among physicians was low: the kappa value for non-invasive ventilation was 0.11, and 0.24 for mechanical ventilation.

David Eddy argued that treatments should only be considered "standard" when there is "virtual unanimity among patients about the overall desirability… of the outcomes," (Eddy, 1990, cited by Barry & Edgman-Levitan, 2012). Clearly, the decision variability in the ETHICA studies demonstrated that initiating life-sustaining treatments in the elderly does not reach Eddy's requirements for a medical standard. Additionally, ETHICA demonstrated that, in the

absence of physician knowledge of patient preferences, patients are more likely to receive treatments they would not choose to receive than be denied treatments they would have chosen.

A simultaneously encouraging and discouraging outcome of the ETHICA studies (part 2) was that in many instances (ranging from 39.9% to 57%, depending on the treatment), physicians were willing to change their treatment plans when they were informed of the patient's preference. This result mirrored that of an international study from two decades earlier where researchers demonstrated that 40% of physicians would choose care that was inconsistent with the known wishes of cognitively impaired older adults (Alemayehu, Molloy, Guyatt, Singer, Penington, Basile, et al., 1991). Not involving or respecting the preferences of patients and their care providers/SDMs in decisions about treatment and interventions when a patient is approaching the EOL is ethically problematic, and can lead to unnecessary and unwanted, burdensome treatments.

EOL decisions when a person dies with dementia most often depend on proxy decision makers, as patients are unlikely to be able to communicate as their dementia becomes advanced. When proxies had a better understanding of the terminal nature of dementia and poor prognosis, invasive and burdensome clinical procedures (e.g., hospitalization, emergency room visit, parenteral therapy, feeding tubes) at the EOL were less likely (Mitchell, Teno, Kiely, Shaffer, et al., 2009). Similarly, when surrogate decision makers had more contact with nurses on the care team, patients with dementia were less likely to receive aggressive treatments at the EOL (Maust, Blass, Black, & Rabins, 2008). Although Belgian physicians were almost twice as likely to consult with family members (OR = 1.96, p=.003) and nurses (OR = 1.64, p=.020) when a patient died with dementia than cancer (Chambaere, Cohen, Robijn, Bailey, & Deliens, 2015), adoption of the shared decision making model is not yet widespread. A systematic review of

health professionals' perceptions about shared decision making suggests that many physicians do not invite patients, families, and team members to participate in decision making because of a perception that it would not be applicable or wanted by patients. Gravel and colleagues (2006) expressed concern for this seemingly *a priori* screening by clinicians because patients' and surrogate decision makers' wish for active involvement may be misjudged. A study involving the family caregivers and medical professionals of N=119 dementia patients who died in LTC found that 39% of family caregivers, compared with 71% of medical professionals, had anticipated the death (van Soest-Poortvliet, van der Steen, Zimmerman, Cohen, Klapwijk, Bezemer, et al., 2012). A systematic review examining the match between cancer patients' preferred and actual level of participation in medical decision making found that patients desired a more active role in the medical decisions than typically occurred (Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010). When residents (or SDMs) from 16 LTC homes in Australia were asked, as part of a systematised ACP programme, 88% selected not to abdicate decisions about medical treatments to their physician (Silvester, Parslow, Lewis, Fullam, Sjanta, Jackson, et al., 2013).

Individual differences in physicians' clinical decisions regarding EOL care can be influenced by the clinicians' religious beliefs, cultural background, training, experience, attitudes and personality factors (Cohen, van Delden, Mortier, Lofmark, Norup, Cartwright, et al., 2008; Sekkarie & Moss, 1998; Wilkinson & Truog, 2013). Wilkinson and Truog (2013) described inconsistencies in EOL decision making as "worryingly arbitrary," (p.1128), noting that EOL decisions can vary depending more on which physician is on-call than by characteristics of the patient and his/her illness.

Systemic factors and institutional culture cannot be ignored as a further source of variance in medical EOL decision making. Significant between-hospital differences in provision

of palliative care seem to endure over time, and subsequent measures of family satisfaction and nurse- and family-rated quality of dying appear to provide validity to the felt impact of differences in EOL care (DeCato, Engleberg, Downey, Nielsen, Treece, Back, et al., 2013). Regional variability in dementia diagnosing was recently and dramatically demonstrated with the publication of the UK Alzheimer's Society's "Dementia Map" (Alzheimer's Society, 2013). Striking regional variations were uncovered, with rates of diagnosis ranging from 31.6% to 75.5% in the UK alone, according to one study (Tesco, Alzheimer's Society and Alzheimer Scotland, January 2013). Parsons and colleagues (2014) demonstrated that physician's country of practice and the patient place of residence (hospital, care home, home) had small but consistent effects on decisions to initiate, withhold, continue, or discontinue medications when patients had end-stage dementia using vignettes and questionnaires. It was reported previously that primary care providers are often not well-versed or comfortable with making a diagnosis of dementia (National Audit Office, 2007), and convey wanting more access to specialized services and supports (Yaffe, Orzeck, & Barylak, 2008). Institutional protocols for initiating EOL discussions and documenting a person's wishes for EOL care (i.e., ACP) are a potential further source of variability in care received. A small qualitative study demonstrated that ACP is not well understood by decision makers and professional caregivers alike, although all participants perceived ACP to be important (Ramsbottom & Kelley, 2014).

Uncertainty in Prognosticating Death in the Presence of Dementia

Dementia does not usually provide a linear and quick downward illness course until death. Instead, death from dementia follows a course that is gradual in its slope and interspersed with acute illnesses and crises, accompanied by fluctuating cognitive impairments such as delirium, from which the patient will often not fully recover (Sachs, Shega, Cox, & Hayley, 2004). Median

survival years after diagnosis range from 3.2 to 6.6 years (Todd et al., 2013; Wolfson, Wolfson, Asgharian, et al, 2001), but estimates are imprecise. Diagnosis is often delayed and prolonged across multiple visits to a specialist. Individuals present for evaluation of their symptoms at different stages of the disease, and many either do not present or are not screened at all. It was estimated that between 40-80% of dementia cases are undiagnosed in primary care settings (Weimer & Sager, 2009), and similar numbers in care homes (MacDonald & Carpenter, 2003; Nygaard & Ruths, 2003; Cahill, Diaz-Ponce, Coen, & Walsh, 2010; Weyerer & Shaufele, 2006). Efforts to predict survival time based on onset of symptoms, although attractive as a measure, are unreliable because they are based on retrospective accounts from patients and family members once the diagnosis has been made, and thus are particularly prone to recall bias (systematic errors in memory for past events). Individuals usually find it more difficult to accurately remember details of events that happened further in the past, and in particular when the event under investigation is critical, there is unclear association with risk factors, or the outcome is undesirable (Hassan, 2005), all of which apply to a diagnosis of dementia.

Declining cognitive and functional abilities are often protracted in dementia, making it especially difficult for physicians and family and friends to conceptualise the patient as dying. After the person dies, death certificates often do not list dementia as a primary or even secondary cause of death (Chambaere, Cohen, Robijn, Bailey, & Deliens, 2015; Ganguli & Rodriguez, 1999) instead listing pneumonia, cardiac disease, an infection, or some other terminal event as the cause (Kammoun et al., 2000; Burns, Jacoby, Luthert, & Levy, 1990). A systematic review by Romero, Benito-Leon, Louis, and Bermejo- Pareja (2014), where two of the seven articles that met selection criteria came from Canada, showed that reporting of dementia on death certificates was quite low, ranging from 7.2% to 34% for deaths where a dementia diagnosis had

been previously confirmed using a two-step validation procedure (i.e., using a validated clinical assessment instrument plus confirmation with clinical examination). The most frequently reported causes of death when dementia was omitted from the death certificate were respiratory or circulatory problems. Clinical experience provides anecdotal evidence that family members, for example, will often recount that the patient 'suffered with dementia for years, and then died of pneumonia.' Although the statement is itself true, it ignores the high incidence of feeding problems in advanced dementia, which can lead to aspiration pneumonia, and perpetuates the false notion that dementia is something people live with and not something they die from. Mortality rates for older adults (70 years and older) with dementia after a hospital admission are twice as high as for those without dementia (Sampson, Leurent, Blanchard, Jones, & King, 2012). A hospital admission with aspiration pneumonia is associated with a 33.3% hospital mortality rate and 50.8% six-month mortality rate in dementia patients aged 75 years and older (Bosch et al., 2012). When patients were admitted with pneumonia, mortality rates differed widely in those with and without dementia. Six-month mortality in the dementia group was 53%, compared with 13% in the non-demented patients (adjusted hazard ratio 4.6, 95% CI: 1.8-11.8; Morrison & Siu, 2000). Clearly then, there is a possibility for a significant number of discrepancies on death certificates for cause of death when dementia is excluded.

Individual characteristics such as age, gender, education and ethnicity are predictive of death in persons with dementia, as well as disease characteristics such as symptom severity, functional impairment, and comorbidity. Todd, Barr, and Passmore (2013) recently summarized these in a review of prospective studies. Although there were some inconsistencies in the literature, being older and male, and possibly being Caucasian, were associated with increased mortality. Higher educational attainment is generally considered a protective factor against the development of

these diseases (Paradise, Cooper, & Livingston, 2009); however its relationship to mortality risk remains unclear. Measures of global impairment (e.g., Clinical Dementia Rating Scale, Morris, 1993; CAMDEX, Roth, Tym, Mountjoy, et al., 1986; Dementia Rating Scale, Blessed, Tomlinson, & Roth, 1968) predicted earlier death in several studies (Andersen, Lolk, Marinussen, & Kragh-Sorensen., 2010; Heyman, Peterson, Fillenbaum, & Pieper, 1996; Llinas-Regla, Lopez-Pousa, Vilalta-Franch, Garre-Olmo, & Roman, 2008; Nitrini, Caramelli, Herrera, et al., 2005; Schaufele, Bickel, & Weyerer, 1999; Larson et al., 2004), as did increased cognitive impairment as measured by the Mini-Mental State Examination (MMSE, Folstein et al., 1975; Larson et al., 2004). Functional impairment, such as having problems with instrumental activities of daily living and increased disability, measured with the Dementia Rating Scale (Mahoney & Barthel, 1965) was also associated with risk of dying (e.g., Ganguli, Dodge, Shen, Pandav, & DeKosky., 2005). Many studies, however, have found no relationship between global, cognitive, and functional impairment and death in persons with dementia (e.g., Aguero-Torres, Fratiglioni, Guo, Viitanen, & Winblad, 1999). Disease comorbidities appear to increase risk of death (Aguero-Torres, Fratiglioni, Guo, Viitanen, & Winblad, 1998, 1999), including hypertension and diabetes mellitus (Guehne, Matschinger, Angermeyer, & Riedel-Heller, 2006). Interestingly, a recent study to determine rates of undetected dementia cases in Ontario institutional care facilities found that diabetes mellitus was a significant factor in *not* having a dementia diagnosis, despite severe impairment in cognitive and global functioning that may be indicative of dementia (Bartfay, Bartfay, & Gorey, 2013).

A prospective study of nursing home residents with advanced dementia showed an age- and sex-adjusted six-month mortality rate of 46.7% when the patient developed pneumonia, 44.5% for a febrile episode, and 38.6% for eating problems. Each of these symptoms was a frequent

occurrence in the advanced stages of the disease, with pneumonia, a febrile episode, and/or an eating problem affecting 41.1%, 52.6%, and 85.8% of consecutively enrolled patients, respectively (Mitchell et al., 2009). In a study by Sampson and colleagues (2009), fully 18% of dementia patients died during an unplanned acute hospital admission compared with only 8% of non-demented patients with a median length of stay of seven days. Despite clear indications that dementia is associated with increased and somewhat predictable mortality, life expectancy in dementia patients is consistently overestimated (Mitchell et al., 2004).

Mitchell and colleagues (2004) were able to reliably predict six-month mortality in patients with advanced dementia using 12 items from the Resident Assessment Instrument Minimum Data Set (RAI), an assessment instrument required at regular intervals in long term care homes in Canada and elsewhere. The 12 risk factors were total functional dependence (score of 28 on the Activities of Daily Living Scale[2]), male sex, presence of cancer, congestive heart failure, oxygen therapy was needed in the preceding two weeks, shortness of breath, less than 25% of food eaten at most meals, unstable medical condition, bowel incontinence, bedfast, over 83 years old, and not awake most of the day. A total risk score (range: 0-19) based on these items predicted six-month mortality as follows: 0 points, 8.9% mortality; 1-2, 10.8%; 3-5, 23.2%; 6-8, 40.4%; 9-11, 57.0%; 12+, 70.0%. Similarly, Hirdes, Frijters, and Teare (2003) developed the Changes in Health, End-stage disease and Symptoms and Signs (CHESS) scale from 11 RAI items to successfully predict mortality and health instability, independent of age, sex, cognition, do not resuscitate orders, and impairment in activities of daily living. Other researchers proposed using stage 7(c) from the functional assessment or functional assessment staging (FAST) instrument as a prognostic indicator for end stage dementia (Hanrahan, Raymond, McGowan, & Luchins,

[2] Activities of Daily Living Scale measures seven functional activities: bed mobility, dressing, toileting, transfer, eating, grooming, and locomotion, rated on a 5-point scale (0 = independence, 4 = total dependence).

1999) that could positively predict death within six months. Unmistakeably, dementia is a terminal disease (Coleman, 2012; van der Steen, 2010; Mitchell et al., 2009; Wolf-Klein, Pekmezaris, Chin, & Weiner, 2007; Zanetti, Solerte, & Cantoni, 2009) and prognosticating death is complicated and imperfect. Consideration of empirical evidence about mortality from dementia combined with frank and shared discussions amongst health care professionals, patients, and family members about EOL wishes, can reduce uncertainty in EOL decision-making (van der Steen, Onwuteaka-Philipsen, Knol, Ribbe, & Deliens, 2013). The European Association of Palliative Care (EAPC) released their white paper in July 2013, making the case for increased research into prognostication and timely recognition of dying in patients with dementia (van der Steen et al., 2013). This domain was ranked by a consensus of over fifty international experts as an area of importance for clinical practice and research.

Death with dementia typically occurs in LTC or hospital. A study examining determinants of place of death in the province of British Columbia, 2004-2008, found that having dementia and being over 80 years old each significantly increased the likelihood of dying in LTC (Jayaraman & Joseph, 2013). The adjusted odds ratio for dying in LTC when diagnosed with a dementia was 3.91 compared to diagnosed with cancer. Adjusted odds ratios for dying in LTC between ages 80-89 and over 90 years were 1.75 and 3.31, respectively, compared with those ages 70-79 years. Although many older adults do die after a move to LTC, dying in an institution with expertise in elder care is, unfortunately, no guarantee that quality EOL care with be provided or even accessible.

Palliative Care

The term ‘palliative care’ refers to a philosophical approach to improving the quality of life of individuals with life-threatening and chronic conditions, and their families. This approach

focuses on the prevention and relief of suffering, which may be physical, psychological, or spiritual. Palliative care interventions do not aim to postpone or hasten dying and they may be applied in conjunction with treatments and assessments that aim to prolong life. It is appropriate to initiate palliative approaches to care at any stage of illness, and in any setting.

Aggressive treatments to manage acute illnesses in persons with advanced dementia commonly have poor outcomes (Morrison & Siu, 2000). It is notable that in a large US study examining the relationship between cognitive impairment and use of hospital services, it was found that the presence of cognitive impairment increased the use of emergency services and subsequent hospitalisation for residents (Stephens, Newcomer, Blegen, Miller, & Harrington, 2014). Palliative care aims to provide management and treatment of acute symptoms, but interventions and treatments are comfort-focused rather than curative. Persons in receipt of palliative care are much less likely to experience aggressive treatments aimed at curing. Persons with dementia are typically underrepresented in hospice and palliative care. Only 7% of hospice[3] patients had dementia in 2001 according to a US study reported by Sachs and colleagues (2004), representing only about 10% of dementia patients in that country at that time (Ewbank, 1999). In 2011 the figure had risen to 12.5% (National Hospice and Palliative Care Organization, 2012). Palliative care pathways for patients dying with dementia do not require a specialised palliative care setting, especially in the absence of serious comorbidity or uncontrolled pain. Guidelines for providing quality EOL care for persons with dementia (e.g., NICE, 2010; van der Steen, Radbruch, Hertogh, de Boer, Hughes, Larkin et al., 2013) were produced, nevertheless getting patients onto an EOL care pathway remains an obstacle (Coleman, 2012).

[3] In the USA, the term “hospice” typically denotes someone who is deemed to be in the final 6 months of life.

Taking a palliative approach to dementia care. All forms of dementia constitute chronic, degenerative illnesses that result in life-shortening. Sampson and colleagues (2012) recommend that physicians consider adopting a supporting approach to care in people with moderate to severe dementia following an emergency hospital admission, given their projected survival time. However, the shift from "curing" to "caring" is often a difficult one for clinicians (Adams, McIlvain, Geske, & Porter, 2005).

Cognitively intact older adults expressed a very reasonable wish to forego life sustaining treatments when they equate to a loss of independence, instead, they valued quality of life over short-term survival (Fried, et al., 2002). Many family members and health care professionals believe that comfort care is the most fitting goal when a person with dementia is dying (Luchins & Hanrahan, 1993) but it is rarely afforded (Mitchell, Kiely & Hamel, 2004). Difficulties estimating life expectancy in persons with dementia and lack of communication between professional caregivers, patients, and their proxies are significant barriers to providing comfort-focused EOL care (Sampson, Ritchie, Lai, Raven, & Blanchard, 2005). Ethical treatment decisions, including the decision to withdraw or forego treatments, must be based on an understanding and weighing of the expected benefits and burdens of the intervention, and best knowledge regarding patient preferences, rather than on patient age or diagnostic status. Ontario law dictates that treatment decisions meet these standards (HCCA 1996, c. 2, Sched. A, s. 21 (2); c. 2, Sched. A, s. 26; Wahl, 2013).

Advance Care Planning (ACP)

ACP is a process that facilitates communication and understanding of an individual's care preferences to health care providers, family, or a SDM, with the intention that future care will be

in accordance with these preferences. The three components of ACP involve consideration of realistic health care options and expression of values, communicating wishes, and documentation (Cantor & Pearlman, 2003). The documentation that results from ACP is an 'advance directive.' ACP completed before or early in the disease course is one way to apportion respect for the autonomous decisions of a person dying with dementia into the future. Documented advance directives that result from ACP can take the form of treatment directives and proxy directives. A treatment directive specifies the types of medical treatments the person wants or does not want under specific circumstances. Proxy directives invest decision-making capacity to another person who is aware of the wishes and preferences of the individual (SDM)[4]. The purpose of ACP is to aid decision making when a person loses capacity[5]. Best practices for ACP were developed by a working group of experts in older adult and palliative care, academics, and staff from the Australian 'Respecting Patient Choices' programme (Silvester, Fullam, Parslow, Lewis, Sjanta, Jackson, et al., 2012). The principals of ACP are outlined in Table 2.

Table 2: Principals for Advance Care Planning (ACP) in Long Term Care (LTC)[1]

1	**Policies.**	Written policies about ACP should be readily accessible in every LTC facility. Policies should include the systems needed to establish ACP as a routine component of care, all aspects of documentation, including where ACP is to be kept, how many copies, when to be reviewed, etc.
2	**Education.**	Education about ACP should be regularly provided to all LTC staff

[4] In Ontario, this is a Power of Attorney for Personal Care (POAPC).

[5] Capacity can be variable and domain-specific. For example, a person may have capacity to make decisions about nutrition or participating in an activity, but not to make decisions about medication or appropriate attire. ACP is only used when a person does not have capacity for the decision at hand or is unable to communicate; the stated wishes of a person with decision-making capacity take precedence over an advance directive. A person with dementia is assumed to be competent unless deemed incompetent by the relevant clinician, and even then they may still be able to participate in the ACP process, even if they are not deemed competent to complete a legal document.

		and clinicians (physicians, nurse practitioners, physician assistants, psychologists, etc.)
3	**Information.**	Information about ACP is best provided to LTC residents and families before admission, followed by well-planned individual discussions as soon as possible after admission- normally within 28 days unless there are unforeseen circumstances.
4	**Routinely administered and reviewed.**	ACP should be incorporated into routine clinical decision making and care planning, at minimum reviewed annually, and reviewed when circumstances change (e.g., exasperation of illness, health deterioration or hospital admission).
5	**Voluntariness.**	While the aim of ACP is to involve every older person in the discussion, no one should be coerced and everyone is free to change their ACP at any time.
6	**Communication is the key.**	ACP should be accompanied by full discussion with the older person and/or family, in private, and initiated by a health professional with relevant skills in this area. ACP forms should not be sent via mail without corresponding personal discussion.
7	**Older person's best interests.**	The older person's treatment should be directed towards their best interests, informed by (a), the competent person's current wishes, (b) the non-competent person's previously expressed wishes, or (c) family's views regarding the older person's wishes. In every case, decisions should be fully supported by appropriate information.
8	**The older person with dementia.**	Every person with dementia should be deemed competent unless deemed incompetent by the relevant medical officer. People with dementia may be able to take part in some aspects of ACP even if they lack competence to complete a legal document.
9	**Inevitability of death.**	Most people requiring admission to LTC have at least one, and in many cases, several life-threatening, incurable illnesses leading to inevitable death. ACP discussions should therefore promote frank discussions of death and dying.

10	**EOL.**	Older persons and their families should be informed about the principles of palliative care, namely that this (a) does not mean 'no treatment'; (b) is offered well before death is imminent; (c) neither hastens death nor unduly prolongs life; (d) is delivered by all health care providers, with assistance from specialist services as required.
11	**Treatment options.**	The focus of the conversation is on reasonable outcomes and quality of life. It should raise the issue of life-prolonging treatment generally and not focus on any specific treatment.
12	**Family's role.**	Families are encouraged to participate in all aspects of the older person's care planning. The family should comply with what is in the older person's best interest even if this is not congruent with their own views.
13	**Physician involvement.**	Best practice is for the most responsible physician to be included in ACP discussions. A copy of the current ACP should be forwarded to the physician.
14	**Confidentiality.**	The older person and/or family should be informed about confidentiality and safekeeping of their documented wishes. Information will only be provided to health care providers as required.
15	**ACP and power of attorney.**	ACP compliments any legally binding power of attorney document.
16	**Information transfer.**	Effective systems to support transfer of information to the older person's medical records, treatment professionals, and local health services is paramount.
17	**Documentation.**	ACP documents should clearly specify (at minimum) (a) nominated substitute decision maker (and contact details) where applicable, (b) resident competency at the time of completion, (c) current state of health, (d) values and beliefs (things that matter most in life), (e) future unacceptable health conditions, (f) specification of resident preferences in relation to life-prolonging treatment and hospital

transfer, (g) specific wanted/unwanted treatments- where applicable, (h) goals for EOL care, (i) appropriate signatures (clear, complete, dated, witnessed), and (j) include evidence of physician review.

[1]Adapted from Silvester, Parslow, Lewis, Fullam, Sjanta, Jackson, et al. (2013)

Compliance with advance directives appears to be quite low (Vogel, 2011), particularly when the intellectual capacity of the patient is in question and when the physician's medical judgement is in opposition to the directive (de Boer, Hertogh, Droes, Jonker, & Eefsting, 2010; Vezzoni, 2005). In a survey of LTC staff, 24.4% (11 of 45 interviewees) reported that, in the preceding six months, they had themselves provided treatment (n=5) or witnessed someone else providing treatment (n=6) to a resident who had previously indicated they did not want treatment (Silvester et al., 2012). How the documents are prepared varies from province to province in Canada, and physicians complain that they are at times "unrecognizable" (Vogel, 2011, E39) because of their complexity. Ambiguity is also not uncommon in written directives or discontinuity between documents. For example, fewer than 40% of LTC residents with a directive indicating a wish not to receive cardiopulmonary resuscitation (CPR) had a corresponding Do Not Resuscitate (DNR) order in a German study (Sommer et al., 2012). Health care providers are obligated to default to full treatment when alternative preferences are unknown or unclear, resulting in burdensome interventions such as hospitalisations, restraint use, intravenous therapy, tube feeding, antibiotics, or life-sustaining medications, (Mitchell, Kiely, & Hamel, 2004; di Giulio, Toscani, Villani, Brunelli, Gentile, & Spadin, 2008; Mitchelle et al., 2009). ACP discussions that take place may not be documented, and extremely high staff turnover rates in LTC (Gruss, McCann, Edelman, & Farran, 2004) mean many staff are simply not familiar with the persons for whom they are providing care. At other times, patients have advance directives in place, but do not know how to bring it up with their care team. Anecdotal evidence suggests physicians feel

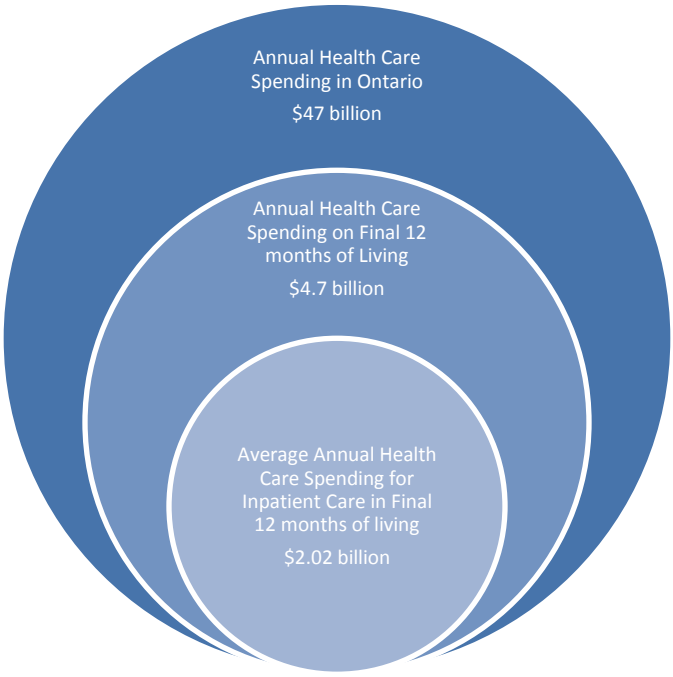
equally uncomfortable broaching the subject with patients, and so the directive is never shared (Vogel, 2011).

When in place and known to professional care providers and family, ACP can reduce hospitalizations and increase the use of palliative care services in persons with dementia (Robinson et al., 2012; Silveira, Kim, & Langa, 2010). Medical inpatients who were 80 years and older and who received an ACP intervention were much more likely to have their EOL care wishes followed. In addition, their family members reported significantly less stress, anxiety, and depression after the death compared with family members in a control group (Detering, Hancock, Reade, & Silvester, 2010). Having ACP in place was also associated with lower resource use in a multi-site Ontario study (average total cost per resident in LTC facility with ACP intervention: $3,490; average total cost per resident in LTC facility without ACP intervention: $5,239, p=.01; Molloy et al., 2000). In a large study in the USA involving N=3,746 individuals aged 60 years or more who died between 2000 and 2006, 70.3% of those whose deaths required decision making lacked decision making capacity, and only 32.4% had advance directives. When advance directives were in place, 92.7% and 96.2% of people requested limited care and comfort care, respectively, and only 1.9% wished for all care possible. Received care was consistent with the advance directive in 83.2% of deaths when limited care was the goal and 97.1% of deaths when comfort care was requested. Requests for all care possible was fully honoured in 50% of cases, however, individuals that had a directive for all care possible were more likely to receive aggressive care compared to those who did not request it (adjusted odds ratio, 22.62, CI: 4.45-115.00; Silveira, et al., 2010).

Approximately 10% of all government-funded health care in Ontario is for care provided in the last year of life, representing $4.7 billion. Inpatient hospital care occurs for approximately

75% of Ontarians during their final 12 months of life, accounting for 42.9% of total costs per decedent (Figure 2). Continuing care (LTC and CCC) costs remained more stable in the final 30 days of life, rising only 33%, compared to a 181% increase in cost of visits to acute care (Tanuseputro et al., 2015). Given that most advance directives prioritise comfort care and natural dying rather than aggressive treatments when death is imminent, it is reasonable to expect an increase in effective ACP documentation to have the consequence of reducing (unwanted) hospitalisations, for significant reductions in health care spending. For example, community-based patients in receipt of home-based palliative care services with a known preference to die at home were more likely to do so (Brink & Smith, 2008).

Figure 2: Average Annual Health Care Spending in Ontario during Final 12 months of Life (2010-2013; based on Tanuseputro et al., 2015)



Overall, despite their high level of reported acceptability to health care providers, very few people have an advanced directive in place (Hirschman, Abbott, Hanlon, Bettger, & Naylor, 2011), and those that are in place often do not achieve their intended goal (de Boer, Cees,

Hertogh, Droes, & Eefsting, 2010), although that is not always the case (Hammes, Rooney, Gundrum, Hickman, & Hager, 2012). A 2012 Ipsos-Reid poll found that most Canadians (86%) did not know what ACP was, and only 9% had spoken to a healthcare provider about their preferences for care (cited by Canadian Hospice Palliative Care Association, 2013). It was estimated that between five and 15% of American adults have an advance directive in place (Sabatino, 2007; Kirschner, 2005); however that number goes up significantly, to 65% in residents of LTC (Jones, Moss, Harris-Kojetin, 2011). In the context of USA's 1990-enacted Patient Self-Determination Act, which required health facilities to inform adults about the rights to execute an advance directive, the numbers remain low. In a clinical sample, only 18% of N=440 patients with a life-limiting chronic disease had discussed prognosis with their physician (Heylan, Allan, Rocker, Dodek, Pichora, & Gafni, 2009). In a LTC setting in Ontario, ACP was poorly understood by both health care workers and family members, but it was nonetheless considered important by both groups (Ramsbottom & Kelly, 2014). LTC staff at multiple facilities in Australia also reported positive attitudes regarding ACP, but had little knowledge, practice, and self-reported skill in having ACP discussions (Silvester et al., 2012). In 1999, Ontario was the first Canadian province to develop a "comprehensive, multifaceted strategy on Alzheimer Disease," (Government of Ontario), which included a strong focus on ACP for all Ontarians.

ACP and dementia. In Ontario and many other jusridictions, treatment directives are legal documents and binding on physicians, however, dying with dementia complicates compliance with these legal documents in several ways. Mitchell and colleagues suggested that not recognising advanced dementia as a terminal disease contributed to their finding that individuals with dementia were less likely than those with cancer to have advance directives in place (2004).

The often-slow progression of dementia makes judgments over decision making capacity less clear than in cases where someone falls into a coma after an acute event. People with dementia remain conscious through much of their disease, and continue to experience their lives subjectively, and continue to express wishes and preferences. Conflict may arise between what was expressed previously and what is expressed, or understood to be expressed, currently. Personal identity can change as the disease progresses, and the philosophical problem of which is the "true" self (de Boer, Hertogh, Droes, Jonker, & Eefsting, 2010) often presents itself very tangibly in medical decision making. Interpreting the intention of an advance directive is difficult to impossible without the possibility of simply asking the patient. For example, when a patient with an advance directive to withhold life-sustaining treatments at the EOL is brought to an emergency department for an acute medical problem, the actions can appear contradictory.

Problems related to unknown ACP, inadequately documented or unavailable ACP documentation, or difficulties with interpretation of ACP documents (Silvester et al. 2012, Silvester et al., 2013, Sommer et al, 2012) can contribute significantly to confusion over how to respond to changes in medical status at the EOL. Indeed, residents with moderate to severe cognitive impairment accounted for more than half of hospitalisation from LTC when there was a Do Not Hospitalise (DNH) order in place (CIHI, 2016). Research suggests these problems are compounded when a person has cognitive impairment consistent with a dementia. Additionally, some evidence seems to suggest that family carers and persons with dementia may have divergent preferences for EOL care (Dening, Jones, & Sampson, 2013; Shalowitz, Garrett-Mayer, & Wendler, 2006). The absence of adequate, known, and effective ACP documentation, therefore, appears to be a particularly critical issue for people who die with dementia. When a "dementia-friendly" ACP programme is in place in LTC, however, positive impacts such as

increased ACP discussions have been reported, according to a systematic literature review (Wickson-Griffiths, Kaasalainen, Ploeg, & McAiney, 2014).

Do Not Hospitalise (DNH) orders. Some ACP may indicate when or whether a resident wishes to be transferred to an acute care hospital for treatment and/or intervention. Usually such interventions would be aimed at life-saving or life-prolonging and rarely for palliative care services. A recent report from CIHI (2016) noted that DNH orders in LTC are uncommon, with only about 21% of LTC residents having one in place. In the community, Brink, Smith, and Kitson found that only 16.7% of palliative patients in receipt of homecare had a DNH in place (2008). Of those LTC residents with a recorded DNH order, about one in 14 were transported to hospital during an acute event, although it wasn't clear how many residents had actually experienced a need and not been transported. More than half of those transported to hospital were moderately or severely cognitively impaired, suggesting they could not consent for themselves. Residents without a DNH were about twice as likely to be transported to hospital.

Need for standardisation in ACP language. The absence of a standardised, evidence-based approach to documenting residents' EOL preferences in a common language across healthcare settings, combined with the likelihood of communication impediments at the EOL (Silveira, et al., 2010), particularly for people who die with dementia (Blasi, Hurley, & Volicer, 2002), LTC workers' lack of accurate ACP knowledge and skill (Ramsbottom & Kelly, 2014; Silvester et al., 2012, Wahl, Dykeman, & Walton, 2016), extremely high LTC staff turnover rates ranging from 40-70% or more (Clancy, 2008; Gruss, McCann, Edelman, & Farran, 2004), and inconsistency in availability and interpretation of EOL wishes and advance directives when decisions are made, combine to potentiate a perfect storm of poorly executed EOL care for people dying in LTC, particularly those with dementia who are at even higher risk.

Implementing standardised documentation as part of an ACP intervention increased specific instructions for EOL care (Molloy et al., 2000) and adherence to wishes compared to a control group (Morrison, Chichin, Carter, Burack, Lantz, & Meirer, 2005). Comparatively, variability in documenting directives lead to variability in interpreting wishes. Sommer and colleagues (2012) studied nurse raters' interpretations of actual LTC residents' advance directives for five clinical decision scenarios and found very low agreement between raters in scenarios involving permanent decisional incapacity due to dementia (inter-rater agreement <43%). Standardising documents may not be feasible due to unique needs of diverse settings, however, standardising the language of ACP on such documents to ensure accuracy should improve communication and thereby improve access to appropriate ACP. There is no literature known to this author which examined the impact or perceived impact of non-standardised ACP documents for patient transfer and communication across health care settings. Recently a report from the Law Commission of Ontario (Wahl et al., 2016) noted the dearth of research in this area.

Summary

Not only do patients with dementia frequently die without optimal EOL care, many die in receipt of suboptimal, unwanted, or even harmful treatments (Vitale, Hiner, Ury, Berkman, & Abronheim, 2006; Sachs, Shega, & Cox-Hayley, 2004; Teno, Mor, Desilva, Kabumoto, Roy, & Wettle, 2002; Ahronheim, Mulvihill, Sieger, Park, & Fries, 2001; Mitchell, Teno, Roy, Kabumoto, & Mor, 2003). Disease characteristics, such as uncertainty in prognostication; clinician factors (individual differences in decision making); and systemic factors, like institutional culture, protocols, and variation in documenting residents' EOL wishes (ACP) all present barriers to anticipating death and to providing appropriate EOL care. These issues may

be more pertinent for people who die with dementia than people die without dementia. Some patients with dementia do receive optimal EOL care despite barriers (Engel, Kiely, & Mitchell, 2006).

Frank conversations about EOL care, such as those which occur in the context of ACP, will contribute significant knowledge of what a person with dementia would consider acceptable, and unacceptable, at the EOL. Additionally, the availability of clearly communicated advance directives will decrease reliance on individual decision makers'(SDMs and clinicians) interpretations or assumptions about what the dying person would want, whether faced with an acute medical emergency or a slow progression toward a natural death. Refining ACP documentation presents a compelling possibility for improving treatment-providers' and decision makers' recognition of the goals of the dying patient with dementia, and permitting them to act in concordance with those goals when the individual cannot speak for themselves, rather than relying on their own views and interpretations, which have been shown to vary significantly independent of patient factors. To date little is known about the content of ACP documents used in LTC and nothing is known about the impact variation in ACP documents might have on EOL decisions or resident care. With regards to LTC, a recent report from CIHI lamented that "little information is currently available to understand what kind of directives are in place, and whether documented patient preferences are being followed in clinical practice and across the continuum of care," (CIHI, 2016). Persons with dementia in LTC may be particularly vulnerable to effects from variation in ACP documents because of specific characteristics of that disease, which severely limit communication and cognitive ability, particularly in the later stages of the disease when death is most likely.

Current Project: Three Studies

Research in LTC ACP to date has focused on changing patterns in the use of ACP, satisfaction related to ACP, quality and acceptability of ACP, and uptake of ACP. On the other hand, research regarding the EOL of people dying with dementia has emphasised the need for ACP and, rarely, on the outcomes of ACP. This research was the first to attempt at an examination of how differences in ACP documentation may affect medical decisions at the EOL for residents of LTC, particularly those with dementia who may be most vulnerable). In Study One, we undertook an audit the content and quality of the variety of ACP documents currently used in facilities where older adults receive care in an Ontario community.Study Two investigated the experiences of health care workers in the same community who use and interpret ACP documents, with an emphasis on the desirability and acceptability of a common language used across health care providers/facilities. Study Three examined actual EOL decisions when LTC residents from across the province of Ontario died, to determine the role of dementia status and ACP in influencing place of death.

Rationale

The long-term and continuing care of older adults, as a sector, has a strong history and tradition of recognising standardisation as a powerful tool for improving the provision of patient-centred care (e.g., RAI 2.0). This research will aid in achieving the goal of good EOL care that is consistent with the wishes and best interest of each resident by attempting to clarify the role ACP documents play in EOL planning and decision-making. Study Three specifically aimed to examine the possible role of ACP documentation practices in EOL decision making when residents of LTC died. The reviewed evidence on ACP and EOL preferences demonstrated that the vast majority of individuals prefer to die in place and, when they are informed, avoid

excessive interventions at the EOL. Furthermore, previous research suggested that ACP is often suboptimal in LTC, but that when they are explicit and known, wishes are usually followed. For this reason, in Study Three, we investigated the role of resident characteristics that were associated in the reviewed literature with EOL and ACP in determining place of death (LTC home, hospital, emergency department). The purpose was to infer from the available data which residents were most likely to have benefitted from ACP, and consequently, which might not have benefited and ought therefore to be prioritised for ACP interventions, such as standardisation of ACP documents. To determine characteristics of ACP what contributed to the EOL decision examined in Study Three, Studies One and Two focused on the content of institutional documents for recording ACP and the experiences of knowledgeable workers who use those documents.

Hypotheses

Study One.

Hypothesis one. Unlike some previous studies, it was expected that all organisations providing long term and acute care to older adults will have an existing advance directive document, as ACP is a stated priority of the Ontario Ministry of Health and Long Term Care (MOHLTC; 2016a, 2016b). Length and focus of documents is expected to vary by site and site type.

Hypothesis two. Quality of ACP documents will vary by site, particularly between hospitals and LTC where goals of care may be different. We did not anticipate that any documents would adhere to all of the best practice principles for ACP documentation. Based on

the literature reviewed earlier, it was anticipated that the quality of ACP documents would be low.

Study Two.

Hypothesis three. There would be variation in healthcare workers' experiences and perceptions with using ACP documents. Based on the experiences of the specialists consulted during the design phase of this project, we expected some workers to report perceiving discontinuity in documents between sites. Perceptions of the quality of ACP documents may not always be in line with the disparities expected between existing documents and the best practice principles for ACP documents. This may be a case of unperceived need, given that previous studies have demonstrated a lack of understanding around ACP. Many workers will not have experience or knowledge of best practice guidelines for ACP.

Hypothesis four. Perceptions about the benefits of standardised language in ACP documents were expected to be inconsistent. This may once again be a case of unperceived need, given that previous studies demonstrated a lack of understanding around ACP. Many workers will not have experience or knowledge of best practice guidelines for ACP. On the other hand, many health care workers who complete the questionnaire are likely to have experienced non-standardisation of ACP documents across settings and see a benefit to standardisation.

Study Three.

Hypothesis five. Because individuals with advanced dementia often cannot communicate their wishes, and because documentation of wishes when capable was likely to be poor, LTC residents who died with dementia would be more likely to receive care that is not in line with current knowledge about the preferences of individuals with dementia who receive adequate

ACP. Specifically, residents with dementia were anticipated to be hospitalised or visit the emergency department more frequently near the EOL than residents without dementia.

Hypothesis six. Possible effects of ACP were explored by examining items from the RAI 2.0 which relate to ACP (i.e., having a living will, DNR, DNH, medication restrictions, feeding restrictions). It was anticipated that having these measures in place would be related to dying in LTC rather that in hospital or emergency services.

Hypothesis seven. It was unclear before undertaking Study One whether ACP documents between participating sites would be different enough from one another to capture effects on place of death. If adequate differences in ACP documentation between LTC sites existed, it was hypothesised that documentation that aligned with more ACP Best Practices would be related to dying in the LTC home rather than in hospital or emergency services.

Research Methods

The Board of Directors of the North West CCAC was approached by the researchers to request a statement of their support for this project. A letter of support was obtained from the Chief Executive Officer of the North West CCAC and was included with REB applications and participation invitations to Directors and Executive Directors at all facilities. The methods for each individual study are discussed separately below.

Study One: An Audit of ACP Documents Used in Long Term Care and Hospitals

Purpose

The purpose of this study was to perform an audit of existing documents used to record and communicate advanced directives in LTC, CCC, and ACH facilities in the community and to compare existing documents to established best practices for ACP documentation (Table 2, #17). This study aimed to answer the following research questions:

1) What are the characteristics of ACP documents in use in LTC, CCC, and ACH?
2) How do the ACP documents compare with the key features for ACP documents, according to the best practice principles of ACP?

Methods

Design

This descriptive research study used a best practices control design with two independent raters. This study was reviewed and approved by three institutional Research Ethics Boards (REB) and one Research Program at a Regional Health Sciences Centre.

Setting and Recruitment

This study took place in a medium sized urban, but geographically isolated, community in Northwestern Ontario, Canada. At the time of the study this community and surrounding area was served by six LTC homes, one complex continuing care (CCC) hospital, and one acute care hospital (ACH). Three of the LTC sites were for-profit and the remaining three were publicly funded and non-profit. The CCC facility is sometimes a transition facility for people who then

enter LTC following a medical crisis or change in health status[6]. The CCC site also has an in-patient hospice unit. Each of these organisations, which either provided or were involved with in-patient and residential care of older adults, was invited to participate.

Invitations to participate (Appendix A) were sent via email to an executive or a director at each site. In many instances, the contact person had been identified during the REB process. Where that was not the case, a researcher identified an appropriate contact person by contacting the Executive Director or Chief Executive Officer of the facility/organisation either by telephone or email. Follow up emails were sent after two weeks if no response was received. Invitations included a detailed description of the purpose of the study, what would be required if they chose to participate including time commitment, steps that would be taken to protect the privacy of each participating organisation, that they would have access to an aggregate summary of results upon completion of the study, and contact information for the researchers and each of the REBs that had reviewed the project. Recipients were encouraged to contact the researchers with questions, concerns, or comments. Invitations also included an institutional consent form to be signed and returned to the researcher (Appendix A). Because of the complimentary nature of Study One and Study Two, these processes were combined (i.e., the invitation contained information about both studies). The institutional consent form gave signatories the option to indicate that they would participate in Study One only, Study Two only, both studies, or that they declined to participate altogether. Completed consent forms were scanned and submitted to the research team by email.

Primary participants. Each participating site was asked to identify a primary participant to liaise with the researcher for the purpose of carrying out the study at that site. The primary

[6] 11.2% of people who died in Ontario spent time in CCC in the final year of life (Tanuseputro et al., 2015)

participant was selected as a person knowledgeable about ACP, the processes followed for documenting ACP at that site, and which individuals at that site were most familiar with site-specific ACP practices (i.e., local ACP experts).

The researcher established contact with each Primary Participant to facilitate carrying out the study at their respective site. The primary participant was asked to provide information about how advance directives were collected, documented, and used at the site, and to provide a blank copy of any ACP form used at that site. Documents were sorted for analysis by type (i.e., LTC or Hospital) rather than site name and given a de-identified label (i.e., LTC1, LTC2, LTC3, and "Hospital" for ACH and CCC sites).

Instruments

Checklist for ACP Document Audit. The best practice features identified in the literature review and through consultation with experts (Table 3) were made into a checklist (Appendix B) and used to rate each institutional ACP document for the presence and quality of information (clearly stated, ambiguous/incomplete, not present). An ACP quality score was given to each document based on its compliance with the ACP best practices checklist. Documents received two points for each ACP feature that was clearly stated, one point for ambiguous or incomplete features, and zero points when that feature was completely absent. ACP Quality scores could range from zero to 22 for LTC sites and zero to 20 for the acute care hospital site (the item relating to transfer to acute care did not apply) and were to be computed and analysed as percentages. The instrument was created for the purpose of this study. Two raters independently scored each document and inter-rater reliability was calculated. The raters were the primary researcher and another research team member with knowledge of, but limited professional experience with, ACP (fifth year Resident in Psychiatry who was living in another

community in the province). Scanned, anonymised copies of the ACP documents were sent electronically to the second rater along with paired Checklists, labeled LTC 1, LTC 2, etc. to be completed and sent back to the primary researcher. Where there were disagreements in ratings, the raters discussed the item and came to a consensus on the rating (Appendix C). The checklist did not have a space for indicating the site name but did have a place to identify whether the rated ACP document was from a LTC home (e.g., LTC1, LTC2,…) or a hospital (CCC and ACH; Hospital 1, Hospital 2). One of the raters (the Author) had access to the key for identifying which facility corresponded to which number. This was unavoidable as the Author received each document from the primary participant, and then coded them.

Table 3: *Best Practice Features for Documenting Advance Care Plans*

i.	Identifies a substitute decision maker (and contact details) where applicable.
ii.	Resident competency at the time of completion is noted.
iii.	Current state of the resident's health is noted.
iv.	Indication of the resident's values and beliefs (things that matter most in life).
v.	Indicates future unacceptable health conditions.
vi.	Specifies resident's preferences in relation to life-prolonging treatment.
vii.	Specifies resident's preferences in relation to hospital transfer.
viii.	Specifies wanted/unwanted treatments- where applicable.
ix.	Clearly specifies goals for EOL care, (e.g., natural death, comfort).
x.	Appropriate signatures (clear, complete, dated, witnessed).
xi.	Evidence of physician review.

Note: Best Practice Domains were adapted from the "Respecting Patient Choices" programme (Silvester et al., 2012) and combined with input from a physician who represented Northwestern

Ontario on the Board of Ontario Long Term Care Physicians and a Nurse Practitioner who was the North West CCAC Community Care Manager and Palliative Pain and Symptom Management Program consultant.

Following submission of the ACP documents, the Primary Participant was also asked to answer questions about ACP processes at their site (Appendix D).

Results

Of the six LTC homes and two hospitals invited to participate, a response was received from all but one site. The eighth site responded indirectly with a message from their head office. The three for-profit LTC sites chose not to participate, stating they were not, at that time, participating in external research. The remaining three LTC homes and both hospitals submitted signed institutional consent and some form of ACP document for auditing. One site did not assign a primary participant and all communications remained between the Director and the researcher. Of the five participating sites, two LTC homes and one hospital were part of the same organisation and the remaining LTC home and hospital were independent of each other.

The same corporate documents were submitted by multiple sites, however, different versions were provided, and one site provided two different versions. The primary participant at the latter site indicated to the researcher that a third version of the ACP document was also available on-site, but it was identical to one of the submitted forms, although it had a different title, and therefore was not submitted for audit. Some of the documents were being used in combination with other documents: either a "Resuscitation Directive" that provided a space to consent to CPR, or a "Do Not Resuscitate Confirmation Form (DNRCF)"[7], or both (Table 4).

[7] The DNRCF was published by the MOHLTC. This document is the only order paramedics and firefighters in Ontario can accept as a true medical directive that allows them to *not* initiate resuscitative measures when a person loses vital signs outside of a healthcare facility. It is important to note that the DNR Confirmation Form is not a DNR order, but rather confirms the existence of a duly filled and signed DNR order.

The submission and use of these multiple documents will be further elaborated on in the below. Each document or set of documents submitted was scored using the Checklist for ACP Document Audit; when multiple documents were submitted to be used in combination, the combination of documents was scored jointly and will henceforth be referred to singularly (i.e., the document, the form).

Table 4: *ACP Documents Submitted by Each Site*

Site	Types of ACP Documents Submitted
LTC 1	Institutional ACP Form, Resuscitation Directive
LTC 2	Institutional ACP Form, Resuscitation Directive, DNRCF
LTC 3	Institutional ACP Form
Hospital 1a	Institutional ACP Form, DNRCF
Hospital 1b	Institutional ACP Form, Resuscitation Directive, DNRCF
Hospital 2	Institutional ACP Form

Interrater reliability was 95.45%. Differences in ratings occurred on three items of a total of 66 possible items (11 ACP best practices items (Table 3) rated for six sets of ACP forms). These were discussed by the two raters and consensus was reached on all three items (details outlined in Appendix C). ACP Quality scores ranged from 31.82% to 45.00%. Documents used in LTC had equivalent scores of 31.82% (7/22). Table 5 shows the features that were clearly stated, ambiguous/incomplete, and absent on the LTC ACP documents. Table 6 shows how

many of the ACP Best practice features were identified on each document, either in part or clearly, at all sites. One of the hospitals submitted forms that scored 31.82%, on par with LTC, and the other hospital submitted a form that scored 45.00%. The two versions of the ACP form that were submitted by a single site (a newer version and an older version) scored equivalently using the checklist, despite slight differences between the forms.

Table 5: *Occurrence of Best Practice Features on ACP Documents Used in Three Long Term Care Homes*[1]

	ACP Best Practice Feature	Clearly Stated (n)	Ambiguous/ Incomplete (n)	Not Present (n)
I	Identifies SDM and contact details	0	3	0
II	Competency at time of completion	0	0	3
III	Current state of health	0	0	3
IV	Values and beliefs	0	0	3
V	Future unacceptable health conditions.	0	0	3
VI	Preferences for life-prolonging treatment	0	0	3
VII	Preferences in relation to hospital transfer	0	3	0
VIII	Wanted/unwanted treatments	0	3	0
IX	Goals for EOL care clearly specified	0	3	0
X	Signatures (clear, complete, dated, witnessed)	0	3	0
XI	Evidence of physician review	0	3	0

Note. N=3 publicly funded, non-profit LTC homes. ACP = Advance Care Planning; SDM = Substitute Decision Maker; EOL = End of life

Table 6: *ACP Best Practice Features on Submitted ACP Documents*

Site	ACP Best Practice Features Addressed in ACP Documents	
	Ambiguous/Incomplete (n)	Clearly Present (n)
LTC 1	I, VII, VIII, IX, XI, X (6)	(0)
LTC 2	I, VII, VIII, IX, XI, X (6)	(0)
LTC 3	I, VII, VIII, IX, XI, X (6)	(0)
Hospital 1a	I, VII, VIII, IX, XI, X (6)	(0)
Hospital 1b[1]	I, VII, VIII, IX, XI, X (6)	(0)
Hospital 2[2]	VI, VIII, IX, (3)	I, X, XI (3)

Note. N=6 ACP documents from n=3 non-profit LTC homes, n=2 hospitals (n=1 ACH, n=1 CCC).
[1]Two sets of ACP forms submitted were submitted by one hospital
[2]XII was not applicable for Hospital 2

ACP documents were identical or nearly identical across LTC and CCC sites. Each form was titled "Treatment Directive[8]," and offered the choice between "Supportive/Comfort Care" and "Primary Therapeutic Care." Supportive/Comfort Care was defined as the provision of certain measures that were likely to be available within the facility, e.g., relief of pain, positioning, oral fluids, mouth care, oxygen (if available). Three of these forms stated, "Transfer to an acute care hospital **will not be utilized** for this level of care," (emphasis appeared on the original documents). The fourth form was a newly updated version that was reportedly not being

[8] A Treatment Directive is a type of document that can arise from ACP to specify the types of medical treatments an individual wants or does not want *under specific circumstances.*

used at the site that submitted it (more on this below). It defined Supportive/Comfort Care in the same way as the others, but had the statement, "transfer to an acute care hospital **may be utilized** for this level of care if it is deemed appropriate by the healthcare provider, and informed consent is provided by the client/SDM" (emphasis appeared on the original document). The Supportive/Comfort Care section of this updated document also had a tick box where the person completing the form could indicate that they had had a conversation with the client or SDM about treatment options available and documented this discussion in the client record. Primary Therapeutic Care was defined on all four documents as including the above-mentioned Supportive/Comfort treatments as well as "antibiotics if indicated" and transfer to ACH "may be arranged", where a physician at the receiving facility would make a decision about admitting or returning the individual to the facility. Below the Primary Therapeutic Care section was a space for the written name and signature of either the Client/Resident or the SDM, for a date, and for a signature of a witness. Below that were several spaces to indicate that the document was discussed or reviewed (signature, date only). Finally, at the bottom of the page it was written: "Note: The form is required to be updated regularly or if change in condition."

For those sites also using a Resuscitation Directive, these consisted of a box to indicate "yes" or "no" to CPR and a place for the name and signature of the client or SDM as well as the date and signature of a witness below the statement, "I understand that I can change my mind at any time." There was also a box to be completed by the attending physician, "if used as a DNAR Order form," where a box for "yes" or "no" could be marked to indicate whether resuscitation was to be attempted in the event of respiratory arrest or cardio respiratory arrest. Confusingly, this was followed by the statement "I hereby provide a **Do Not Attempt Resuscitation order** for the above-named patient" (emphasis in original), suggesting that the "yes" box was not to be

used. One hospital and one LTC facility provided a copy of their institutional policy regarding ACP.

The two-page ACP document from the other hospital was called a Code Status Form and provided space for assignment to one of five code status levels,

- Level 5: Full Resuscitation (Full Code): All resuscitation therapies within medically appropriate limits
- Level 4: Limited Resuscitation (Respiratory Code): No CPR, trial of intubation and ventilation, no chest compressions
- Level 3: Limited Resuscitation (Respiratory Code): No CPR, no intubation, trial of non-invasive ventilation, no chest compressions
- Level 2: No Resuscitation (No Code): No CPR, no ventilation, otherwise full medical and surgical therapy
- Level 1: EOL Care (No Code): No CPR, no ventilation, comfort measures only

Below the code status levels was a small area to indicate any addenda. The document specified where to place the document in the patient's chart and that a copy must be given to the patient or the SDM. There was an area to indicate that the form was discussed (or not) and space to provide a reason, also whether discussions occurred with the patient or the SDM, or both, and the name of the SDM and their relationship to the patient. The bottom of the first page had spaces to indicate the physician's printed name, date, time, and signature, as well as the name and (optional) signature of the patient or SDM who participated in the discussion. Policy at this site permitted the directive order to be taken over the phone by an R.N. or R.P.N., however if the directive was anything other than a Level 5, it must be reviewed with the patient, by the treating

physician, "as soon as is reasonably possible but no later than 24 hours after being notified". There was no indicated mechanism for verifying that the review occurred, nor any indication of consequences for not doing so. The second page of this document consisted of guidelines for completing the form, essentially summarising sections of the full policy. These included:

- Information on determining the SDM and the responsibilities of the SDM
- Criteria for deferral of the code status discussion (i.e., the treating physician can designate the individual as Code 5 without discussion with the patient or SDM) when
    - 1) cardiac and/or respiratory arrest is unanticipated,
    - 2) the provision of CPR or other life sustaining treatments would be clinically appropriate, in the opinion of the treating physician, or
    - 3) the treating physician has "no reason to believe CPR and/or ALST[9] would be refused;"
- Criteria for a mandatory code status discussion (i.e., a discussion was requested, a code status of less than five would be appropriate, the patient has an end-stage disease status);
- Procedures for a nurse to designate a code status level, including the requirement of physician review within 24 hours for any code status changes.

The primary participant from one hospital submitted two sets of ACP documents and explained that a new version of the ACP document was "supposed to be used", but that staff were at that time "refusing" to use it. It was reported by that individual that nursing staff in particular had concerns about professional liability related to the new form, specifically that the new set of forms did not include the Resuscitation Directive and therefore did not have a space for the patient or SDM's signature indicating their wish for no resuscitation. Further, they stated

[9] ALST = Advanced Life Sustaining Treatment

that staff had not received training on how to use the new form and associated new practices, which included ticking a box on the ACP form indicating that they had documented on the patient chart that a discussion regarding EOL care had occurred. That primary participant felt that many staff did not have training on what was required and how to have those conversations, which contributed to their concerns over documenting that such a discussion had taken place. It was further reported by the primary participant that the document had changed names a number of times and that multiple versions were currently available on site, potentially adding to confusion about which document to use.

Discussion

Hypothesis One was supported in that all organisations/facilities enrolled in the study identified having an ACP document and the documents' content did vary between the ACH and other sites. Hypothesis Two was partially supported: ACP documents had low ACP quality scores across all settings (LTC, ACH, and CCC), however the quality of documents did not appreciably vary.

Six documents (or sets of documents) were submitted for audit from five sites. It was unanticipated that the documents would be as similar as they were, particularly across hospital and LTC settings, where needs were expected to differ. Five of the documents scored identically on all eleven best practice features of ACP documentation. These five documents were from three LTC homes and one hospital, the latter of which submitted two documents, one was a recent revision of the other. Two of these LTC homes and the hospital belonged to the same organisation. Except when necessary to distinguish between sites, these are referred to

collectively as the "LTC group" and the remaining document is referred to as the "hospital document."

Completely Absent Features of ACP

Five of the eleven (45.45%) identified best practice features of ACP documentation were completely absent on all of the documents submitted from LTC group and four of ten (40%) features were completely absent from the hospital document[10]. Of particular concern was that none of the documents identified the resident/patient's competency at the time when the directive was taken (ACP Best Practices Feature II). This was a significant oversight given that only a competent individual can participate in ACP, and one can only participate in ACP for oneself. People have a right to make individualised plans that reflect their values and what is important to them (e.g., eating on one's own, dying naturally, terminal sedation, spending conscious time with friends and family, privacy, spiritual practices and beliefs; Government of Ontario, Ministry of the Attorney General, 2012; ACP Best Practices). None of the documents indicated residents' values or beliefs, or conditions they would consider unacceptable (ACP Best Practices Features IV and V). ACP is an expression of wishes, not a consent to treatment or non-treatment. If, on the other hand, the Treatment Directive (i.e., LTC documents) was meant to be used as a treatment *decision* and *not* for ACP purposes, then, per the HCCA, the *decision* would need to relate to a specific medical need or condition, a specific treatment, and be fully informed. Not one of the documents (LTC group or hospital) made space for recording the current state of the resident's health (ACP Best Practices Feature III), leaving open the possibility that the treatments selected on the form may or may not be related to a particular state or condition or disease process. The latter is a more likely scenario in the LTC setting than the hospital settings. An

[10] The hospital document was only scored on 10 features because transfer to hospital was not applicable (i.e., feature VII).

SDM cannot participate in ACP as SDMs, by definition, only make decisions and they do not express wishes. Further, the HCCA requires competency to be assessed on a situational basis, meaning that a resident may be competent at one time of day but not another, or for one decision (e.g., to take pain medication) but not another (e.g., to consent to an invasive procedure). Fluctuations in capacity are particularly relevant when an individual is affected by cognitive impairment due to dementia. Each of the submitted documents required only one signature (either the individual resident or their SDM) to endorse a suite of possible treatments, subsumed under vague headings, and not necessarily any particular treatment. This is problematic because the resident may wish for some of the treatments offered and not all of them, or may be competent to do so for some and not all.

Ambiguous and Incomplete Features of ACP

All documents in the LTC group had six features which were either ambiguous or incomplete, the hospital had three features which were either ambiguous or incomplete (Table 6).

The HCCA ensures that no individual is ever without an SDM by providing the hierarchy of SDMs (Appendix E). If a competent individual chooses to specify ahead of time a specific person or people to be their SDM for treatment decisions (i.e., power of attorney for personal care), they may do so using a widely available and free form[11]. Given that the purpose of ACP is to communicate an incapable individual's wishes to their SDM, it follows that identifying the SDM when ACP is documented (ACP Best Practices Feature I) would make the document more functional and better meet the needs of the individual doing ACP. Five of the ACP documents reviewed (the LTC group) did not clearly state the name of the SDM unless the SDM was the

[11] From the Ministry of the Attorney General, https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.php

individual completing the document[12] (i.e., the resident/patient was already deemed incompetent), therefore anyone who was competent to participate in their own ACP was not provided a space on the form to identify who would make decisions on their behalf, should they become incapacitated. The hospital form did provide a space for recording the SDM, as well as guidelines for determining the SDM. None of the documents reviewed provided space for recording SDM's contact details.

An important part of ACP discussions is determining an individual's EOL goals and identifying treatments which would be wanted or unwanted (ACP Best Practices Features VIII and IX). These can be broad, for instance, someone might specify that having a natural death, pain management, staying conscious as much as possible, or feeling dignified as goals of EOLC. Goals can also be specific, for instance, someone might wish for life prolonging/sustaining treatments to help them live until some milestone (e.g. ,birth of a grandchild, visit from a loved one) and may only wish for that when certain conditions can be met (e.g., pain can be managed in a conscious state). The goals of EOL care were incomplete or ambiguous on all reviewed ACP documents and only addressed medical treatments. The hospital document was very specific with regards to treatments that would be provided, if medically appropriate, at each code status level. The LTC group of documents were extremely non-specific and grouped vaguely described treatments, some of which may not even have been available at each site (e.g., "oxygen, if available") under two headings. The hospital document provided a line to stipulate addenda, which could foreseeably be used to specify wanted and unwanted treatments from those listed. The LTC group forms were completely ambiguous in this regard. None of the forms provided

[12] Under the HCCA, only a competent individual can complete ACP for themselves, and an SDM can only make decisions and not express wishes, therefore an SDM should not be completing true ACP forms on anyone else's behalf. An SDM may make treatment decisions on another person's behalf.

any space for advance care planners to indicate goals, conditions, or circumstances when their wishes would or would not apply.

None of the LTC group of documents clearly identified who was reviewing the document (i.e., whether it was reviewed by a physician offering the treatment, as required by the HCCA; ACP Best Practice Feature XI). There was a space for "Reviewed By" and a date and signature, but no space to identify the printed name or qualifications of the individual providing review, nor their relationship to the resident/patient. Consistent with the insufficient evidence of physician signature and review, the LTC documents did not provide sufficient space for the signatures (ACP Best Practice feature X) in that only one individual could sign the document- either a resident/patient or an SDM but not both. There was, however, space for one signature, their printed name, date, and a witness. The HCCA does not require that ACP documents be signed, but it is generally considered a good practice as a means of ensuring that the document was reviewed and understood by those completing it.

Do Not Hospitalise (DNH) orders. There was disagreement between documents used in a single setting over whether Supportive/Comfort Care "may" or would "not" include transfer to an acute care facility. The documents reviewed were abstruse with regards to DNH, and none provided a space to clearly identify a standalone wish not to be transported to hospital, nor under which circumstances such a transfer would be acceptable or not acceptable (ACP Best Practices Feature VII).

Review of Institutional/Organisational Policy

Although not requested as part of the study, two policies regarding ACP were submitted and subsequently reviewed by the researcher. One was an organisational policy that was

applicable at three sites, the other was from the ACH. Interestingly, the organisational policy on Advance Care Planning that applied to three of the participating sites summarised appropriately the intent and purpose of ACP. For example, the one page policy stated that ACP is "a means of communicating clients' healthcare wishes;" "communicating about healthcare and life sustaining treatments before a crisis situation arises;" and a means of allowing individuals "the opportunity to provide direction for family and caregivers should they become incapable." The policy goes on to explicitly state that clients are not required to complete an advance care plan. The policy also stated that in instances where there is no advance care plan and the individual becomes incapable of making decisions, the healthcare team will consult with the SDM about treatment decisions. On this last point, it should be noted that this seemed to indicate a misunderstanding about ACP and ACP documents that permeated the results of this entire study, namely that, in Ontario, an ACP document is *not* a decision maker, it is a place to record a person's wishes for their own care that is used to guide decision makers when the individual is incapable. When an individual is deemed incapable of making an informed treatment decision by the individual offering that treatment (e.g., a physician, psychologist, nurse practitioner, occupational therapist), then the SDM must be consulted, if possible, to make the treatment decision. The decision made by the SDM must take into account their knowledge of the individual's wishes and values, be made in the best interest of the individual, and be informed by the current situation. It can be both legal and ethical for the SDM to make a decision that contradicts the recorded wishes of the individual under circumstances that warrant it, therefore, the document itself does not function as a decision maker and should not be consulted *in lieu* of a decision maker (HCCA Act. 1996, c. 2, Sched. A, s. 10 (1)). There was no mention or reference in the policy to the Treatment Directives document or any other means of documenting ACP

discussions. Indeed, the Treatment Directives document seemed to be at least in part at odds with the organisational policy on ACP in that it did not aid in facilitating communication about life-sustaining treatments outside of CPR (e.g., artificial nutrition and hydration, different types of ventilation, medical assistance in dying), and does not give residents/patients the option to decline completing a treatment directive (i.e., there is no place for the healthcare provider to indicate a discussion was offered and declined, and the wording that the Treatment Directive "is required to be updated" may be misleading to some).

The ACH policy required the use of coloured armbands to identify patients with differing code status levels. It was an interesting practice demonstrating how challenging it can be to balance legal and ethical dilemmas in EOL care. On the one hand, a patient's personal health information will be put on display, potentially breaching their right to protect that information and the requirement[13] of the health care providers to do so, and on the other hand, ensuring that the patient receives the level of treatment or non-treatment requested. One health professional recounted having a patient "who always took her armband off, she said that it ID'd her as a 'dead woman walking,'" highlighting the disparity between the needs of the health providers for clarity and the needs of the individual for privacy and avoidance of stigma.

Legislated Considerations and Requirements

Under the LTCHA, ACP and levels of care documents are regulated documents. Regulated documents are documents containing a consent or a directive concerning treatment[14]. It is legislated that these documents must meet the requirements of informed consent set out in

[13] Personal Health Information Protection Act (PHIPA)

[14] Treatment, as defined by the HCCA, is anything that is done for therapeutic, preventative, palliative, diagnostic, cosmetic, or other health related purposes and includes a course of treatment or plan of treatment. Treatment includes EOL care.

the HCCA, although a directive is not a consent. Whether individuals signing these forms are sufficiently informed was impossible to know from an audit of the form, however, taking into consideration the anecdote from one primary participant (i.e., that health professionals completing the form at that site were not confident about how to have or document ACP discussions), and the evidence reviewed demonstrating that healthcare workers often do not understand ACP, it can be surmised that individuals are not fully informed in at least some instances. Only one site submitted policy specifically detailing what needed to be included in ACP discussions to achieve informed consent. At one of the hospitals, the policy permitted a physician to forgo any conversation with the patient and to simply document on the health record that the individual is to be full code (i.e., all interventions possible, full resuscitation), however there were specific health conditions with high mortality risk which made ACP discussions mandatory and examples of these were listed on the document itself.

Under the LTCHA it is specifically required that regulated documents contain a statement that consent can be withdrawn at any time. Only the Resuscitation Directive, which was being phased out at the time of this study, contained any indication that an individual could change their mind.

Section 80(1) of the LTCHA requires that, before any regulated document is presented for a signature, it must comply with all requirements of the HCCA and LTCHA, and it must be certified by a lawyer. According to elder law specialist Judith Wahl, B.A., LL.B., lawyer certification must ensure that when staff see the document they must understand (1) that consent must be informed (and what that means) and (2) that consent must come from the appropriate person (i.e., the SDM according to the HCCA). Wahl goes on to write,

> "Review by lawyer should ensure that when staff see the document that staff understand that: only resident can provide an 'advance directive' or 'wish' about future care; that SDM cannot advance care plan for resident; that 'level of care' forms are **not consents**; that there is no requirement for signature of a level of care form or any other form of directive and lack of signature is not an impediment to care delivery," (Wahl, 2011).

It was unknown whether any of the audited forms were certified by a lawyer, but it appeared that none of these requirements were met by the LTC group documents. Further, it was possible that these documents were being used as consents to treatment, which is not allowed under the HCCA or the LTCHA, but seemed to be implied in the policy of one organisation and not expressly stated on any of the audited documents.

It is clearly stated in the LTCHA (section 83) that coercion is prohibited, specifically, that a resident or prospective resident cannot be forced into completing a directive or required to do so. This appears not to be uniformly understood or made clear on the documents themselves, which, as noted, have a statement saying the form is "required" to be updated. Using the word "required" may be misleading to some, whether residents, SDMs, or health care workers, who might assume the form itself is required. When asked whether every resident had a completed Treatment Directive at a particular LTC home, the primary participant at that site responded by email that, "all residents have the [organisation] treatment on file… [It] is part of our admission process and NEEDs to be completed. If they have their own we could incorporate it but ours would still need to be completed," (emphasis in original). Another primary participant reported that "all residents have a treatment directive on file," and another stated, "Every patient is supposed to have been reviewed and documented in the electronic record… It doesn't always happen." Evidently, it was not universally understood that LTC home residents could not be

required to complete ACP/Treatment Directives. It may be that no resident or potential resident has questioned or hesitated completing the directive, one primary participant reported, “we have never had an issue with someone refusing to fill it out.”

Limitations and Strengths

One significant limitation of this study was that for-profit LTC homes were not included. Three of six LTC homes in the community were run by a private organisation (50.00%), two were non-profit (33.33%), and one was municipal (16.17%). This was reminiscent of the provincial average, where 58% of homes are privately owned, 23% are non-profit/charitable, and 16% are municipal (MOHLTC, 2017). It was a strength of this study that there was representation from both non-profit and municipal LTC homes, accounting for half of the LTC homes in this community. Previous EOL care studies in this community did not have participation from more than one LTC home provider.

It may be considered a further limitation that retirement and assisted living homes were not invited to participate in this research, as they are also places where older adults may receive care up to the EOL. This study was attempting to ascertain how ACP was documented when individuals were at greatest risk of needing ACP (i.e., unable to communicate their wishes). Older adults living in LTC homes were more likely to be living with more advanced disease processes and greater likelihood of cognitive impairment compared with those living in more independent living environments such as those provided by retirement living or assisted living residences, thus we chose to focus on LTC homes. Individuals may have completed ACP while living independently or in an assisted/retirement living situation and subsequently moved into LTC with their previously completed ACP, however, that did not appear to be the case given

comments from primary participants that, for example, “there are no residents with their own advanced directive document to my knowledge,” and, “if they had their own we could incorporate it but ours still needs to be completed.”

This audit returned identical results across participating LTC homes in this community and in one hospital, however, the representativeness of these results is not generalizable to LTC homes across the entire community, nor the province, nor beyond, as each home or provider may be using its own ACP document. It was notable, however, that every LTC document audited was identical in both format and wording, with only the logo distinguishing them. The duplicate content and design of ACP documents across settings and providers (municipal and non-profit) might indicate that there was sharing of resources at a local level or beyond (e.g., online internationally, inter-provincially, through professional networks, etc.). Indeed, Wahl, Dykeman, and Walton (2016) identified that many care providers across this province do turn to other jurisdictions for EOL resources. Interestingly, perhaps alarmingly, the requirements laid out in provincial laws (HCCA, LTCHA) were not clearly adhered to, which may reflect interjurisdictional resource sharing, where regulations can vary widely.

The audit tool itself could be both a strength and a limitation of this study. The best practice features were primarily identified by an Australian working group of experts (Silvester et al., 2012), and amended and ratified by experts at the local level. Participation from international, interprofessional front-line and academic experts in establishing the best practice features used in this document audit was a definite strength of this study. At this stage of research on this topic, empirical evidence does not exist in sufficient amounts to establish best practices, thus expert consensus is the current gold standard. Using a second rater to verify the accuracy in interpretation of the audit tool was another strength.

The development and proliferation of electronic health records may make the format of the audit checklist used in this study antiquated. For example, the SDM's contact info may linked within the resident's electronic record and therefore not need to be recorded in the same way (i.e., not on a form or sheet of paper). Similarly, the contact information and credentials of the reviewer signing an ACP document could be automatically recorded, along with a date and time stamp. The fundamental aspects of the checklist would not change, however, as the recording of and access to the identified best practices features would remain the variable of interest. At all participating sites in this study, ACP was documented on a form that may then have been scanned and uploaded to the resident/patient's electronic record. If this study was repeated in a setting where purely electronic health records were kept, an additional level of REB review and institutional clearance may be necessary for researchers to gain access to electronic records. For this study, all sites provided a paper document for audit.

Integrated electronic health records across settings (e.g., health records available to care providers across LTC, ACH, and primary care settings) will allow for real-time and efficient information sharing across facilities and between departments. As was noted by one primary participant at a hospital, "their wishes should always be transferred with them… [Advanced] directive wishes are always sent between facilities if known, this includes other hospitals, long term care, supportive and retirement living;" however, this was contradicted by the primary participant at another facility, "The resident's treatment directive is always sent with them when transferred to another facility… [we] rarely see them returning from hospital admission with these." It was a limitation that we were not able to verify how frequently or infrequently the documents were sent between facilities or read. It was a limitation of this and previous research

(Wahl et al., 2016) that we did not examine how EMRs are used in the documentation of ACP and this will be an important area for future investigation.

Although the purpose of this study was to establish the characteristics of ACP documents in use in LTC, CCC, and ACH and how those characteristics compared with ACP best practice guidelines, some may consider it a limitation that we did not examine the completeness and accuracy of what was in actuality recorded on ACP documents. It was our intention to establish what each site aspired to collect and document in a best-case scenario (i.e., each document completed in full) as a baseline starting point for a research programme which could then be broadened.

Conclusions and Future Directions

The quality of ACP documents in the places where older adults receive care in this community was low and almost equivalent across all settings. One hospital setting provided a document for recording patients' ACP that scored slightly higher than all other settings due to addressing specific life-sustaining treatments as opposed to only CPR, and to demonstrating clearly that a physician had reviewed the document.

None of the submitted documents, strictly speaking, met the definition of ACP, which is an expression of wishes. Not a single form used the word "wishes" and none made clear that these forms could not be used to consent to treatment or non-treatment, in accordance with Ontario law (i.e., HCCA). For example, if a resident indicated a wish for supportive care that did not include transfer to hospital, and later that resident suffered a stroke and was no longer able to communicate her wishes, an SDM would still need to be contacted to make a decision regarding care, i.e., consent to transfer to hospital for acute care or receive comfort measures at the

residence. The SDM could use the Treatment Directive to guide their decision making, but the treatment directive cannot itself communicate a decision. These findings were mirrored in the audit of n=43 ACP-related documents from various care settings in Ontario (including policies, discussion guides, brochures, standard forms, educational resources, etc.) completed by Wahl and colleagues (2016), where they found tools using unclear or incorrect language, forms used incorrectly as a consent, limited or inappropriate treatment options, a preoccupation with treatment-centered decisions, among other issues.

All of the audited ACP documents pertained to treatments likely to be offered or relevant only at the very EOL (i.e., acute dying phase) or in the event of a cardiac or respiratory arrest. The types of information relevant to living in accordance with ones wishes as one approached the EOL (and not just as one was dying) in LTC was not conceptualised as part of ACP. Many LTC residents live there over many years and they may experience multiple transfers between facilities during that time, usually for treatment of remediable (i.e., non-fatal) injuries or symptoms. Residents with dementia in particular are at heightened risk of living through a protracted period of moderate to severe illness, punctuated with acute health crises requiring health care decisions. Information about each resident's values and beliefs, future unacceptable health conditions, specific preferences for life-prolonging treatment, and goals for EOL care (i.e., ACP best practices features that were absent or incomplete) would be valuable throughout their stay in LTC. Undoubtedly, some of this information will be known to some members of staff through interactions with the resident, or the family members, and/or friends who may visit the resident. It may also be recorded elsewhere, for example, as part of the resident's RAI and in case notes by specific disciplines (e.g., social work). Whether that information is readily available to any staff, health professionals, or decision makers when needed is unclear. Primary

participants were not limited in the number of documents they could submit; therefore, it is reasonable to suspect that any documents or means of recording wishes, values, goals, were simply not considered relevant by the primary participants for inclusion in the audit.

There seemed to be a rigid insistence on completing a facility's specific form, rather than on the outcome of ACP or the function of the ACP document. It would be reasonable to assume that in many cases, the person entering LTC would have cognitive impairment that might limit their ability to participate in ACP. It was ethically and legally problematic that any ACP completed when that individual was competent to do so would then be re-done in a new format, particularly given the apparent weakness of the documents reviewed in this audit. It would be useful to examine patterns of sharing and using previously completed ACP when individuals enter LTC from the community or retirement/assisted living residences. For completeness, such research would benefit from including primary care providers who may have discussed ACP with patients, family members, as well as professional residential care providers, and gate-keepers such as the LHIN, in ascertaining whether ACP existed before admission to LTC and if so, when or under which circumstances it was or was not shared upon admission to LTC.

One of the primary participants recounted, "we often hear that they do not look at the documents we send, particularly in the emergency department, and if they look at our documents, we do not know that the directives we use are clear and understood by receiving facilities." An electronic health record would potentially leave a 'footprint,' potentially allowing researchers and clinicians and family members to track who had reviewed an ACP document, when, for how long, et cetera. Availability of such data could open the door to future research examining how ACP documents are used in facilities providing health care, and can inform the development of research examining how well ACP, as recorded, is understood and utilised. A

further example of how electronic health records may facilitate ACP is through the use of prompts and checklists for ACP discussions, thereby limiting variability between health care providers when ACP discussion occur, and encourage completeness of discussions and documentation of such discussions. Future research could examine the effectiveness of the use of prompts and guides and their acceptability to both staff and residents/SDMs/family members. It will be imperative that all staff be adept at using the technology and software to access needed information in timely manner, and improve accessibility across settings while ensuring patient confidentiality. Empirical evaluation of training programmes on electronic health records in the context of ACP would be beneficial.

Institutional policy, by its very nature, is meant to shape institutional practices. The purpose of having policies in place regarding ACP is for ensuring provision of quality care and quality of dying for people receiving care in LTC homes and hospitals at the EOL. It is also meant to aid organisations in meeting their regulatory and legal, as well as ethical, responsibilities. Policies are not meant to be aspirational but rather to guide practices within an organisation or facility. The two policies reviewed in this study demonstrated the difficulty balancing the needs of organisations with the needs or wishes of individuals relying on those organisations for support at the EOL. One of the policies reviewed was applicable at three of the sites audited. That policy emphasised that ACP discussions are an important part of providing compassionate and holistic care, that ACP is encouraged as a means of communicating healthcare wishes, that ACP does not replace informed consent, and that decisions can be changed at any time. While the sentiments expressed in that policy may, in practice, guide health care workers' discussions with residents/patients and SDMs about ACP, the ACP recording documents, in addition to anecdotal evidence from the primary participants, did not lend

confidence to the likelihood that this policy has been promoted or enabled in practice. The limited scope and unclear presentation of EOL care options combined with a lack of clarity over whether a DNH order was wanted by or available to the resident/patient, seemed out of line with the goals outlined in the policy. It would be appropriate for organisations providing care to older adults to review both policy and practices related to ACP and EOL care for compatibility not only between the policy and practice but also with relevant legislation, and with the principals of biomedical ethics[15].

This document audit was undertaken to compare current practices for recording older adults' wishes for EOL care with identified best practices in ACP documentation. Results demonstrated plainly that processes in place for documenting ACP in places where older adults receive care, particularly EOL care, can be improved in both content and clarity, when compared to best practices. Whereas ACP best practice standards are built on a holistic and person-centred model of EOL decision making, the documents reviewed seemed built to meet the medical-model needs of institutional care providers. The lack of concordance between audited documents and best practices, therefore, are hypothesised to stem from the differing needs of the individuals who will live and die in care, and the LTC homes and hospitals providing that care. Based on this study, it would be beneficial to consult with all stakeholders (residents, families, health professionals and other staff, LTC homes, hospitals) to better ascertain what ACP-related information is accessible versus missing, and how to optimally offer that information to decision makers when needed. There is ample evidence supporting the need for good ACP and its beneficial impact for persons who die and their survivors when ACP is done well. Less evidence has been gathered regarding the needs of health care providers and institutions or facilities where

[15] The four principles of biomedical ethics, as described by Beauchamp and Childress (1979) are: 1) Principle of respect for autonomy, 2) Principle of nonmaleficence, 3) Principle of beneficence, and 4) Principle of justice.

older adults receive EOL care and where ACP is likely to be implemented. Future research should consider the experiences and needs of health care providers for documenting and communicating ACP.

Study Two: Healthcare Workers' Perceptions of Institutional ACP Documents

Purpose

The purpose of this study was to describe the views of health care workers with expertise in ACP at participating facilities and organisations (LTC, CCC, ACH, CCAC) regarding the usability of existing ACP documents and perceived potential impact of implementing a standard local ACP language. The study aimed to answer the following research questions:

1) What are healthcare workers' experiences and perceptions regarding existing ACP documents?
2) Do health care workers perceive benefit from standardising the language used in ACP documents?

Methods

Design

Purposive expert sampling techniques (Bowling, 2014) were proposed for this study. The technique is utilised when information is sought from individuals who have particular expertise in the area under study. In this study we were seeking information from healthcare workers with expertise using ACP documents in general, and specifically, using site-specific ACP documents. This sampling approach was selected because prior research indicated that not all health workers who used ACP were equally experienced with ACP and we wished to elicit information from those who were most familiar with the documents and related processes. The recruitment procedure was modified, however, in order to more fully protect potential participants from pressure they might have felt from being invited to participate by a manager or director.

A modified sampling technique was adopted in which the primary participant would identify five to ten individuals at their workplace who were familiar with the completion and use of ACP documents as a part of their regular duties. An additional level of separation was introduced in that an additional research team member was added, and that individual had the role of receiving the five to ten names from the primary participant through a specially set up email account and then randomly selecting two to three individuals from the names provided by the primary participant. The randomly selected potential participants were sent an information letter and questionnaire via inter-office mail. At the two sites where inter-office mail did not apply, the materials were simply dropped off and placed in the potential participant's mailbox. Anyone sending an email to the PFD-LTC address received an automatic reply thanking them for contacting the study and directing that any questions or concerns should be sent to the primary researcher or any of the REBs who had reviewed the study. The third team member had no direct contact with any participants or potential participants. This study was reviewed and approved by three institutional Research Ethics Boards (REB) and one Research Program at a Regional Health Sciences Centre.

Setting and Recruitment

The setting and organisations described in Study One were also invited to participate in Study Two. In addition, another type of organisation was invited to participate in Study Two. The North West Community Care Access Centre (CCAC) was an organisation of diverse health professionals that had the role of coordinating health care services in Northwestern Ontario, including gate-keeping individuals' access to LTC and home care. The same week we contacted the CCAC about participating in this study, however, those duties were taken over province-wide by Local Health Integration Networks (LHIN) while the 14 provincial CCACs were dissolved.

With funding from the Province of Ontario, LHINs are mandated to plan, integrate and fund local health care, and to deliver and coordinate home and community care. The CEO of the CCAC made a request to the North West LHIN's new Director of Home and Community Care Planning and Strategy that the study continue to be supported despite the transition. That request was honoured by the LHIN's CEO.

Primary participants. As in Study One, each participating site was asked to identify a primary participant to liaise with the researcher for the purpose of carrying out the study at that site. The primary participant was selected by the Director as a person knowledgeable about ACP, processes followed for documenting ACP at that site, and knowledgeable of who else at that site was most familiar with ACP practices for that site. The primary participant selected and communicated the names of five to ten individuals from their site who were familiar with using (completing or interpreting) ACP documents and sent them to a researcher via email, the persons identified names became potential participants.

Potential participants. The primary participant identified the potential participants. These could be any individual worker who, in the opinion of the primary participant, was knowledgeable on the use of that site's ACP document(s). The names were sent in an email to a member of the research team who was not involved in other aspects of the research. That other researcher randomly selected 2-3 names from each list and, using inter-office mail, distributed an information letter, copy of the Advance Directive Questionnaire for HealthCare Providers (Appendix F), and a stamped, addressed envelope for anonymously returning the questionnaire to the main researcher. Consent was accepted as implied when the questionnaire was completed and returned.

Instruments

Advance Directive Questionnaire for HealthCare Providers. This instrument (Appendix F) was designed by the researcher for the purpose of this study, with the input from an experienced manager with expertise in EOL care and a qualified LTC physician. It contained six questions that asked about the equivalence of ACP documents across facilities, perspectives on standardisation of ACP language, and whether ACP documents support EOL decision making. Possible responses were yes, no, not applicable, and prefer not to answer. After each question, there was a space to provide comments. The questionnaire was anonymous and explicitly stated that respondents should not record their name or place of work on the form.

Analysis

The data analysis was descriptive. The small number of facilities precluded analysis by facility type, thus the decision to keep the questionnaire anonymous for setting and not to employ inferential statistics. Qualitative responses were grouped thematically.

Results

Questionnaires were distributed at two LTC homes, two hospitals (CCC, ACH), and the regional LHIN. Because of the blinding procedure, it was unknown how many questionnaires were distributed in total (two or three per site). Eleven of a possible ten to fifteen questionnaires were completed and returned to the researcher by mail, for a minimum response rate of 73.3%, or up to 100%. Frequencies of categorical responses are displayed in Table 7. None of the respondents selected the “prefer not to answer” category for any question and it was removed from the displayed results.

Table 7: Frequencies of Health Care Providers Perceptions Regarding ACP Documents

	Yes % (n)	No % (n)	Not Sure % (n)	N/A % (n)
Are documents for recording treatment directives equivalent across local facilities where older adults receive care (i.e., hospitals, LTC, CCC)?	18.2 (2)	72.7 (8)	9.1 (1)	-
Is it straightforward to transfer the intent of treatment directives from one institution to another when a patient relocates?	18.2 (2)	72.7 (8)	9.1 (1)	-
Would a standardised treatment directive document (i.e., common language used at all facilities) ease communication of a person's wishes across treatment settings?	90.9 (10)	-	9.1 (1)	-
Would a standardised treatment directive document (i.e., common language used across all facilities) improve patient care?	90.9 (10)	-	9.1 (1)	-
Does the treatment directive document at your primary workplace contain sufficient information to support EOL treatment (or non-treatment) decisions?*	30.0 (3)	60.0 (6)	-	10.0 (1)
Is the treatment directive document at your primary workplace easy to use and interpret when needed to guide EOL decisions?	45.5 (5)	45.5 (5)	-	9.1 (1)

Note. N=11 participants.
*Item 5 was left blank by one participant, therefore n=10 for item 5.

Most participants chose to provide explanations and comments to accompany their responses on the questionnaire. These were analysed by the researcher and grouped into themes. Themes identified were: not "speaking the same language", confusion/inconsistency, support for standardisation in ACP, and ACP documents as barriers to care. Examples from each theme were provided below. Complete qualitative responses are detailed in Appendix G.

Themes[16]

Not "speaking the same language".

"At times, we have clear directives in place but when a person goes to acute care, their wishes are not clear to them as they don't speak our language."

"Hospital has 5 code status levels but community care not educated on this system."

"When we send older adults to the emergency department, they often don't look at the directives we send and if they do - I don't believe they understand the meaning. They work in a setting where they do everything they can to 'save' a person, they often don't think about this like we do."

"We all need to talk the same language within and outside health care organisation."

Confusion/inconsistency.

"Not clear at all. Support/Comfort Care vs. Primary Therapeutic Care. Same staff unsure which to check off. Very confusing."

[16] "pt" is an abbreviation for "patient" used by many of the participants and recorded here verbatim.

"Confusion on admission at times."

"Lots of room for misinterpretation, lacks clarity for care givers."

"Very difficult to explain, especially for new staff."

Support for standardisation in ACP.

"Absolutely, we need to speak the same language."

"[Standardisation] would be a more efficient use of everybody's time and would be more empathetic to pt/family's situation."

"Should be across the province."

"Especially if it was electronic and all facilities used same electronic system"

"Any improvement in communication and understanding will improve patient care"

"Could improve/educate on the process. Make it easier for all levels of care providers to complete."

"Would be consistent."

Current ACP document as a barrier to care.

"Does not reflect level of care available in LTC."

"Because each institution has different documentation, often health care professionals have to discuss treatment directive with pt again in order to clarify."

"Usually a paper form that often gets lost."

"[Standardisation would mean] a person's wishes would be considered in discussions in all settings and their individual needs would be met."

"[Standardisation would] more easily provide appropriate care."

"It does not go into detail like the code status level at the hospital so for pts who want more than just comfort measures, it does not provide an area to document specific pt wishes but works well in cases of 'comfort measures only.'"

"It isn't very clear. Nurses don't always explain it to clients in the same way either."

"Addressing escalation of care preferences can be challenging in acute care setting esp. in 'unstable' end-stage patients."

Discussion

Hypothesis three was supported. There was some variation in health care workers perceptions of ACP document equivalency and quality. In addition, there was variability in participants' familiarity with ACP principals and with ACP processes inside and outside of their primary workplace.

Support for Hypothesis four was mixed in that participants' views on the benefits of standardisation were consistent and in-favour of standardisation, whereas we had hypothesised there would be a small amount of variation in health care provider's opinions on standardisation, with the majority in favour. More than 90% of participants reported supporting the concept of standardising ACP language, both to facilitate communication of EOL wishes and to improve

patient care. None of the participants believed that standardisation would not improve ACP processes (i.e., none selected the "no" response).

Perceptions on ACP Document Equivalence

The majority of participants (72.7%) responded that ACP documents were not equivalent across facilities. That result was somewhat surprising given that Study One demonstrated that ACP documentation was nearly identical across all participating LTC sites and one of the hospital sites. Qualitative information further elucidated the discontinuity in participants' views. One participant explained, "every place has something different," and another wrote, "every institution has different forms if at all," when in fact, at least half of the LTC homes and one hospital in this community used a nearly identical form to record ACP and all six[17] LTC homes were using a form of some sort at the time of the study. Other participants were aware of the similarities, saying "no different for LTC," or perceived near-equivalency across all sites, "[Hospital 1], [Hospital 2], and LTC homes all have slightly different processes and forms," despite Hospital 1 having a very different format of ACP documentation and related practices from the other sites (e.g., five code status levels, use of armbands). It is unknown whether the three non-participating, for-profit LTC homes where using a different form and/or practices than the ones used in the non-profit and municipal LTC homes.

Confusion persisted concerning how readily shared or available ACP documents would be when a resident transferred between facilities. On one end of the spectrum were participants reporting that documents are not always available on transfer or had the potential to be physically lost in the process, and on the other end was the participant who reported electronic transfer between all hospitals in the region was already in place, including the CCC and ACH

[17] Includes the three for-profit LTC facilities which did not participate in this research.

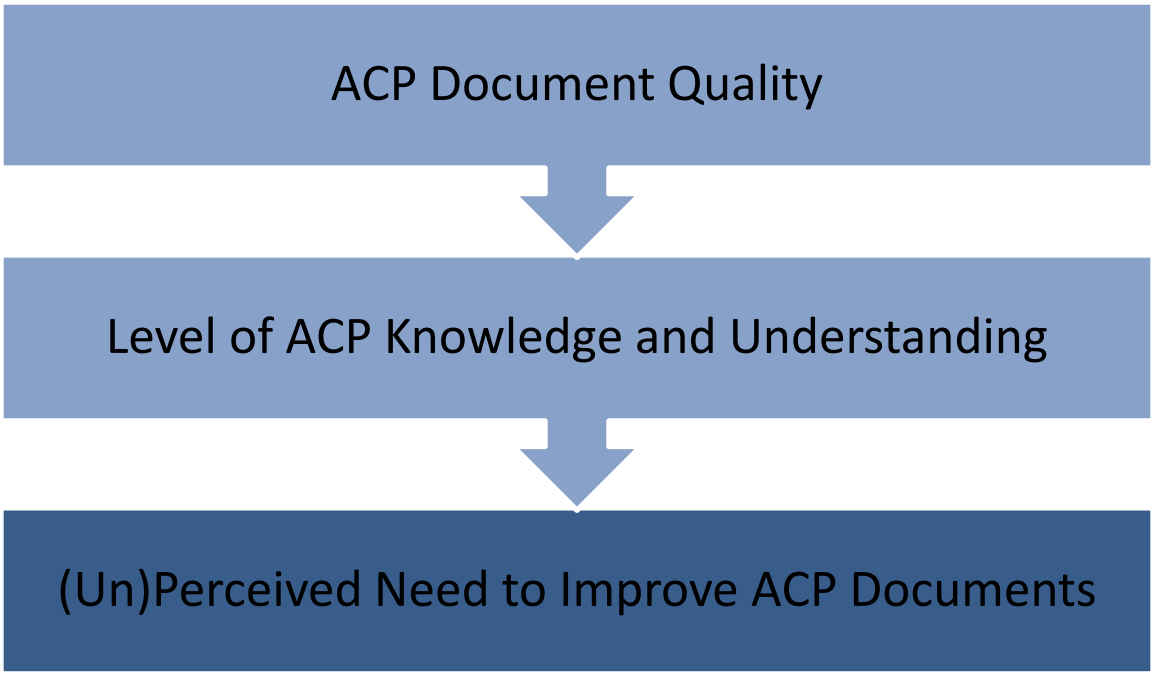
participating in this study. Although the CCC was part of the same non-profit organisation that governed two local LTC homes, it was unclear whether the latter were included in this information-sharing arrangement. Consistent with the 'confusion/inconsistency' theme, most participant responses suggested any existing document-sharing either was not known by or available to them.

Health care workers' perceptions of the quality of ACP documents also varied significantly and appeared to be bimodally distributed. Some participants described their workplace's ACP documents as "basic but easy to understand" and providing "sufficient information" whereas others described the documents as "very difficult to explain," "not clear at all," "lots of room for misinterpretation," and "it isn't very clear." Slightly more than half of participants (54.5%) did not believe ACP documents at their workplace contained sufficient information to support EOL decision making, and just under one third (27.3%) did believe the documents were sufficient. One individual chose not to place a mark in any of the boxes (yes, no, not sure, prefer not to answer, not applicable), but provided the comment that "it does not provide an area to document specific pt. wishes but works well in cases of 'comfort measures only,'" signifying a perception that the document could be effective for some residents and not for others. It is worth considering that two to three participants may be from the hospital site where ACP consisted of highly specific code status levels. Unfortunately, it was impossible to know whether these were the participants who felt their workplace's ACP documents were sufficient to inform EOL decision making due to the blinding procedures. While highly specific code status levels can be helpful when EOL decisions are emerging, they do not capture the comprehensive purpose of ACP, which is to record a person's wishes and what they value, both while they are capable and before the time when decisions are imminent. Thus, it was possible

that the individuals who perceived the ACP documents used at their workplace as sufficient only had a very narrow understanding of ACP, and the timing of ACP.

Overall, hypothesis three was supported in that health care workers who were identified at their workplace as having familiarity in the area of ACP documentation and practices in this community demonstrated variation in their perceptions and experiences with ACP. Specifically, participants were inconsistent in their knowledge of how ACP was carried out both inside and outside of the places where they worked, and participants varied in their perceptions of the quality of the ACP documents they used. One interpretation of these outcomes that is consistent with existing literature on ACP in healthcare settings is that ACP is not well understood by healthcare workers (e.g., Ramsbottom & Kelly, 2014; Silvester et.al., 2012) and users alike. Study One demonstrated that the quality of ACP documents used in this community is uniformly low across multiple settings. It is possible that variation in perceptions of ACP document quality is partially attributable to having an unperceived need for more effective ACP documents, mediated by a lack of knowledge and understanding of ACP principals (Figure 3).

Figure 3: Hypothesised Mediation Model for Unperceived ACP Documentation Needs.



Perceptions on ACP Document Standardisation

Healthcare providers who completed the questionnaire were enthusiastic supporters of standardising ACP documentation and language for the purpose of easing communication of a person's wishes. Ten of eleven (90.9%) supported the standardisation of ACP language across settings and one (9.1%) was not sure. When asked whether standardising ACP documents would improve patient care, support was again overwhelmingly consistent, with ten of eleven participants in favour and one who was not sure. Several participants expressed a wish to see standardisation of ACP documentation that was province-wide, and based in an electronic health record.

The primary reasons given for wanting a common ACP language used across facilities were to improve communication, decrease confusion, and improve patient care. In addition to the theme 'support for standardisation,' each of the other three themes bolstered this finding. Workers expressed frustration with having different functions and understandings from their

peers (‘not speaking the same language’ theme), particularly acute care. Communication with residents/SDMs was also experienced as difficult when it came to ACP, and participants perceived that standardising ACP could offer improvements. In particular, ACP documents were reported to be confusing and easy to misinterpret, leading to potential inconsistency in care offered and care provided (‘confusion/inconsistency’ theme; ‘ACP documents as barriers to care’ theme).

Perceptions on ACP Document Effectiveness

The theme of ‘Current ACP document as a barrier to care’ was evident both in the comments of participants and questionnaire item responses. Several participants provided anecdotal evidence of how ACP documentation practices impeded patient care, and impeded even the purpose of ACP itself. Most ACP documents offered vague and “outdated” treatment offerings that made it difficult to know whether any resident or SDM who had completed the form understood what was offered and appreciated what would or could not be offered. Whether transfer to an acute care facility would be available was also unclear. Participants noted that documents lacked clarity for care givers and staff alike, and remarked that different staff may explain the document in dissimilar ways, and may also be unsure of when a resident’s wishes fit into the Support/Comfort Care category or the Primary Therapeutic Care category. One health care provider specifically identified addressing escalations in care preferences as challenging in “unstable” or “end-stage” patients, a process that would be further complicated if communications about treatments and services were unclear, muddled, or inaccurate.

Regular reviews of ACP or treatment options with competent residents and SDMs is encouraged as an important element of ACP, especially as health changes occur and treatment goals and options evolve. The practice of requiring incoming residents to replace existing ACP

with the facility's own ACP document is troubling and should not automatically be considered a valid form of ACP review, although review may simultaneously occur. Although many individuals do enter LTC due primarily to disease processes that only affect their independence through physical impairment, the vast majority enter LTC due at least in part to neurodegenerative processes and consequent cognitive impairment[18]. Many of these will arrive in LTC with a degree of cognitive impairment that limits their ability to participate in making changes to their own ACP. Additionally, because existing ACP documents were uniformly incomplete and narrow in scope, it is possible that ACP completed outside of the LTC home or other institution would not be fully captured by the facility's ACP document.

Only two of eleven (18.2%) of participants thought it would be straightforward to transfer the intent of ACP from one institution to another (e.g., when a resident goes from LTC to another LTC facility or a hospital or *vice versa*). As one participant noted, the ACP document at their workplace (presumably Hospital 1) "does not reflect the level of care available in LTC."

Limitations and Strengths

Recruitment procedures were altered during the REB review process with the intention to protect the privacy of potential participants, which might have affected the outcome of this study. Purposive expert sampling was proposed for this study based on previous research; however, a diluted version of this technique was used instead. Whereas we had originally sought only participants identified as having the most familiarity with institutional ACP, we instead had a random selection from a larger pool of workers experienced with ACP. This methodological change might have reduced the level of expertise in our sample. Another consequence of the

[18] In Ontario, 90% of LTC residents have some form of cognitive impairment and one in three are severely cognitively impaired, comparatively 38% need monitoring for an acute medical condition (MOHLTC, 2017).

change was that we do not know the exact number of invited participants nor their role in conducting ACP and interpreting ACP documents. It was a strength, however, that the pool of potential participants were selected by an individual at each site who was considered an expert in ACP by their director, lending credibility to the technique beyond what would have been possible by other means (e.g., selecting based on job title or department, when in fact there is variability in the ACP knowledge of workers). Our confidence was further bolstered by the thoughtfulness and completeness of collateral information provided by participants when completing the questionnaire.

Conclusions and Future Directions

In this study, we demonstrated that health care workers have diverse experiences and perceptions regarding ACP documentation both in their workplaces and outside of them. Many workers perceived the documentation practices at their workplaces as barriers to providing the best possible resident/patient care. They cited confusion over the meaning and use of the documents and accessibility issues- both in terms of locating the information and interpreting it for use in their context- when residents transferred between facilities. Standardising the language of ACP documents across settings, potentially across the province, was nearly universally extolled by workers as a means of developing consistency in communication between workers and residents/patients/SDMs, clarifying ACP decision making and decisions, and increasing the appropriateness and patient-focussed nature of resident/patient care.

While different facilities will invariably offer different treatment options to meet different health care goals, standardising the language of treatments offered, or discussing a resident's wishes and goals, can only make for more effective and person-focussed ACP. Education

initiatives to improve workers' understanding of ACP concepts and features should be evaluated in applied settings for effectiveness and impact on communication around ACP and EOL care wishes and goals. The mediation model proposed above (Figure 3) could also be tested as a part of such an evaluation. Recognising what is lacking in ACP documentation, for example, may be a valid indicator of when a worker has understood the concept of ACP, and its purpose, and is able to apply that knowledge in their workplace.

Having a common language for discussing, clarifying, and documenting wishes and goals for care, as well as the treatments and interventions available to a person approaches the EOL is desirable to health care providers. It will be important going forward to clarify the educational and professional needs of healthcare workers, and the administrative, legislative, and policy needs of organisations, and then balance those with the needs of residents/decision makers. Future research could build on this study by incorporating the experiences and perceptions of residents/patients and their SDMs and other informal care providers (i.e., family, other persons with a significant relationship to the resident/patient). The input of all stakeholders will be essential to improving ACP and related processes in LTC and other health care settings.

Study Three: Relationship Between Advance Care Planning and Place of Death in Long Term Care Residents With and Without Dementia

Purpose

This study aimed to evaluate the impact of ACP and dementia status on EOL decision making when LTC residents died. The EOL decisions examined in this study were decisions to transfer a patient out of the LTC home near the end of life, captured by having a place of death either in an inpatient acute care setting or emergency services.

This study aimed to answer the following research questions:

5) Are EOL treatment decisions (i.e., place of death) different when LTC residents die with a dementia versus no dementia?

6) Does place of death vary according to resident characteristics, dementia status, and the presence of recorded ACP?

7) Does the quality of ACP documentation in LTC differentially affect place of death for residents with and without dementia?[19]

Study Three retrospectively examined demographic and clinical characteristics, ACP, and place of death of LTC residents from across the province of Ontario, who died over a one year period, using administrative data.

[19] It was not possible with the data available to identify individual LTC homes, thus, a retrospective examination of data, matched to each site's ACP document feature (from Study One), to look for relationships between ACP features and EOL decisions was not possible

Design

This was a retrospective analysis of administrative data used in Ontario health care facilities, including LTC. Data from three datasets were linked for resident codes (i.e., resident identification) across facilities, and then encrypted for residents and facilities by CIHI.

The primary data source for this study was the Resident Assessment Instrument – Minimum Data Set 2.0 (RAI). RAI is a standardised clinical assessment instrument containing more than 500 data elements and used to document and track resident characteristics. It was originally developed in the United States of America (USA) following introduction of the Nursing Home Reform Act in 1987, which called for a standardised way of assessment and data collection. The RAI is used in LTC settings to ensure collection of the minimum amount of data needed to guide care planning and monitoring, including both needs and strengths. Functional and clinical characteristics are assessed; some examples include skin condition, psychosocial wellbeing, mood and behaviour, nutrition and oral status, continence, physical function, and cognition. The RAI has several built-in clinical assessment protocols which are used to identify risk and aid in care planning, and outcome scales which summarise function (e.g., frailty/instability, cognitive functioning, physical functioning). Aggregate data from the RAI can be used to produce twenty-four different facility- and system-level quality indicators and used in conjunction with other sources of information about care processes to inform quality improvement initiatives (Hutchinson, Milke, Maisey, Johnson, Squires, Teare, & Estabrooks, 2010). The RAI is used in LTC homes globally[20] and has been extensively and continuously evaluated and refined to ensure and maintain high levels of reliability (Hirdes et al., 2008; Poss et al., 2008; Hutchinson et al., 2010), validity (Lix, Yan, Blackburn, Hu, Schneider-Lindner, &

[20] Use of interRAI Instruments Worldwide: http://www.interrai.org/worldwide.html

Teare, 2014; Hoben, Poss, Norton, & Estabrooks, 2016; Hutchinson et al., 2010; Poss et al., 2008), and utility (Armstrong, Daly, & Choiniere, 2016; Drummond, Slaughter, Jones, Wagg, & Batchelor-Murphy, 2015, Feng et al., 2009).

The RAI has been used in CCC facilities and LTC facilities in Ontario since 1996 and 2005, respectively. In 2005, the MOHLTC mandated use of the RAI in all LTC homes in Ontario by June 2010. There is mandatory reporting of RAI data to CIHI, and the data is maintained on-site at the LTC home for at least one year post-discharge, in compliance with the Long Term Care Homes Act[21] (2007; Reg. 79/10, s. 233 (2)).

The data used in this study represent a full year census level of data collected in 2010/11 and 2011/12, when all LTC facilities in this province were using the RAI. RAI data is available from the Canadian Institute for Health Information (CIHI), along with linkages to other datasets. All Canadian hospitals (except in Quebec) submit to the Discharge Abstract Database (DAD), which captures administrative, clinical and demographic information on hospital discharges (including deaths, sign-outs and transfers). DAD data covers hospital discharges such as inpatient acute care, chronic diseases, and rehabilitation. The National Ambulatory Care Reporting System (NACRS) contains data collected at time of service for all hospital-based and community-based emergency and ambulatory care. NACRS data contains information from day surgery and outpatient clinics, for example.

Only residents who died during the study period were included in analyses. This was because place of death was the dependent variable and residents who survived the study period were not significant to the inquiry. Where it was deemed relevant for descriptive purposes,

[21] Available from: https://www.ontario.ca/laws/statute/07l08

characteristics of the entire sample were described. The resident-level outcome of interest was whether death occurred inside the LTC home or outside of it, denoting a decision to transfer the resident near the EOL. The actual place of death (i.e., during transfer to hospital, in acute care, in the emergency department) was not relevant to this research and places of death were combined to form a dichotomous variable for place of death, for death occurring either inside the LTC home or outside of it. A secondary effect of this approach was to increase the power of the study. This study was submitted to the Lakehead University REB and granted an exemption due to using anonymised secondary data.

Participants

Data were a one year census level incidence sample of new admissions into LTC aged 65 and older, with up to 13 months follow-up, with RAI data matched with mortality and admissions data from DAD and NACRS. Data were obtained from CIHI for the fiscal years 2010-2011 and 2011-2012. There were 76,536 entries from 20,414 individuals, of which n=5677 died during the study period. Only data from the final assessment before death were included in the study.

Instruments

Resident Assessment Instrument - Minimum Data Set 2.0 (RAI). RAI is a standardised assessment and care planning tool that has been mandated for use in all LTC facilities in Ontario since 2010. It is administered by the interprofessional care team on admission, quarterly, when there is a significant change in the health status of a resident (decline or improvement), and annually. Inter-rater reliability for RAI is high (Mor, Angelelli, Jones, Roy, Moore, & Morris, 2003). The RAI contains seven direct measures of cognitive performance (short term memory, long term memory, four measures of orientation, decision making ability)

and 15 indirect measures of cognitive performance (comatose status, communication, eight ADL measures, problem behaviours, continence). Measures thought to be relevant to participating in ACP and EOL decision making were selected for inclusion in this analysis and these are described below.

The Cognitive Performance Scale *(CPS*; Morris, Fried, Mehr, Hawes, Philips, et al., 1994). The CPS uses five items from the RAI to create a single, functionally meaningful hierarchical measure of cognitive performance. The RAI items are: B1 Comatose, B2a Short term memory, B4 Cognitive skills for decision making, C4 Making self understood, and G1hA Eating ADL: Self Performance. CPS scores range from 0 (intact) to 6 (very severe impairment). CPS scores correspond closely with scores on the Mini Mental State Examination (Hartmaier, Sloane, Guess, Koch, Mitchell, & Phillips, 1995). A CPS score of five or six is considered to be indicative of severe dementia (van der Steen, Volicier, Gerritsen, Kruse, Ribbe, & Mehr, 2006).

Activities of Daily Living Scale *(ADL*, Morris, Fries, & Morris, 1999*)*. The ADL examines a person's ability to perform normal day-to-day activities and places them on a hierarchy from 0 (independent) to 6 (total dependence). The four RAI items used are: personal hygiene, locomotion, toilet use, and eating. ADL takes into account and scores early loss ADLs (e.g., dressing) lower than late loss ADLs (e.g., eating), which are scored higher. ADL was shown to detect clinically meaningful change in physical functioning in LTC residents with moderate and severe dementia (Carpenter, Hastie, Morris, Fries, & Ankri, 2006).

Changes in Health, End-Stage Disease and Symptoms and Signs Scale *(CHESS*; Hirdes, Frijters, & Teare, 2003). CHESS predicts mortality and clinical instability to identify persons in institutional care who are at risk of serious health decline. It is calculated by adding

sign and symptom variables from the RAI (dyspnea, vomiting, peripheral edema, weight loss, insufficient fluid, dehydrated, fluid output exceeds input, decrease in food or fluid) and adding the variables change in decision making, change in ADL status, and end-stage disease. Scores range from 0 (no health instability) to 5 (very high health instability).

Advance Care Planning items. Some items from the RAI 2.0 were especially relevant to having participated in some form of ACP. These were[22]:

Living will **(A10 A):** Having a document specifying the resident's preferences regarding measures used to prolong life when there is a terminal prognosis.

Do not resuscitate **(DNR; A10 B):** In the event of respiratory or cardiac failure, the resident, or SDM has directed that no CPR or other life-saving methods will be used to attempt to restore the resident's respiratory or circulatory function.

Do not hospitalise **(A10 C):** Specifies that the resident is not to be hospitalised even after developing a medical condition that usually requires hospitalisation.

Feeding restrictions **(A10 F):** The resident or SDM does not wish the resident to be fed by artificial means (e.g., tube, intravenous nutrition) if unable to be nourished by oral means.

Medication restrictions **(A10 G):** The resident or SDM does not wish the resident to receive life-sustaining medications.

Analyses

Descriptive statistics were obtained for all measures. The main analyses used binomial logistic mixed modeling from SPSS (IBM) 25.0's generalized linear mixed model (GLMM)

[22] Definitions adapted from Centres for Medicare and Medicaid Services (CMS) RAI Version 2.0 Manual (2008).

battery. The primary reasons for using this type of analysis was to accommodate the non-independence of residents from within the same facilities, and to take into account missing data.

Extensive research supports the strong inter-rater reliability of the RAI (Hutchinson et al., 2010; Moris, Moore, Jones, et al., 2002), however, some research has demonstrated wide variation in reporting across LTC homes (Mor et al., 2003). Mor and collegues (2003) compared RAI assessments by highly trained "gold standard" nurses with LTC facility nurses at over 200 LTC facilities in the USA and found "excellent" inter-rater reliability for fifteen data elements (i.e., Kappa >.75) and "poor" reliability for twenty-eight data elements (i.e., Kappa <.4). These results were due to highly skewed percent agreement data (i.e., a small number of assessments were very far off the gold standard nurse assessments while most showed a very high level of agreement). Examination revealed no significant differences between the LTC homes with high versus low inter-rater reliability. Other researchers have also demonstrated significant random disagreement and variation between facilities. Abt Associates (2001) examined thirty facilities and found disagreement rates that averaged 11.7%, ranging from 7.8% to 14.5% (as reported in: General Accounting Office, 2002). Wu and colleagues (2009) compared over 5000 pairs of RAI assessments from over 200 LTC homes and found significant coding differences between facility nursing staff and study nurses. While resident characteristics accounted for only negligible variation, LTC home characteristics accounted for between 4% and 20% and variation in RAI coding. Inter-facility variation exists in programs, services offered, design, location, special interest groups (e.g., ethno-culture specific LTC homes) strongly suggesting that residents in LTC are not statistically speaking independent, but rather that they exist within their particular care setting, and will therefore be affected by this variation. GLMM is used for analysing clustered data such as students in classrooms, patients in clinics, or residents in LTC homes.

Models produced are linear in parameters and covariates can be a combination of fixed and random effects, while the effects of data nested within clusters are modeled as random effects which are non-linear (West, Welch, & Galecki, 2014; Song & Lee, 2006). GLMM was the best approach to analysis of this data because it allows for the inclusion of individual-level covariates such as age and dementia-status while adjusting for the random, unobserved effects associated with each cluster, (i.e., the LTC homes).

Only residents who died were included in the analysis. The target variable was place of death. Residents who died in acute care and the emergency department were combined in a target variable of either death inside LTC or death outside LTC, with dying in LTC as the reference category. The random intercept in all models was institution code at entry. The main fixed effects, added in steps, were CHESS, Age, Sex, dementia status, and RAI items indicative of ACP (Living Will, DNR, DNH, Feeding Restrictions, Medication Restrictions). Continuous variables (CPS, Age) were centred on grand means. Interaction terms were calculated for the ACP items with dementia.

Results

Sample Characteristics of Residents Admitted to LTC

LTC residents who died in the LTC home during the study period and residents who died outside of the LTC home (i.e., in the emergency department or as a hospital inpatient) were examined on demographic variables and the most recent (i.e., last before death) CHESS, ADL, and CPS scores. Results appear in Table 8. LTC residents were more frequently female regardless of where they died. Residents who died in the LTC home were slightly older at admission. The distribution of marital status varied slightly between the groups. Information on

rural or urban status of the LTC resident prior to admission was available for 91.6% of the sample (n=5201). The majority of LTC residents were from urban settings (83.1%). The mean age of rural and urban residents was equivalent, at 85.6 years and 85.4 years, respectively. Residents who died in the LTC home were more impaired on average.

Table 8: Characteristics of Residents who Died and Did Not Die In 13 Months After Admission to LTC

	Died in LTC Home (n=3945)	**Died Outside of LTC Home (n=1732)**	**All Deaths (N=5677)**
Mean Age on Admission[1] (SD)	85.95 (7.07)	84.44 (7.13)	85.49 (7.12)
Range (years):	65 – 106	65 – 102	65 - 106
Sex (% Female)[2]	61.9%	58.9%	60.2%
Marital Status[3]			
Married	32.3%	34.7%	33.0%
Widowed	58.3%	53.9%	57.0%
Divorced/Separated	4.8%	6.9%	5.4%
Never Married	4.6%	4.4%	4.5%
Rural Status (% Rural)	18.3%	14%	16.9%
Mean CHESS Score[4]	1.55 (1.30)	1.07 (1.05)	1.40 (1.25)

(SD)			
Mean ADL Score[5]	4.04 (1.44)	3.51 (1.53)	3.88 (1.49)
(SD)			
Mean CPS Score[6]	2.94 (1.69)	2.29 (1.67)	2.74 (1.71)
(SD)			

Note. Mean age for males =84.25 (SD=7.04) and for females =86.34 (SD=7.02). CHESS= Changes in Health, End-Stage Disease and Symptoms and Signs Scale, ADL=Activities of Daily Living Scale, CPS=Cognitive Performance Scale.

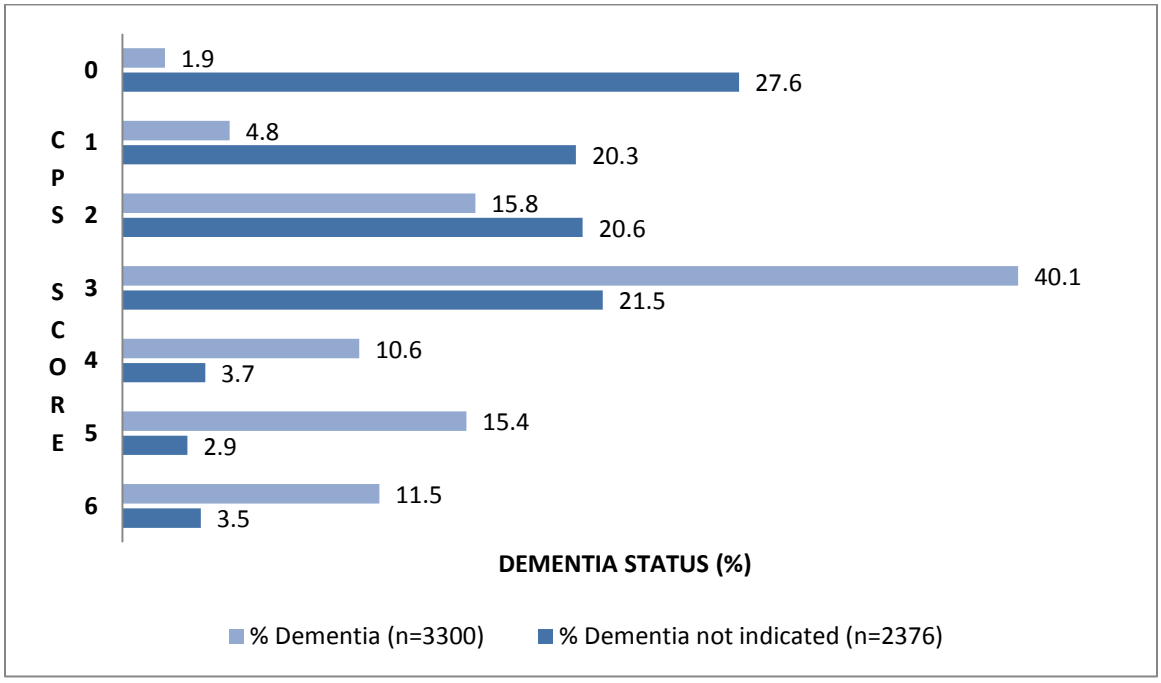
Dementia Status

One indicator of cognitive impairment and two diagnostic indicators of dementia were examined from the RAI 2.0: CPS score and a check box for the presence or absence of dementia (Alzheimer's disease and/or dementia other than Alzheimer's disease). The diagnostic accuracy of a CPS score of two or greater was previously demonstrated for identifying nursing home residents with mild cognitive impairment or dementia using the Cambridge Examination for Mental Disorders of the Elderly – Revised (CAMDEX-R; Paquay, Lepeleire, Schoenmakers, Ylieff, Fontaine, & Buntinx, 2007), and CPS was shown to correspond closely with neurological diagnoses of Alzheimer's disease (Morris, et. al, 1994). For the purpose of this research, the check box measures were combined to form a single dementia item (present, absent). It is important to note that residents may have been identified on the RAI 2.0 as having a dementia without the presence of a formal diagnosis or neurological examination, however, this indicator of dementia was utilised elsewhere and considered to be accurate (e.g., CIHI, 2010; Woo, Chi, Hui, Chan, & Sham, 2005).

Cognitive impairment was measured using the CPS. Overall, 87.4% of residents had some degree of cognitive impairment, with 29.1% (n=1652), 40.0% (n=2271), and 18.3% (n=1037) falling in the mild, moderate, and severe range. This was slightly below what was reported in this province, where 90.0% of LTC residents were said to be affected by cognitive impairment, and considerably below the reported one in three LTC residents who fell in the severely cognitively impaired range (Ontario Long Term Care Association, 2016). In terms of dementia status, 58.1% (n=3300) of residents who died were identified on the RAI 2.0 as having a diagnosis of dementia[23], again, below the 2016 provincial average of 63.1%, but above the 2010 average of 56.0% (Ontario Long Term Care Association, 2016). Examination of the data revealed that dementia status and CPS were moderately correlated ($r=.49$, $p<.001$) and followed a bell-shaped distribution, where residents with a CPS score of three, or moderate, were the most likely to be documented as having dementia (40.1%) while those with a CPS score or four (moderate) or five (severe) were proportionately similar to individuals with a CPS score of two (mild) in terms of having a documented dementia status (Figure 4).

[23] In the entire sample of LTC residents, which included those who died during the study period and those who did not, the prevalence of dementia was 61.5% (N=76,502)

Figure 4: Proportion of LTC Residents Identified as having Dementia by CPS Score



Note. N=CPS=Cognitive Performance Scale, where 0=no impairment, 1-2=mild impairment range, 3-4=moderate impairment range, and 5-6=severe impairment range.

Correlation between dementia and having a CPS score of three or greater fell somewhat to r=.46, p<.001. Of residents with a CPS score of three or more, 77.4% were also identified as having a dementia. Dementia is known to complicate compliance with following ACP, and to be a risk factor for not having ACP or not having adequate ACP (de Boer et al., 2010; Mitchell et al., 2004). Most older adults with ACP choose to forego heroic measures near the end of life, however, many residents are still transferred to acute and emergency services near the end of life. The possible relationship between dementia and place of death, therefore, was examined.

Place of death. Nearly one third of all deaths occurred outside of the LTC home (Table 9). About half of the residents who died outside of the LTC home had dementia, however,

residents without dementia were 1.43 (RR) times more likely to die outside of the LTC home than residents with dementia (95% C.I. = 1.32 – 1.55; p<.001).

Only n=79 (1.39%) LTC residents were identified as having received hospice care just prior to dying, and they were just as likely to have dementia as not (n=40 without dementia, n=39 with dementia). Only two residents (2.53%) who received hospice care died outside of their LTC home; one of them had dementia and the other one did not.

Table 9: Place of Death of LTC Residents Who Died With and Without Dementia

	Died in LTC Home % (n)	**Died Outside of LTC Home % (n)**	**All Deaths % (n)**
Dementia	62.04% (2447)	49.25% (853)	58.1% (3300)
No Dementia	37.96% (1497)	50.75% (879)	41.9% (2376)
Total	69.49% (3944)	30.51% (1732)	--

Evidence of EOL planning among LTC residents in Ontario

RAI 2.0 items indicative of ACP were compared for LTC residents who died inside and outside of a LTC facility. Residents who died inside their LTC home were more likely to have a DNR, DNH, feeding restrictions, and medication restrictions in place at the time of their final assessment, and less likely to have a living will, the degree of difference varied by dementia status for having a living will, having feeding restrictions, and medication restrictions (Table 10). Having a DNR or a DNH were more likely for residents with dementia, RR = 1.07 (95% CI:

1.0408 – 1.1004, p<.001) for DNR, and RR=1.20 (95% CI: 1.0906 – 1.3110, p<.001). Residents with and without dementia were as likely to have a living will (RR=1.13, 95% CI: 1.0047 – 1.2748, p=.042), feeding restrictions (RR=1.15, 95% CI: .9180 – 1.4402, p=.224), or medication restrictions, (RR=1.08, 95% CI: .8648 – 1.3535, p=.49) documented on the RAI 2.0 prior to dying.

Table 10: LTC Residents With Evidence of EOL Planning in Place on RAI 2.0

	Died in LTC Home % (n=3945)	**Died Outside of LTC Home % (n=1732)**	**All Deaths % (N=5677)**
Living Will			
Total	15.2	20.1	16.7
With Dementia	15.5	16.7	15.8
Without Dementia	14.7	23.5	17.9
Do Not Resuscitate			
Total	84.7	67.7	79.5
With Dementia	85.3	71.7	81.8
Without Dementia	83.8	63.7	76.4
Do Not Hospitalise			
Total	32.3	12.0	26.1
With Dementia	33.3	12.8	28.0
Without Dementia	30.5	11.2	23.4
Feeding Restrictions			

Total	6.3	3.6	5.5
With Dementia	6.7	3.2	5.8
Without Dementia	5.6	4.0	5.0
Medication Restrictions			
Total	6.2	3.6	5.5
With Dementia	6.5	3.1	5.6
Without Dementia	5.8	4.2	5.2

Note. Residents with missing data removed. Living Will N=5476; Do Not Resuscitate N=5559; Do Not Hospitalise N=5562; Feeding Restrictions N=5549; Medication Restrictions N=5554; RAI = Resident Assessment Instrument; EOL = End of Life.

Relationship between Place of Death, Clinical Characteristics, ACP, and Dementia Status

Generalised Linear Mixed Modeling (GLMM) was used to explore the relationship between place of death and the fixed effects. Five models were constructed. The first included no added fixed effects (the null model); the second added CHESS, sex and age, both centred on the grand mean; the third model built on the second and added the ACP variables (living will, DNR, DNH, feeding restrictions, medication restrictions); the fourth model added dementia[24], and the final model included the addition of the interaction of dementia with the ACP variables. Facility (i.e., LTC home where the resident resided, N=650) was a random variable in each of the models to account for similarities of ACP and other practices within each LTC home (e.g., types of

[24] Cognitive impairment is common at the end of life, regardless of dementia status (Burton, Twamley, Lee, et al., 2012). Dementia was selected for inclusion in the model over CPS because analyses were performed on only the final assessment before dying, which likely would show a greater incidence of cognitive impairment that was worsened or newly-developed as the resident approached EOL, but may not have affected the resident's participation in ACP to the same degree earlier on. Whereas dementia processes are chronic and progressive and might have prevented ACP for a number of years, other causes of EOL cognitive impairment may not. The strategy of using dementia in the GLMM model rather than CPS was intended to limit the effect of later-onset cognitive impairment on ACP and place of death.

treatments or EOL interventions available, presence of a dementia ward, staff with specialisation in pain management). The target variable was a binary variable, place of death (inside LTC or outside of LTC), and the distribution used a binomial distribution with logit link. Continuous variables were centred on their grand means for consistency. Sex was tested as a fixed effect in the second model but was removed as it detracted from the model fit.

The null model (no fixed effects) provided a base measure for all subsequent models. All residents were included in the model. There were n=5677 residents included in the analysis. The overall correct classification for this model was 71.4%. The null model correctly predicted place of death for 98.2% of residents who died in LTC but only 10.3% of residents who died outside of LTC. The random variable of facility had a significant effect on the place of death, (Table 11).

Table 11: GLMM Null Model Intercept

Random Effect					95% Confidence Interval	
Covariance	Estimate	Std. Error	Wald Z	p-value	Lower	Upper
Intercept	.374	.051	7.276	<.001	.286	.489

Note. The 95% Confidence Interval is an interval estimate combined with a probability that the true estimate would fall between the lower and upper limits with 95% accuracy.

Model Two A built on the null model by adding CHESS, age, and sex as fixed effects. There were n=80 residents excluded from this model due to missing or invalid data, leaving n=5597. Correct classification increased to 72.6% in this model (Table 12). This model improved on the null model by correctly predicting the place of death for 18.4% of residents who died outside of LTC (compared with 10.3% in the null model), and 96.5% of residents who died inside LTC (compared with 98.2% in the null model). Residents with lower CHESS scores,

indicating less impairment, and lower age, were more likely to die outside of their LTC home while sex did not contribute to improving prediction of place of death (Table 13).

Table 12: GLMM Model Two A Intercept

Random Effect					95% Confidence Interval	
Covariance	Estimate	Std. Error	Wald Z	p-value	Lower	Upper
Intercept	.355	.051	6.900	<.001	.267	.472

Table 13: GLMM Model Two A

Model Term					95% Confidence Interval	
	Coefficient	Std. Error	t	p-value	Lower	Upper
Intercept	-.897	.0412	-21.759	<.001	-.978	-.8160
CHESS	-.328	.0278	-11.803	<.001	-.382	-.273
Age	-.033	.0044	-7.442	<.001	-.041	-.024
Sex	-.018	.0642	-0.282	.778	-.144	.108

Model two was repeated (Model Two B) with sex removed from the model (Table 14). In this analysis only n=7 residents were excluded for missing data, leaving n=5670 residents in the analysis. With sex removed, overall correct classification was slightly higher, at 72.8%.

Prediction of place of death was correct for 18.6% who died outside of the LTC home and remained constant at 96.5% for those who died inside LTC. Once again, less impairment, (lower CHESS score), and lower age were predictors of death outside of the LTC home (Table 15). Model Two B was retained and (with the exception of Table 22) model Two A will not be reported on further.

Table 14: GLMM Model Two B Intercept

Random Effect					95% Confidence Interval	
Covariance	Estimate	Std. Error	Wald Z	p-value	Lower	Upper
Intercept	.354	.051	6.914	<.001	.267	.470

Table 15: GLMM Model Two B

Model Term					95% Confidence Interval	
	Coefficient	Std. Error	t	p-value	Lower	Upper
Intercept	-.901	.0411	-21.935	<.001	-.982	-.820
CHESS	-.337	.0272	-12.383	<.001	-.390	-.284
Age	-.032	.0043	-7.441	<.001	-.040	-.024

In the third model, we again estimated a mixed effects logistic model, predicting place of death from CHESS scores, age, and ACP variables (living will, DNR, DNH, feeding restrictions, medication restrictions). We allowed the intercept to vary randomly by each LTC facility. There were n=266 residents excluded from this model due to missing or invalid data, leaving n=5411. The overall correct classification of place of death for this model was 74.2% (Table 16). The addition of ACP variables improved prediction of place of death outside the LTC home from 18.6% in model two to 27.1% in model three, with only a slight decrease in correct prediction of death within the LTC home, from 96.5% to 94.3%. Having a living will was a significant predictor of dying outside of LTC, while having a DNR or DNH were predictors of dying inside LTC ($p<.001$). Feeding restrictions and medication restrictions were not a significant predictors of place of death at the $p<.001$ level (Table 17).

Table 16: GLMM Model Three Intercept

Random Effect					95% Confidence Interval	
Covariance	Estimate	Std. Error	Wald Z	p-value	Lower	Upper
Intercept	.295	.050	5.873	<.001	.211	.412

Table 17: GLMM Model Three

Model Term					95% Confidence Interval	
	Coefficient	Std. Error	t	p-value	Lower	Upper
Intercept	-.309	.0733	-4.218	<.001	-.453	-.165

CHESS	-.295	.0283	-10.424	<.001	-.351	-.240
Age	-.025	.0046	-5.568	<.001	-.034	-.016
Living Will	.407	.0931	4.368	<.001	.224	.589
DNR	-.546	.0789	-6.925	<.001	-.701	-.392
DNH	-1.020	.0916	-11.135	<.001	-1.200	-.840
Feeding Restrictions	-.375	.1829	-2.050	.040	-.733	-.016
Medication Restrictions	-.140	.1805	-.774	.439	-.493	.214

The fourth model added dementia to the previous model. There were n=267 residents excluded from this model due to missing or invalid data, leaving n=5410. Overall classification improved slightly, to 74.7% (Table 18). The prediction of place of death outside of LTC again improved, with 29.7% correctly classified, and 94.0% correctly predicted to die within LTC. In this model, having dementia was a significant predictor of dying inside the LTC home (Table 19).

Table 18: GLMM Model Four Intercept

Random Effect	95% Confidence Interval

Covariance	Estimate	Std. Error	Wald Z	p-value	Lower	Upper
Intercept	.281	.050	5.662	<.001	.199	.397

Table 19: GLMM Model Four

Model Term					95% Confidence Interval	
	Coefficient	Std. Error	t	p-value	Lower	Upper
Intercept	-.072	.0810	-.885	.376	-.231	.087
CHESS	-.304	.0285	-10.694	<.001	-.360	-.249
Age	-.024	.0046	-5.316	<.001	-.033	-.015
Living Will	.394	.0932	4.231	<.001	.212	.577
DNR	-.527	.0793	-6.648	<.001	-.682	-.371
DNH	-1.013	.0918	-11.024	<.001	-1.193	-.832
Feeding Restrictions	-.374	.1836	-2.037	.042	-.734	-.014
Medication Restrictions	-.139	.1809	-.768	.443	-.494	.216

Dementia	-.446	.0658	-6.767	<.001	-.575	-.316

The fifth and final model added the interaction of dementia with the ACP items to the previous model. Once again, there were n=267 residents was excluded from this model due to missing or invalid data, leaving n=5410. Correct held at 74.7% (Table 20), however, correct prediction of place of death outside of LTC fell slightly from model four to 28.6%, but remained higher than model 3. Prediction for place of death inside the LTC home was slightly higher, at 94.4%. The only significant effect from an interaction was for having a living will with dementia, which contributed significantly to predicting a death inside the LTC home, in contrast to having a living will alone (i.e., without the interaction with dementia), which predicted dying outside of LTC (Table 21). This outcome suggests that the effect of having a living will on place of death decreases in the presence of dementia.

Table 20: GLMM Model Five Intercept

Random Effect					95% Confidence Interval	
Covariance	Estimate	Std. Error	Wald Z	p-value	Lower	Upper
Intercept	.281	.050	5.662	<.001	.199	.397

Table 21: GLMM Model Five

Model Term					95% Confidence Interval	

	Coefficient	Std. Error	t	p-value	Lower	Upper
Intercept	-.021	.1023	-.207	.836	-.222	.179
CHESS	.304	.0285	-10.649	<.001	-.359	-.248
Age	-.024	.0046	-5.257	<.001	-.033	-.015
Living Will	.645	.1314	4.907	<.001	.387	.902
DNR	-.672	.1152	-5.835	<.001	-.898	-.446
DNH	-1.002	.1361	-7.360	<.001	-1.269	-.735
Feeding Restrictions	-.336	.2643	-1.270	.204	-.854	.182
Medication Restrictions	.029	.2598	.112	.911	-.480	.538
Dementia	-.545	.1350	-4.039	<.001	-.810	-.281
Dementia x LW	-.472	.1732	-2.725	.006	-.812	-.133
Dementia x DNR	.273	.1553	1.760	.079	-.031	.578
Dementia x DNH	-.034	.1806	-.189	.850	-.388	.320

Dementia x Feed. Restrict.	-.096	.3594	-.268	.789	-.801	.608
Dementia x Med. Restrict.	-.309	.3608	-.857	.392	-1.016	.398

The information criterion value used to compare models was the -2 log likelihood. This is a measure of model fit, where smaller numbers indicate a better fit. When interpreting the -2 log likelihood, the absolute value is not as important as the relative difference between the models. Table 22 and Table 23 shows the change in model fit and overall correct classification across the five models, respectively. Classification was slightly improved by the addition of dementia, however, the model fit was not. Of note, the number of correctly classified deaths outside of LTC rose from 10.3% in the null model to a high of 29.7% in model 4, while correctly classified deaths inside LTC fell only slightly, from 98.2% in the null model to 94.0% in model 4.

Table 22: GLMM Model Fit Across 5 Models

	Model	df[a]	-2LL[b]	D[c]	p-value[d]
1	Null	0	25118.830	n/a	n/a
2A	CHESS, Age, Sex	3	25053.139	-65.691	<.001
2B	CHESS, Age	2	25399.274	280.444	<.001
3	CHESS, Age, ACP	7	24713.246	**-686.028**	**<.001**

4	CHESS, Age, ACP, dementia	8	24790.697	77.451	<.001
5	CHESS, Age, ACP, dementia, Dementia x ACP interaction terms	13	24803.429	12.732	.469

Note. CHESS = Changes in Health, End-Stage Disease and Symptoms and Signs Scale; ACP = Advance Care Planning variables: Living Will, Do Not Resuscitate, Do Not Hospitalise, Feeding Restrictions, Medication Restrictions
[a]df = number of parameters included in the model
[b]-2LL = negative two log likelihood, or -2 log likelihood.
[c]D = Difference. D compares the fit of each model against the previous model as predictors were hierarchically added, i.e., D is the comparison of the -2LL of the previous model to the -2LL of the current model with the added predictors. A negative number indicates improvement to the model fit over the previous model while a positive number indicates that model fit worsened.
[d]P-value calculations performed with tools from:
https://www.danielsoper.com/statcalc/calculator.aspx?id=11 and
http://www.socscistatistics.com/pvalues/chidistribution.aspx

Table 23: Correct Classification of Residents' Place of Death Across Five Models

	% Correct Classification		
Model	Died Outside LTC	Died Inside LTC	All Deaths
Null	10.3%	98.2%	71.4%
Model 2B			
CHESS, Age	18.6%	96.5%	72.8%
Model 3			
CHESS, Age, ACP	27.1%	94.3%	74.2%

Model 4			
CHESS, Age, ACP, Dementia	29.7%	94.0%	74.7%
Model 5			
CHESS, Age, ACP, Dementia, Dementia x ACP interactions	28.6%	94.4%	74.7%

Note. CHESS = Changes in Health, End-Stage Disease and Symptoms and Signs Scale; ACP = Advance Care Planning variables: Living Will, Do Not Resuscitate, Do Not Hospitalise, Feeding Restrictions, Medication Restrictions

Discussion

This study was undertaken to examine the role of ACP on place of death for residents of LTC who died with and without dementia. There were many factors explored in the literature for why dementia status may be an important consideration when making EOL decisions and for determining whether a resident would have ACP in place. In this study, place of death was examined as an indicator of the EOL decision to move an individual out of their LTC home near the end of life. It was not possible to know whether they were moved for treatment (i.e., curative intent), symptom control, or some other reason. We chose this EOL decision after reviewing evidence that most older adults choose to forego heroic EOL measures and die a natural death in place when ACP is carried out in accordance with best practices. When death occurred outside of the LTC home, therefore, it may be an indication of inadequate ACP processes. Examples of inadequate ACP processes include providing limited ACP options to residents, residents not understanding ACP options, ACP not documented clearly, ACP not understood by decision

makers, or the resident not having ACP in place at all. Given the progressive nature of dementia, LTC residents with dementia would have fewer opportunities or lack the ability to express their EOL wishes at the time of dying, thus, documented ACP was anticipated to be a factor in predicting place of death.

Resident Demographics

Cognitive impairment was common in LTC residents in this sample, with 58.3% having impairment in the moderate to severe ranges and 58.1% identified as having dementia. Despite being the same age, on average, residents who entered LTC from a rural versus an urban setting were more likely to die during the study period. Rural residents may have been choosing to wait longer before leaving their home communities and therefore be in a more advanced stage of disease or disability when they arrive in LTC. Alternatively, due to the disparity in health care services (Sibley & Weiner, 2011), rural residents may not have received the same access, quality, or consistency of care while in their community (e.g., home care services, access to primary care) and may simply be in a worse state of health overall. It is important to note that most older adults do not require admission to LTC and therefore these findings cannot be generalised to the entire rural and urban populations, although mortality rates are higher in rural settings (CIHI, 2006).

Evidence of ACP

Evidence of documented ACP in this sample suggests ACP is uncommon in LTC beyond a DNR. Overall, 77.5% of residents had a DNR in place, and information about a DNR order was missing for 20.5%. About a quarter (26.1%) of residents had a DNH and three quarters (73.9%) did not. Residents who died with dementia were more likely to have a DNR (81.8%) and DNH (28.0%) in place than residents who died without dementia (DNR = 76.4%, DNH =

23.4%). Given the nature of the ACP documents audited in Study One (i.e., documents did not offer many concrete options aside from resuscitation, availability of options was unclear, some documents were accompanied by a DNR confirmation form), and the impression by many health care workers that institutional ACP documents were required to be completed on admission (Study Two), it was not surprising that DNR orders were highly utilised and that DNR orders were the exception when it came to ACP utilisation among LTC residents, according to the information available. DNH orders in our sample were slightly more common than the 21% reported elsewhere (CIHI, 2016). It was unclear whether DNH order utilisation decreased in the intervening years between collection of the present data and CIHI's finding, or whether the discrepancy had to do with sampling.

Having a living will, medication restrictions, and feeding restrictions were not significantly different between residents with dementia or without dementia. Overall, 16.7% or residents had a living will, 5.5% had medication restrictions, and 5.5% had feeding restrictions.

Place of Death

In stark contrast with our fifth hypothesis, residents without dementia were 43% more likely to die outside of a LTC home compared with residents with dementia. Residents of LTC who died outside of the LTC home where they lived were slightly younger and more likely to be male. They had greater independence in their activities of daily living, a higher level of cognitive functioning, and less health instability compared to LTC residents who died inside the LTC home.

In line with hypothesis six, ACP was related to place of death in the expected direction: having a DNR, DNH, medication restrictions, and feeding restrictions were each related to dying

inside the LTC home in the sample of all deaths. When residents did have dementia, medication and feeding restrictions were related to dying inside LTC but not for residents without dementia.

For residents without dementia, having a living will was related to dying outside of the LTC home. This finding seems counterintuitive on the surface, given that research showed older adults would prefer to forego heroic measures and receive comfort-care at the end of life when opportunities for effective ACP are available. Our findings did show that individuals who were less impaired, had greater independence, and were younger were more likely to die outside of LTC. Underpinning an individual's ability to create a living will (i.e., engage in ACP), they must be well enough to participate in that process, thus, more likely to be transferred to acute care for treatment. We cannot comment on the content of an individual's living will as these were not examined as part of this study, likewise we cannot know whether living wills were followed or even available to decision makers.

Specialised care. Hospice care was equally inaccessible to LTC residents regardless of dementia status. Of N=5677 deceased residents included in this study, only n=79 (1.4%) were identified as receiving care in a hospice unit at the last assessment before death. Hospice was utilised equally by residents with dementia (n=39) and without dementia (n=40). Only two residents with hospice care (2.5%) died outside of the LTC home, one with and one without dementia. In comparison, 37.0% of non-dementia deaths and 25.9% of deaths with dementia occurred outside of the LTC home. This pattern suggested that receipt of hospice care is a protective factor against dying outside of LTC in this sample, a finding that was in line with the existing literature.

ACP and Dementia as a Predictor of Place of Death

The addition of ACP variables and dementia (model 3 and model 4) to the GLMM model significantly improved the prediction of place of death outside of the LTC home, with relatively little loss of accuracy in predicting death inside the LTC home. These results demonstrate the importance of ACP and dementia status in predicting place of death, even with the small number of residents who had documented ACP in place. Strengthening ACP and EOL care practices in LTC settings seems to offer an effective tool for enabling older adults (with and without dementia) to die in a setting that aligns with their stated or interpreted wants and goals.

The best model fit was for Model Three, when ACP variables were added. The addition of dementia in Model Four decreased the fit of the model slightly but significantly, and simultaneously increased the classification of residents who died outside of their LTC home, the latter of which was the goal of the model hierarchy. The decrease in model fit was likely due to the slight decrease in classification of residents who died inside of LTC, as these residents outnumbered their counterparts.

Limitations and Strengths

This study did not require a confirmed diagnosis of a dementia in residents, for example: evidence of a neuropsychological examination or confirmation of a formal diagnosis. Instead, inclusion in the dementia group relied on having been identified on the RAI 2.0 as having a dementia at the last assessment before death. The RAI 2.0 provides an area to identify residents with dementia, as well as a measure of cognitive impairment (CPS). CPS scores were also examined and shown to correlate moderately with dementia status. The researchers chose to use dementia in our analysis both because it was in-line with previously published provincial LTC data on dementia prevalence and because it was a slightly better fit to the statistical model (CPS

model not shown). Although previous work (Foebel, Hirdes, Heckman, Kergoat, Patten, & Marrie, 2013) has demonstrated an imperfect relationship between RAI 2.0 dementia status and hospital records of the diagnosis (i.e., DAD and NACRS databases), those authors concluded that the RAI 2.0 had good sensitivity for dementia and could be "used with confidence for health research." Other authors have opted to use both a CPS score cut-off and the RAI 2.0 indicator of dementia, for example, Kosteniuk, Morgan, O'Connell, and colleagues (2015) used any mention of dementia or a CPS score of two or above to demarcate Saskatchewan residents with dementia. While the RAI 2.0 does not rely solely on strict diagnostic criteria (e.g., ICD, DSM) to identify cases of dementia, it is common for dementia to be identified for the first time on admission to LTC using the RAI 2.0 (Kosteniuk, Morgan, O'Connell, et al., 2015). Additionally, cognitive impairment is known to be common near the EOL for patients with and without dementia (Burton et al., 2012). The authors chose to include dementia status and not CPS scores in the analytical models because of the protracted nature of dementia-related cognitive impairment, which would be more likely to have affected residents' ability to initiate or participate in ACP. We considered it likely that the CPS score of residents at their last assessment before death would be overly inclusive in that residents not previously affected by cognitive decline would be improperly labeled in the analyses as having a dementia. Misclassifying residents in that way might have confounded results by including those who did not have dementia and may have been capable of participating in ACP up until recently in the dementia group. We felt that using the RAI 2.0 for dementia status was a good balance of sensitivity and specificity. Cognitive impairment resulting from neurodegeneration before death was a significant characteristic of interest, and all people with an advanced dementia are affected, therefore, dementia subtyping was not seen as pertinent.

By restricting the data to only new entries to a LTC home over one census year, we were able to capture the entire stay of residents who died in the first thirteen months after admission, which was a strength of this study. The study period of thirteen months, however, left several residents out of the analyses as many residents admitted to LTC lived longer. Residents who died in the first thirteen months may be different from residents who live longer in LTC. Residents who died within thirteen months of admission may have been at a more advanced stage of disease when entering LTC and may have been less capable of expressing their wishes. Additionally, SDMs and residents who were at a more advanced stage of disease upon admission may have been more prepared and confident about making concrete EOL treatment and non-treatment decisions. On the other hand, there may have been a precipitous decline in health status, leaving little time to prepare for EOL decision making. Future research examining patterns of ACP (e.g., having a DNH, medication restrictions) recorded in the RAI over time may shed light on how changes in health status might contribute to changes in ACP. Prospectively enrolling community-dwelling older adults and their care providers and following them longitudinally as some enter the LTC setting would enable researchers to better examine different pathways to ACP and EOL decision making.

The data used in this study were from residents admitted to LTC beds in Ontario. The way these beds are categorised may not line up directly with how LTC homes were conceptualised in this study (i.e., residential care). It is likely that a small number of residents were in short term beds that are funded for LTC use, for example in a rural hospital, respite, *et cetera*. It was impossible to know details of the included LTC beds from the data available due to the anonymisation procedures in place. Given that the vast majority of LTC beds are actually

located in a LTC home as conceptualised, we expect the potential effect of a few non-residential beds would have been negligible.

The cause of death or reason for being outside of the LTC home at the time of death was not known. The ambiguity surrounding diagnostic practices in dementia and high incidence of comorbid diseases confound citing dementia as a cause of death. When the precise neurodegenerative mechanisms leading or contributing to death are unknown or obscure, physicians may be unwilling to record dementia as a cause of death. For this study, we were examining the impact of dementia symptoms for EOL care, and so it was not necessary to establish the cause of death, but rather that dementia was a risk factor for death and a potential contributor to differences in ACP and place of death compared to LTC residents without dementia symptoms .

Conclusions and Future Directions

The data and outcomes examined in the present study lend support to our previous two studies showing that ACP in LTC could be strengthened and suggests that ACP documentation may make a difference in EOL decision making. ACP documentation and dementia status appeared to play a meaningful role in predicting place of death when LTC residents died, particularly when they died outside of the LTC home.

Being younger and in a less advanced state of decline and disability increased the chances of LTC residents dying in an acute care facility, as well as the likelihood of having a living will. Given that the majority of LTC residents were documented as having significant (moderate to severe) cognitive decline and/or dementia, it is likely that these residents were not capable of participating in an ACP process. Current legislation does not allow for family members or other

care givers to engage in ACP on behalf of incapable persons, including those in LTC. A different approach to EOL care planning that is person-focused and sensitive to the unique needs of LTC providers should be given consideration.

Research Summary

The results of these studies show that only the narrowest definition of ACP is occurring in any of the participating LTC homes, or the CCC or ACH hospitals in the community. Study One demonstrated that the ACP documentation practices used across settings were not aligned with the philosophy of ACP, and in many instances were not aligned with current legislated requirements for ACP. Each of the reviewed documents lacked the majority of ACP Best Practices features, as identified from the literature review and from consultation with two local experts. Study Two demonstrated that health care workers with first-hand knowledge of ACP documentation and familiarity with the transfer of residents/patients between facilities often felt impeded by the ACP documents in their workplaces, were frustrated by a lack of clarity and understanding of EOL treatment options both within and between the places where older adults received care, and were almost entirely in favour of standardising the language of ACP to improve communication and their ability to provide patient care. Study Three demonstrated that ACP and dementia status are significant predictors of place of death, and that ACP remains uncommon in LTC across this province.

Challenges

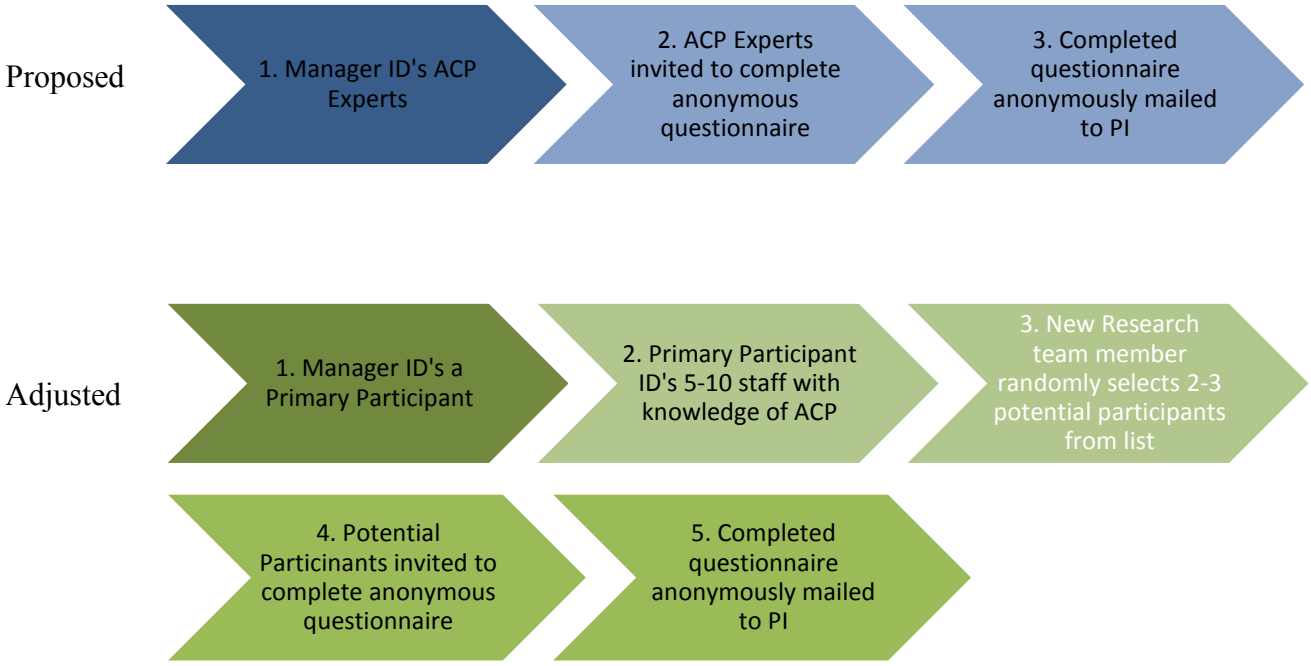
There were significant challenges encountered during this research, which resulted in delays in obtaining the support needed to proceed with these studies, changes to the study protocol, and prevented Study Three part B, from taking place.

Privacy concerns. Ethical review plays a necessary and intrinsically important role in conducting research. We were grateful for the thoughtful feedback and many discussions we had with the three REBs who reviewed this project. Overall, the REB process strengthened these

studies. At times, however, we were surprised with some of the conclusions and concerns expressed by reviewers, and these issues deserve mention.

The methodology proposed for Study Two was purposive expert sampling, meaning that only workers identified by their peers and supervisors as having expertise in ACP would be invited to participate. Whereas probabilistic or random sampling ensures generalisablity and minimises bias, purposive sampling ensures information-rich sampling from experienced and willing informants. We chose this technique based on the literature review, which indicated that many workers in LTC do not possess expertise or even a strong understanding of ACP. Purposive sampling is widely used with applications in health care and elsewhere (e.g., see Palinkas et al., 2015). We proposed to protect the privacy of potential participants through anonymisation techniques (i.e., returned questionnaires would be mailed and did not identify the respondent, their workplace, or their professional role) and giving respondents the option to leave any item blank, or select "prefer not to answer". We proposed that a manager would be well situated to identify workers with expertise at each site, believing the anonymisation procedures mentioned above would be sufficient to protect workers from undue pressure to participate or to participate in a certain way. Protecting the privacy of workers is very important and REB members expressed concerns that our methodology, as proposed, could put workers at risk by potentially exposing them to pressure (perceived or actual) from managers to participate in the research, as such, these REBs did not feel that the safeguards in our design were sufficient. We were grateful to the REB for proposing a change in methodology to allow us to proceed with this portion of the project, and we adopted their proposed changes. In short, the new methodology would see two added layers of separation between potential participants and both the primary researchers and the manager/director at each site (Figure 5).

Figure 5: Study Two Research Methodology: Proposed and Adjusted.



There were privacy-related consequences from this change in methodology. Specifically, under the adjusted methodology, potential participants were spared from having a person in a supervisory role identify them or request their participation in this research. Instead, the primary participant role was introduced, and the primary participant was identified and asked by a person in a supervisory role to participate in this research. At the same time, instead of the primary researcher knowing the identity of potential participants, a different researcher knew the identities of potential participants. The anonymisation of received questionnaires remained the same.

Study Three B also ran into REB challenges related to privacy. This study proposed a retrospective secondary analysis of aggregate, anonymous data from LTC residents who died over a 12 month period in the local community. An REB expressed concerns about accessing the

records of clients, deceased or otherwise, without consent. The researchers cited TCPS 2, Article 3.7, "Alterations to Consent Requirements," and explained that this research was deemed to involve no more than minimal risk by two other REBs. Retrospective anonymous client level data was proposed to be obtained from existing medical records and aggregated by facility. The welfare of the deceased person (and their surviving family/friends) would not, we argued, be adversely affected in any way by not obtaining consent to access their medical record. It would also not be feasible to contact participants to obtain consent. Debriefing would not be completed since there would be no possible contact with participants, and there would be no interventions. Per the LTCHA (2007), under sections 233(1) and (2), the records of deceased residents must be maintained for 10 years, and maintained on-site for a minimum of 12 months following their death/discharge, and were therefore expected to be available. The REB expressed concerns that obtaining these data would be onerous. We explained that the data we were seeking was submitted by each LTC home in aggregate form to the Canadian Institute for Health Information (CIHI) on a quarterly basis, so it was anticipated that these data could be easily extracted. The institutional privacy commissioner was invited to contribute to the discussion and they expressed an opinion that LTC homes did not have “the legal authority to access the health record without consent/proper authority, because the issue of accessing the record of a deceased is different as defined by Ontario's Privacy Legislation (PHIPA).” It was new information to this researcher that TCPS 2 and PHIPA could be incompatible, and this researcher thought, irrelevant to the study. The researcher explained that personal health information, by definition, must relate to an identifiable individual, and that the data we proposed to access in Study Three B would not contain identifiers and therefore did not fall under PHIPA. This statement was met with silence. At that time, the researchers requested that the REB sever Study Three B from the review

application so that studies One and could proceed, and this was granted. A formal decision on Study Three B was never communicated to the research team.

Protection of the public, particularly those who are vulnerable (e.g., workers) or unable to speak for themselves (e.g., people with dementia, deceased) is of utmost importance. Indeed, this research project was designed and implemented with the goal of ameliorating the lives of vulnerable persons. The potential repercussions of the methodological changes for the validity of this research were discussed previously, while the benefit of these changes for the protection of participants and potential participants remains unclear. Legal and ethical standards in place in Ontario and its institutions are superb guides for determining whether a project or request for data should be granted and how it should proceed. It is a strength of the REB system that reviews proceed on a case-by-case basis. In the two examples given above, aspects of the REB process seemed laden with misunderstanding or some other barrier to effective, although genial, communication between the researchers and the members of an REB. The result was that potentially valuable research did not occur as intended, or at all.

Staff turnover. The reviewed literature indicated a significant amount of staff turnover at the front-line level. Our experiences in this study demonstrated that frequent staff turnover at the level of Directors and Managers was also common in LTC and other settings which might affect the care older adults receive. Multiple transitions occurred during the REB application process that required us to repeatedly establish organisational impact and re-obtain support for the project prior to the REB accepting the submission for review. In the case of one Director's position this happened three times. Other manager's or directors in "acting" roles were hesitant to commit to a project when they were not sure how long they would be in that role. As discussed in Study Two, the organisation that previously oversaw access to LTC and home care

was dissolved and those duties were subsumed by another governmental organisation. We witnessed/experienced the effect of multiple personnel changes at those organisations both before and after the transition. The full impact of high turnover at the managerial, and director level of LTC could not be assessed in this study, however, we did anecdotally see how leadership inconsistencies could potentially limit the ability of workers and organisations to provide care to older adults at the EOL. In one instance, for example, a new director was not aware whether ACP was recorded or documented in that LTC facility. In another instance, a participant complained to the researcher of not feeling prepared or trained to do the tasks newly required of them. Communications between the researcher and executive level staff at several facilities often occurred well after regular office hours and on weekends, suggesting the possibility that these individuals were working significantly more hours than an average work week and potentially contributing to burnout. It was clear in all instances by their questions and interest in the topic of the research that these were compassionate professionals, but it appeared that they felt pulled in many directions and may not have had sufficient supports in place to sustain them in their roles. Assessing the impact of high turnover at the executive and managerial level of LTC and related services has not, to our knowledge, been studied before and would be a worthwhile area of future study, specifically with the aim of informing training that is appropriate, increasing mentoring and other support, and enabling suitable expectations for these important roles.

Conclusion

A Person-Focused Approach to Directives in LTC

The findings from Study One and Study Two denoted a lack of understanding of ACP within LTC and hospitals, mirroring what was frequently noted in the literature reviewed above.

Going forward, it will be important to consider that ACP, as defined, does not meet the needs of organisations and facilities providing care to older adults, many of whom are cognitively impaired upon entry and may not be able to fully or even partially engage in ACP. Facilities and organisations offering care for older adults have diverse needs, with clarity around treatment and non-treatment decision making in an acute crisis or as the end of a resident's life approaches, among them. A person-focused directives model could be developed to meet the needs of all stakeholders, giving consideration to individual needs and differences, ethical principles, professional requirements, organisational and administrative needs, and legislative considerations. The latter have potential to vary jurisdictionally and over time as laws change (e.g., the passage of Bill C-14 allowing for Medical Assistance in Dying (MAiD) across Canada in 2016; ongoing national-level discussion of whether and how to incorporate MAiD into ACP, e.g., Mikail and Wilson, 2016). In light of the findings from Study One and results of a simultaneously conducted study from the Law Commission of Ontario (Wahl et al., 2016), which indicated resource-sharing and replication across settings, any newly developed model or process of documenting a person's wishes for care will need to unambiguously address its jurisdictional context and limitations.

The development of a Person-Focused Directive for LTC (PFD-LTC) is proposed to be an EOL decision making model for residents of LTC who have lost the luxury of planning in the future tense due to disease processes or any other cause of cognitive impairment which prevents participation in ACP (e.g., developmental disability). A PFD-LTC model would need to be developed in thoughtful collaboration with lawmakers, healthcare providers, patient advocates, care providers, individuals with lived experiences of disability, biomedical ethics expertise, funding bodies, and others. It is likely that the frequently inapplicable definition of ACP is

restricting LTC homes and other care-providers from more thoroughly engaging family members in EOL care planning and documentation, and leading to ongoing confusion and frustration of well-meaning workers within the health care system. Resources such as the Hospice Palliative Care Ontario Community of Practice review process for Health Care Consent and ACP materials[25] can be utilised to ensure the language of ACP on newly revised or developed documents complies with the Ontario Legal Framework.

It is beyond the intention or ability of this author to propose specific recommendations for the PFD-LTC beyond stating and empirically supporting, through these studies, that there is a need for change in EOL decision making processes in LTC. The need for a PFD-LTC is supported on humanitarian, philosophical, and economic levels.

[25] Available from: http://www.speakupontario.ca/wp-content/uploads/2016/04/Review-Process-Final.pdf

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Appendix A

Organisational Invitation and Consent

Dear Potential Participant;

[Name of Facility] is invited to participate in a research study looking at how advance care planning (ACP) is documented across different settings where residents of long term care (LTC) may access healthcare services (e.g. LTC homes, acute care). This project is part of a Ph.D. Dissertation titled, Person Focused Directives for Advanced Care in Long Term Care (PFD-LTC). The results will help us learn about differences and similarities in the ways ACP is documented in different health care settings. Specifically, this study will be looking at features and characteristics of documents used for recording ACP (Phase I), and the experiences of selected health care workers who regularly encounter and use those documents (Phase II).

For Phase I, you will be asked to submit a copy of the ACP and/or Advanced Directive document(s) from your facility to the researcher. The features of the document(s) (e.g. identifies a substitute decision maker) will be coded and entered into an encrypted database by the researcher alone. For Phase II, you will be asked to identify a primary participant. The primary participant will identify 5-10 health care workers at your facility whom they recognise as having experience and knowledge about ACP and ACP documentation, one of whom may be the primary participant. The primary participant will send those names to a research team member via email (PFDLTCstudy@gmail.com). A random selection of 2-3 identified workers will be invited by mail and informed that participation is completely voluntary. To protect the identities of all potential participants, they will be asked not to identify themselves or the name the place where they work. Potential participants may decline altogether, return a blank copy, or leave blank any questions they do not want to answer. To further protect the anonymity of participants, there is no individual consent form for Phase II and consent will be implied by completing and returning the questionnaire. Questionnaires should be completed during work time.

Participating in this project is completely voluntary, you may withdraw at any time, and you may opt to participate in only one phase of the project. In the second phase (anonymous questionnaire), it will not be possible to withdraw once a submission has been made because it will not be possible to identify individuals. Participating in this project may benefit society by increasing knowledge regarding LTC residents' ACP, and the ways ACP documents are perceived and used by healthcare workers. There are no anticipated risks to participating in either Phase I or Phase II. All data will be kept secure at Lakehead University for five years following completion of the research, and then destroyed.

A summary of results can be obtained from the researchers when the project is complete. The aggregate results of this research (i.e. individuals and facilities will not be available or identifiable) may be presented in academic journals, conferences, and/or other settings where ACP is of interest (e.g. in a presentation to stakeholders such as yourself). If you have any questions or concerns about participating in this study, or to obtain a summary of the results, please contact, Kathleen

Bailey, at 807-474-8453 or skbailey@lakeheadu.ca, alternatively you can contact Gordon Hayman, PhD (Research Supervisor) at 807-343-8441 or ghayman@lakeheadu.ca.

This study has been approved by the Research Ethics Boards of the Thunder Bay Regional Health Sciences Centre (ResearchEthics_Chair@tbh.net), St. Joseph's Care Group, and Lakehead University. If you have any concerns regarding your rights as a research participant, or wish to speak to someone other than a research team member about this research project, you are welcome to contact the: Chair, Research Ethics Board, St. Joseph's Care Group, 580 N. Algoma St., Thunder Bay, Ontario P7B 5G4; phone: 807-346-3697, Toll Free within Ontario and Manitoba 1-855-239-8070, fax: 807-343-4376; email contact for REB Chair: REB_Chair@tbh.net. Alternatively, if you have any questions related to the ethics of the research and would like to speak to someone outside of the research team please contact Sue Wright at the Lakehead University Research Ethics Board at 807-343-8283 or research@lakeheadu.ca.

This paper is yours to keep for your records. Please review the information on this sheet then sign and follow instructions on the accompanying sheet to participate in this client-focused research initiative.

Sincerely,
Gordon C. Hayman, Ph.D., Associate Professor, and S. Kathleen Bailey, M.A., Ph.D. Candidate

Appendix B

Checklist for ACP Document Audit

Document Name: _____

Facility Type: ☐ Hospital ☐ LTC:_____

I.	Identifies a substitute decision maker (and contact details) where applicable.	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present
II.	Resident competency at the time of completion is noted.	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present
III.	Current state of the resident's health is noted.	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present
IV.	Indication of the resident's values and beliefs (things that matter most in life).	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present

V.	Indicates future unacceptable health conditions.	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present
VI.	Specifies resident's preferences in relation to life-prolonging treatment.	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present
VII.	Specifies resident's preferences in relation to hospital transfer.	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present
VIII.	Specifies wanted/unwanted treatments-where applicable.	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present
IX.	Goals for EOL care clearly specified (e.g. natural death, comfort)	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present
X.	Signatures (clear, complete, dated,	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present

	witnessed)			
XI.	Evidence of physician review	☐ Clearly stated	☐ Ambiguous/ Incomplete	☐ Not present

Scoring: 2=Clearly Stated, 1 = Ambiguous/Incomplete, 0=Not present **SCORE: /22**

Additional Notes:

Appendix C

Disagreement Items between Rater One and Rater Two

Hospital 1b

ACP Best Practices Feature III: Current state of the resident's health is noted

Rater One ranked this item as completely absent while Rater Two rated it as ambiguous. Upon second evaluation, Rater Two agreed with Rater One that there was no place to describe or label the resident's health status or any diagnostic information and consensus on “completely absent” ranking was achieved.

Hospital 2

ACP Best Practices Feature I: Identifies SDM and contact details

Rater Two rated this item as “clearly stated,” while Rater One rated it as “incomplete.” Consensus was reached that contact details would be available in the patient’s electronic medical record “clearly stated” was agreed upon.

ACP Best Practices Feature X: Signatures (clear, complete, dated, witnesses)

Rater Two rated this feature as “clearly stated” while Rater One rated it as “incomplete.” It was re-examined and agreed that a witness’s presence was implied by having multiple signatories on the document and consensus was reached to use “clearly stated.”

Appendix D

Optional ACP Process Questions for the Primary Participant

Below are questions about how the [Form Name] is used at [Site]. You can respond to each one by writing below and sending it back to me.

1) Is there a protocol in place for having discussions about EOL care/Advance Directives and for documenting those discussions? (e.g., time frame before/after admission, timeline for review of directives, specific individual(s) responsible for initiating the discussion and completing the form). If so, please tell me about it.

2) Does every resident/patient have a completed [Form Name] on file? Are there, to the best of your knowledge, any residents who have used their own Advance Directive/Treatment Directive document instead and/or foregone the standard form for any reason? Please tell me briefly how that situation is/would be responded to.

3) Who on staff has access to the information on the [Form Name]? Are there ever any limitations on who has access or when they have access, for example, to protect resident/patient privacy?

4.a) In the event that a resident/patient is transferred to another facility, are they always accompanied by their [Form Name]? If so, do you know how that document is used at the next facility?

4.b) When a resident/patient is admitted from or returns from another facility, are they accompanied by that facility's Advance Directive/Treatment Directive/Code Status Form? If so, how is that information used at [Site]?

5.a) Are you aware of situations when the [Form Name] was, for any reason, disregarded (e.g., resident/patient is transferred to hospital despite a Treatment Directive for Supportive/Comfort Care)? If so, please provide an example (e.g., patient family member's request).

5.b) Based on your own professional experience, would you say people who died with a dementia over the last 12 months were as likely, more likely, or less likely to die at "home" (i.e., at [Site]) versus in hospital, compared with residents who died without a dementia?

Appendix E

Hierarchy of SDMs in the Health Care Consent Act, s.21

1. Guardian of the Person with authority for Health Decisions

2. Attorney for personal care with authority for Health Decisions

3. Representative appointed by the Consent and Capacity Board

4. Spouse or partner

5. Child or Parent or CAS (person with right of custody)

6. Parent with right of access

7. Brother or sister

8. Any other relative

9. Office of the Public Guardian and Trustee

Appendix F

Advance Directive Questionnaire for HealthCare Providers

The purpose of this questionnaire is to gather information from your experiences using documents for EOL care planning (i.e. Advance Directive) with older adults. *This questionnaire is anonymous; please do not indicate your name or the facility where you work*.

1) **Are documents for recording treatment directives equivalent across local facilities where older adults receive care?**

☐ Yes ☐ No ☐ Not sure ☐ Prefer not to answer

Please explain.

2) **Is it straightforward to transfer the intent of a treatment directive from one institution to another when a patient relocates (e.g., from CCC to LTC, or LTC to hospital)?**

☐ Yes ☐ No ☐ Not sure ☐ Prefer not to answer

Please explain.

3) **Would a standardised treatment directive document (i.e. common language used at all facilities) ease communication of a person's wishes across treatment settings?**

☐ Yes ☐ No ☐ Not sure ☐ Prefer not to answer

Please explain.

4) **Would a standardised treatment directive document (i.e. common language used at all facilities) improve patient care?**

☐ Yes ☐ No ☐ Not sure ☐ Prefer not to answer

Please explain.

5) **Does the treatment directive document at your primary workplace contain sufficient information to support EOL treatment (or non-treatment) decisions?**

☐ Yes ☐ No ☐ Not sure ☐ Prefer not to answer ☐ n/a

Please explain.

6) **Is the treatment directive document at your primary workplace easy to use and interpret when needed to guide EOL decisions?**

☐ Yes ☐ No ☐ Not sure ☐ Prefer not to answer ☐ n/a

Please explain.

7) **What is your role at the facility/organisation (e.g., Manager, PSW, RN, MD)?**

Thank you for your time and input!

Appendix G

Qualitative Responses to Advance Directive Questionnaire for HealthCare Providers

Question	Responses Provided
Are documents for recording treatment directives equivalent across local facilities where older adults receive care (i.e., hospitals, LTC, CCC)?	1. "Every institution has different forms if at all." 2. "Every place has something different" 3. "ID bracelets like [hospital 1] indicating client's code status should be identified here at [facility]" 4. "Most settings have different forms to document advance directive and often when notified of pt's advance directive will complete their own form for pt's file instead of using the form that was completed in pt's previous setting." 5. "No different for LTC. Not equivalent across the board." 6. "see #2" 7. "[Hospital 1], [Hospital 2], and LTC homes all have slightly different processes and forms."

Is it straightforward to transfer the intent of treatment directives from one institution to another when a patient relocates?	1. "Between [hospital 1] and [hospital 2] electronic transfer is in place as well as all the hospitals in the NW LHIN. Each different LTC home differs as well as the supportive housing and retirement homes." 2. "Because each institution has different documentation, often health care professionals have to discuss treatment directive with pt again in order to clarify ie. hospital has 5 code status levels but community care not educated on this system and no document forwarded to community that records pt's treatment directive." 3. "Confusion on admission at times." 4. "Hospital uses different form/language for directives that LTC" 5. "Not sure of the process for all facilities. I know we do not always get on transfer." 6. "Usually a paper form that often gets lost"

	7. “When we sent older adults to the emergency department, they often don't look at the directives we send and if they do - I don't believe they understand the meaning. They work in a setting where they do everything they can to 'save' a person, they often don't think about this like we do.”
Would a standardised treatment directive document (i.e., common language used at all facilities) ease communication of a person's wishes across treatment settings?	1. “Absolutely - across the whole province.” 2. “Absolutely, we need to speak the same language. At times, we have clear directives in place but when a person goes to acute care, their wishes are not clear to them as they don't speak our language.” 3. “All speaking the same language with same direction and explanation” 4. “decrease confusion” 5. “especially if it was electronic and all facilities used same electronic system” 6. “It could easily be faxed to other

	members of circle of care and/or other settings as pt's care is transferred- would be a more efficient use of everybody's time and would be more empathetic to pt/family's situation." 7. "Should be across the province" 8. "Would make it easier"
Would a standardised treatment directive document (i.e., common language used across all facilities) improve patient care?	1. "A person's wishes would be considered in discussions in all settings and their individual needs would be met." 2. "any improvement in communication and understanding will improve patient care" 3. "Anytime a pt's wishes for treatment can be relayed to other members of the circle of care, this improves pt. care - prevents a pt/family from having to have those difficult conversations over and over again." 4. "Document does not describe what hospital could offer for the elderly or

	does not describe in length what a long term care facility can offer (outdated)" 5. "More easily provide appropriate care." 6. "No confusion at all" 7. "Obviously an individual's choices would be honoured" 8. "Would be consistent" 9. "Yes provide clear communication"
Does the treatment directive document at your primary workplace contain sufficient information to support EOL treatment (or non-treatment) decisions?	1. "Does not reflect level of care available in LTC" 2. "It does not go into detail like the code status level at the hospital so for pts who want more than just comfort measures, it does not provide an area to document specific pt wishes but works well in cases of 'comfort measures only.'" 3. "It isn't very clear. Nurses don't always explain it to clients in the same way either. We all need to talk the same language within and outside health care organisation."

	4. "Lots of room for misinterpretation, lacks clarity for care givers" 5. "Not clear at all. Support/Comfort care vs. primary therapeutic care. Same staff unsure which to check off. Very confusing." 6. "Sufficient information provided" 7. "[Hospital 1] covers 5 levels of advance directive" 8. "To a point. Exploration of specifics needs to be done frequently. Addressing escalation of care preferences can be challenging in acute care setting esp. in "unstable" end-stage patients."
Is the treatment directive document at your primary workplace easy to use and interpret when needed to guide EOL decisions?	1. "Could improve/educate on the process. Make is easier for all levels of care providers to complete." 2. "Have to explain what staff would do, and provide examples. Very difficult to explain, especially for new staff." 3. "It is basic but easy to understand."

4. “Not used enough”
5. “Same as above.”
6. “See above.”