Orchestrating Comfort: Getting Everyone on the Same Page: Long Term Care Nurses' Experiences with Advance Care Planning

by

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Abstract

Background: The majority of residents in long term care (LTC) facilities are older and frail, with multiple comorbidities and reduced cognitive capacity. Although the evidence suggests that advance care planning (ACP) improves the quality of end-of-life (EOL) care and promotes a good death for residents of LTC, such planning rarely occurs in these settings. Moreover, while nurses are in the ideal position to facilitate ACP, there is a paucity of empirical research examining their engagement in ACP.

Purpose: The purpose of this qualitative study was to develop an inductively derived empirical model aimed at understanding the experiences of nurses working in LTC facilities, specifically with regard to their engagement in the ACP process.

Design: A constructivist grounded theory (CGT) methodology was used to conduct this study. Symbolic interactionism (SI) and the socio-ecological model (SEM) served as sensitizing theoretical perspectives for this study. Purposive and theoretical sampling were used to recruit 25 registered nurses (RNs) from 18 proprietary and non-proprietary LTC facilities in Winnipeg, Manitoba who had worked a minimum of three months in LTC, were able to read/speak English, and were willing to provide consent to participate in the study.

Methods: Data were collected using a demographic questionnaire; in-depth, semi-structured, audio-recorded, face-to-face/telephone interviews; field notes; and memos. Demographic data were analyzed with descriptive statistics. Verbatim transcriptions of the interviews were analyzed with specific CGT coding procedures.

Findings: The basic social problem that emerged from the data was that of nurses trying to craft and implement an ACP level that they believed would optimize residents' comfort in LTC. The empirically derived theoretical model that captured the experiences, processes, and strategies of nurses trying to address the identified social problem was *orchestrating comfort: getting everyone on the same page*. This model encompassed two main processes, downgrading and upgrading ACP levels, and two pre-conditions, piecing together the big picture and selling the big picture. The nurses were able to maximize residents' comfort at EOL and during acute events by downgrading and upgrading ACP levels, respectively. The nurses believed that a universal understanding of the residents' condition would lead to a realistic ACP level that would, in turn, optimize comfort. The nurses identified several facilitators and barriers at the resident/family, healthcare provider, and organizational levels for the processes of downgrading and upgrading ACP levels. Several positive and negative consequences of orchestrating comfort at the resident, family, and nurse levels were also noted in this study.

Conclusion: This study fills an important gap in the literature by explicating the ways in which LTC nurses engage in ACP as well as the factors that facilitate or constrain their ability to optimize resident comfort. It was the first Canadian study to illustrate the micro- and macro-perspectives of ACP through the dual lens of SEM and SI. A multitude of implications for the healthcare system and future research arose from this study, specifically with regard to practice, education, research, and policy development.

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Dedication

To my grandparents: Vasudevan and Sarojini, you are always watching over me from above.

To my PhD colleague: Celeste, you lifted my spirit and helped me realize what was possible.

List of Abbreviations

ACCEPT – Advance Care Planning Evaluation in Elderly Patients

ACP – Advance Care Planning

ACP-C – Comfort Level Advance Care Plan

ACP-GOC – Advance Care Plan-Goals of Care

ACP-M – Medical Level Advance Care Plan

ACP-R – Resuscitative Level Advance Care Plan

ADLs – Activities of Daily Living

ALC – Alternate Level of Care

ARNM – Association of Regulated Nurses of Manitoba

CASCADE – Choices, Attitudes, and Strategies for Care of Advanced Dementia at End-of-life

CLGT – Classic Grounded Theory

CGT – Constructivist Grounded Theory

CHESS – Changes in Health, End-Stage Disease and Signs and Symptoms

CHPCA – Canadian Hospice Palliative Care Association

CHPC-NG – Canadian Hospice Palliative Care Nurses Group

CIHI – Canadian Institute of Health Information

CLHIA – Canadian Life & Health Insurance Association

CNA – Canadian Nurses Association

CPR – Cardio Pulmonary Resuscitation

CRN – Clinical Resource Nurse

C – Comfort care

DOC – Director of Care

DNH – Do Not Hospitalize

DNR – Do Not Resuscitate

ED – Emergency Department

EOL – End-of-Life

FHA – Fraser Health Authority

GOC – Goals of Care

GCD – Goals of Care Designation

GT – Grounded Theory

HCAs – Health Care Aides

HCP – Health Care Provider

HMO – House Medical Officer

ICU – Intensive Care Unit

IEN – Internationally Educated Nurse

IOM – Institute of Medicine

KTA – Knowledge to Action

LMS – Learning Management System

LPP – Letter project Pilot

LTC – Long Term Care

M – Medical care

MDS – Minimum Data Set

MHSAL – Manitoba Health, Seniors and Active Living

MNU – Manitoba Nurses Union

MOST – Medical Orders for Scope of Treatment

NHs – Nursing Homes

NP – Nurse Practitioner

PCH – Personal Care Home

PGT – Public Guardian and Trustee

POA – Power of Attorney

PT – Physiotherapist

POLST – Physician Orders of Life-Sustaining Treatments

PSDA – Patient Self-Determination Act

R – Resuscitative care

RN – Registered Nurse

SEM – Socio-Ecological Model

SGT – Straussian Grounded theory

SI – Symbolic Interactionism

SLP – Speech Language Pathologist

SMM – Shared Mental Model

SPA-LTC – Strengthening a Palliative Approach to LTC

SPSS – Statistical Package for the Social Sciences

SUPPORT – Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments

RAI-MDS – Resident Assessment Instrument Minimum Data Set

RCM – Resident Care Manager

RESPECT – Risk Evaluation for Support: Predictions for Elder-Life in the Community Tool

TCPS – Tri - Council Policy Statement

TCU – Transitional Care Unit

TPB – Theory of Planned Behavior

UK – United Kingdom

US – United States

WHO – World Health Organization

WRHA – Winnipeg Regional Health Authority

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Chapter 1: Introduction

The aim of this introductory chapter is to provide a context for the study. This chapter will: (a) outline the statement of the problem; (b) state the purpose of the study; (c) identify the research questions; (d) discuss the significance of study findings; and (e) provide definitions of terms used frequently in this document.

Statement of the Problem

Advance care planning (ACP) is a public health issue (Prince-Paul & DiFranco, 2017) of particular significance for older adults living in long term care (LTC) facilities. Advance care planning ensures that individuals' choices for end-of-life (EOL) care are respected. For many, this means being treated as an individual, with dignity and respect for one's personal choices and preferences, in familiar surroundings, and in the company of those who are well-known to them (Thomas & Lobo, 2011). In practice, LTC facilities are the providers of geriatric palliative care, so EOL care and ACP are critically important to these settings (Jeong et al., 2010). Advance care planning is fundamental to guiding medical care at EOL and aims to achieve the best possible patient outcomes while maintaining acceptable standards of care (O'Hanion et al., 2018). Even though death and dying are becoming the central features of LTC, with deaths occurring frequently in these settings, excellence in EOL care has not yet been achieved (CIHI, 2018; Stall et al., 2017; Thompson & Chochinov, 2006). Effective ACP is an essential component of quality palliative care; knowing and honouring residents' preferences for care and allowing them to die where they choose are recognized as gold standards in palliative care (Robinson et al., 2013).

Advance care planning is an ongoing dynamic process of communication between healthcare providers, residents, and their families that seeks to clarify the residents' and families' understandings, wishes, values, and potential concerns about treatment and care at EOL (Flo et al., 2016; Rietjens et al., 2017). The Winnipeg Regional Health Authority (WRHA) defines ACP as a process of considering, discussing, and planning for future healthcare in the event that the individual is incapable of consenting to treatment; it is based on the individual's wishes, values, and beliefs (WRHA, 2011). According to Corbin and Strauss (2008), "a process is ongoing action/interaction/emotion taken in response to situations or problems, often with the purpose of reaching a goal or handling a problem" (p. 97). According to the WRHA, there is no structured process for the implementation of ACP; instead, ACP is loosely defined as a shared decision making process that takes place among key decision makers (WRHA, 2011). In this researcher's experience, the ACP process usually consists of checking off a box on a form for the purpose of meeting institutional policy requirements. There is usually minimal discussion around the preferences or values of residents/families and the interventions required in relation to residents' prognosis and comorbidities. Allison and Sudore (2013) stated that the disregard of patients' preferences is a medical error and suggested that discussions about goals of care (GOC) and code status should be treated as a medical procedure, similar to surgery. They advised that clinicians should pay more attention to in-patient code status discussions and complete accurate documentation of real-time patient preferences, in order to improve patient safety and reduce medical errors of omission. A study conducted in a LTC facility in Winnipeg, Manitoba emphasized the importance of ACP for improving EOL care and showed that comprehensive, up-to-date advanced care plans (ACPs) can help create peaceful environments for dying residents and their families (Krishnan et al., 2015). The researchers concluded that ACP can avoid unnecessary, burdensome interventions and reduce overall healthcare expenditures.

Even though ACP is essential in LTC, its prevalence remains low. A nationwide study from Flanders, Belgium, showed that the completion rate of ACP (52%), including 'do not hospitalize (DNH)' orders (37%), remains substantively low among nursing home (NH) residents (De Gendt et al., 2013). In addition, almost one-half (n= 1357) of residents had at least one hospital transfer during their last three months of life (De Gendt et al., 2013). A national sample of United States (US) NHs studied over a nine year period (1999 to 2007) showed that one in seven NH residents had a terminal hospitalization in the last seven days of life, and DNH orders were completed in less than 4% of this population (Teno et al., 2011). Canadian findings have been similar in that only one in five residents in LTC facilities have DNH orders and 21.8% of residents were hospitalized (n=27, 243) while 9.8% received medical resuscitation in the last 30 days of life (Stall et al., 2017). Overall, worldwide evidence shows that NH residents frequently experience terminal hospitalizations, a finding that may reflect inadequate ACP (CIHI, 2016, 2018; De Gendt et al., 2013; Stall et al., 2017; Teno et al., 2011).

Many studies have indicated that, in the absence of a clear ACP, healthcare providers default to intensive interventions in the event of clinical deterioration, and this often results in hospitalization and unnecessary suffering (Cantor & Pearlman, 2003; O'Hanion et al., 2018; Triplett et al., 2008). This is especially true for residents with dementia in LTC facilities (Cantor & Pearlman, 2003; Triplett et al., 2008). Thus, it is important to identify and clarify ACP objectives to optimize residents' EOL care (Institute of Medicine [IOM], 2015).

Evidence shows that it can be challenging to implement ACP in LTC (Martin et al., 2016; Nicholas et al., 2014; Thoresen & Lillemoen, 2016). There are several complexities around ACP that are unique to LTC facilities, including: high prevalence rates of dementia; reduced physician involvement; and the lack of timely communication among key decision makers (Shield et al., 2005; Thompson et al., 2012). Easson (2005) argues that engagement in the current ACP process has been disappointing, and improvement can only be realized through rigorous qualitative research.

Much of the literature examining the ACP process has been from the perspectives of residents and their families (Bern-Klug, 2009; Thompson et al., 2012; Waldrop & Kusmaul, 2011). Inadequate communication has been studied for many years and is the main issue in EOL care decision making (Shield et al., 2005; Thompson et al., 2012). In contrast, the perspectives of LTC nurses, who are key members of the healthcare team most involved with LTC residents and are in a crucial position to unpack the ACP process, have been largely absent from the literature.

Based on the researcher's experience and literature review, there is an increased need for more extensive knowledge and understanding of how ACP discussions are being conducted in LTC settings. The core rationale for this study was the explication of nurses' perspectives and understandings of the ACP process, specifically in the context of LTC in Canada. In addition, this study sought to address the need for more rigorous research regarding the ACP process.

Purpose of the Study and Research Questions

The purpose of this constructivist grounded theory (CGT) study was to develop an in-depth, theoretical understanding of how LTC nurses experience the process of ACP. The goal of this study was to develop an inductively derived empirical model to understand the ACP process from the perspectives of LTC nurses. The four broad initial research questions explored in this study were:

1. What are the experiences of nurses regarding the process of ACP in LTC settings?
2. What factors facilitate the process of ACP?
3. What factors inhibit the process of ACP?
4. What are the consequences/outcomes of this process?

Significance of the Study

This study fills an important gap in the literature by explicating the ways in which LTC nurses engage in the process of ACP and by examining the factors that facilitate or constrain their ability to optimize residents' comfort. It is the first Canadian study to illustrate the micro and macro perspectives of ACP through the dual lens of symbolic interactionism (SI) and the socio-ecological model (SEM). The study findings should make an important contribution to the field of geriatrics, especially for EOL care of LTC residents, who are the most vulnerable members of our population. The theoretical understandings developed through this research provided insight into how nurses engage in the process of ACP in their daily work in LTC facilities. The inductively derived empirical model would benefit healthcare providers who wish to incorporate meaningful resident-centered, goal-consistent, evidence-based care for older Canadians as they near EOL. Theoretical understandings of the ACP process gained from this study helped address a pressing national priority identified by the Canadian health research community, clinical stakeholders, and consumers of healthcare services – to narrow the gap between the care that patients prefer and the care they actually receive (Fowler & Hammer, 2013). The study findings have the potential to decrease resident, family, and clinician barriers to ACP, thus increasing the uptake, impact, and access to ACP for older Canadians across LTC settings. In general, improvements in ACP can reduce unwanted hospital transfers and their inherent risks. Advance care planning can also facilitate a dignified, peaceful death for LTC residents by averting medical interventions that may cause needless pain, prolonged suffering, and transfers out of their familiar surroundings. As a result, this study has the potential to achieve the IOM's (2015) triple aim of: improving care, improving health, and reducing costs.

While theoretical understandings of ACP are important, the knowledge itself is of limited use unless it is translated into practice. Therefore, it is important to work toward positive changes that aim to improve the ACP process. Insight and information gained from this study could inform and support necessary changes in clinical practice, education, and policies to improve the quality of EOL care for LTC residents.

Definitions of Terms

Advance care planning: Advance care planning is an ongoing process of open communication and information sharing between the healthcare team, the patient, and their family (Baughman et al., 2013; Zhou et al., 2010). Substitute decision maker(s) are involved in the communication process if the patient is not capable of making decisions for himself/herself (Canadian Hospice Palliative Care Association, 2012). This process of communication promotes the sharing of the patient's wishes, by the patient or substitute decision maker, for future medical care and treatment, and seeks to explore and support these wishes in a manner that facilitates informed decision making for the patient's best interests (Baughman et al., 2013; Zhou et al., 2010).

Long Term Care: In Manitoba, Canada, LTC facilities are also known as personal care homes (Banerjee, 2007). Long-term care facilities are those that provide 24-hour professional nursing care and supervision in a protective, supportive environment for people with complex care needs who can no longer be cared for in their own homes (Fransoo et al., 2013).

Nurse: In Canada, a nurse is defined as an individual who: has graduated from an approved nursing education program or a program that meets the requirements set out in nursing regulations; has passed a national nursing licensing examination; and holds valid registration with the appropriate regulatory body and practices nursing under a code of ethics for their profession (Canadian Nurses Association, 2018).

Facilitator: A factor that helps the nurse to engage in the process of ACP. This factor can be at the resident/family level, healthcare provider level, and/or healthcare system level.

Barrier: A factor that hinders the nurse to engage in the process of ACP. This factor can be at the resident/family level, healthcare provider level, and/or healthcare system level.

Consequences: The outcomes or results of the ACP process. These outcomes can be at the resident/family level and/or the healthcare provider level, and can be positive or negative.

Summary

This introductory chapter outlined the rationale for this study, its purpose, research questions, significance of the study, and definitions of concepts related to the study's purpose, as noted in the empirical and practice-based literature. The literature that was critically reviewed for this study is presented in chapter two.

Chapter 2: Literature Review

This chapter begins by describing the traditional use of literature in conducting research, then outlines the purpose and timing of a literature review in using GT. This chapter describes the different perspectives of a literature review in GT and the approach taken in this study regarding use of the literature. The latter part of this chapter provides a critical synthesis of the literature examined in this thesis research.

Traditional Use of Literature in Conducting Research

The literature review is usually undertaken in the early stages of a research project and is an integral part of the project's development. The literature review serves to provide the background of current knowledge on a certain topic and highlights the potential significance of the study that is underway. Priest and Roberts (2010) suggest that one of the main purposes of the literature review is to make a convincing argument for the research by identifying a gap in the current knowledge that the research study aims to fill. Other reasons cited for carrying out a literature review at the commencement of a study are: to acknowledge those who have worked in this area; avoid duplicating other people's work; assist in defining the research question; and place the proposed research study in the context of other studies (Holloway & Wheeler, 2010).

Uses of Literature in Conducting Grounded Theory Research: Purpose and Timing

In GT methodology, the existing literature is not used as theoretical background but in the analytical process (Ramalho et al., 2015), as data is theoretically sampled according to the directions indicated by developing categories (Charmaz, 2006, 2014; Strauss & Corbin, 1998). Therefore, grounded theorists have historically debated whether a literature review should be employed at the beginning of a study and, if so, how the literature should be used during its initial stages. The timing of the literature review in GT methodology is influenced by the researcher’s epistemological perspective, previous background, and knowledge in the research area (Giles et al., 2013). Glaser (1978, 1992), Strauss and Corbin (1994), and Charmaz (2006, 2014) agreed that a theory developed through GT methodology should be grounded in the data rather than in the existing literature. As the originators of GT, Glaser and Strauss advocated in 1967 that the literature review should be delayed until data analysis had been completed. Their rationale for recommending this delay was to avoid importing other writers’ ideas and having these ideas impose upon the new study. In other words, this was a deliberate attempt to liberate the researcher from previous ideas and encourage them to articulate their own original thoughts. Glaser has robustly defended this perspective over the years, and maintains that delaying the literature review keeps the GT researcher as free and open as possible to the discovery of theoretical interpretations within the data (Glaser, 1978).

In his later work with Corbin (Strauss & Corbin, 1990), Strauss questioned whether the original GT perspectives of the literature review were naïve. Strauss came to believe that it is inevitable that all researchers bring some professional and disciplinary knowledge to their research endeavours. Therefore, Strauss and Corbin (1998) argued that a researcher’s previous knowledge should be combined with a wide variety of literature throughout all phases of the research, from conception to conclusion.

In constructivist GT methodology, Charmaz (2006) takes a pragmatic view and deems it acceptable to engage in background reading of significant studies and theories in the field of enquiry. Charmaz (2006) has argued that this approach enables the researcher to outline a general direction of travel and, thus, satisfy the requirements of research institutions. However, Charmaz has cautioned researchers to resist the tendency to allow earlier studies or theories to unduly influence the development of original theories. Charmaz favours letting such material “lie fallow" (2006, p. 166) until after the GT has been substantially developed. It is at this stage that the research can be located within the relevant literature. Articulation of the researcher's original ideas, inducted from the original data, is of paramount importance in Charmaz's approach to GT.

In constructivist GT, a preliminary review of the literature helps researchers contextualize the background of the study, identify knowledge gaps, provide rationale for the study, stimulate research questions, and enhance theoretical sensitivity (Giles et al., 2013). A focused secondary literature review, conducted during data collection and analysis, can create a link between existing research and theory and the concepts, constructs, and properties of the new research. This process demonstrates how the researcher(s) built upon and further advanced existing empirical work, allowing them to situate their work within the body of related literature and validate their new emerging theory (Charmaz, 2006; Giles et al., 2013).

The Use of Literature Within This Study

Consistent with constructivist GT methodology (Charmaz, 2006, 2014), a preliminary review of the literature was conducted to contextualize the background of the study, identify knowledge gaps, provide rationale for the investigation, and stimulate research questions. The initial literature review served to outline the general path of enquiry, without restricting original theoretical ideas. In addition, the literature review satisfied the requirements of the university research proposal process and helped orientate the study and researcher toward enhanced theoretical sensitivity. To mitigate the risk of pre-existing knowledge having undue influence on theory development, the researcher engaged in reflexivity throughout the research process by acknowledging her existing knowledge in the area of interest through the use of memos. Memo writing is an informal method of taking notes that has been characterized as "the cornerstone of quality" in GT (Birks & Mills, 2015, p. 39). It is seen as vital in allowing researchers to minimize preconceptions, maintain reflexivity, engage in critical thinking, and remain connected with the data (Glaser & Holton, 2007). A more focused secondary literature review was conducted during the data collection and analysis phases of the study to link and validate the emerging theory with existing literature.

The preliminary literature review conducted for this study provided a critical synthesis of the current knowledge and key findings in five areas relevant to this thesis: (a) the impact of the aging population on the Canadian healthcare system; (b) the organizational structure of LTC facilities; (c) the complexities of care in LTC settings; (d) the ACP; and (e) nurses' engagement in ACP. This literature search was undertaken using major electronic bibliographic databases, including CINAHL, Web of Science, Medline, Ageline, and PsycINFO. There was a major focus on nursing literature since this research is situated within that discipline. Several other disciplines, such as medicine, social work, and education, were also recognized as being essential to informing this work. The reference lists of the retrieved articles were used to identify additional publications. A variety of current EOL care and ACP textbooks were surveyed for relevant chapters and reference citations. Searches were also conducted for grey literature on the websites of relevant government agencies and organizations. Additional concepts and topics were explored in a focused secondary literature review that critically examined the emerging new theory against the relevant extant literature.

Impact of the Aging Population on the Canadian Healthcare System

The phenomenon of population aging is a serious social problem around the world. It is expected that people aged 65 years and older will account for up to 25% of the total Canadian population by 2036. The number of people aged 65 years and older is projected to increase from 5 million in 2011 to 9.8 million in 2036 (Statistics Canada, 2016a), leading to a doubling of the annual expected deaths (Fowler & Hammer, 2013). Between 2011 and 2016, the number of people aged 85 and older grew by 19.4%, and represented 2.2% of the Canadian population. The number of centenarians grew by 41.3% between 2011 and 2016; it is estimated that this number could increase from 8,230 in 2016 to nearly 40,000 by 2051 (Statistics Canada, 2016b). Due to advances in medicine and public health, many older adults are living longer and have complex multi-morbid illnesses, many of which contribute to frailty and impaired cognitive and physical function (World Health Organization [WHO], 2011).

The incidence of dementia increases exponentially with advancing age and doubles approximately every five years, with estimates as high as 41% per year in centenarians (Corrada et al., 2010). Currently, over 500,000 Canadians have dementia and 25,000 new cases are diagnosed every year. It is projected that the number of Canadians with dementia will double to 1.4 million by 2031 (Alzheimer Society of Canada, 2017). More than 22,500 Manitobans have some form of dementia and, by 2038, it is anticipated that more than 40,700 will have a dementia diagnosis (Alzheimer Society of Manitoba, 2018). The number of dementia cases in Manitoba are projected to increase by 20% from 2015 to 2025, 68% from 2015 to 2035, and 125% from 2015 to 2045 (Adlimoghaddama et al., 2018). These projected statistics paint a stark picture for the aging population and healthcare system in Canada and represent the most pressing policy imperatives of this century (Canadian Medical Association, 2016).

Raising Demands on Long Term Care

The Canadian population includes an expanding cohort of individuals who are not only older, but also experiencing varying levels of disease burden. These demographic shifts are causing an increased demand for formal care services, such as NHs or LTC facilities, to provide care to these individuals (Doupe et al., 2011). Advanced age (Wolinsky et al., 1992) and a diagnosis of dementia (Garner et al., 2018) are strong predictors of admission to LTC facilities. In Canada, seven percent of older adults reside in LTC facilities, where one in three are over 85 years and two in three are centenarians (Statistics Canada, 2016c). According to a 2017 report from the Conference Board of Canada, Canada will require 43,000 new LTC beds over the next five years due to the aging baby boom generation. By 2035, there will be a need for an additional 199,000 LTC beds, nearly double the existing 255,000 beds (Gibbard, 2017). There are currently 10,000 licensed LTC beds in 125 facilities across Manitoba, with the majority being in Winnipeg (Wilson et al., 2017). Recent projections estimate that Manitoba will require more than 16,000 additional LTC beds by 2036 to accommodate the aging population (Chateau et al., 2012).

Impact of Aging on Healthcare Expenditures

There is a direct correlation between healthcare expenditures and age, with more than 40% of total Canadian healthcare spending being attributed to those aged 65 years and older (CIHI, 2007). In 2017, the estimated nationwide cost of dementia was $33 billion per year; by 2040, this figure is expected to increase to $293 billion per year (Alzheimer Society of Canada, 2016). The total economic burden of dementia in Manitoba is close to $1 billion and is expected to grow to more than $28 billion by the year 2038 (Adlimoghaddama et al., 2018). It is projected that over the next 40 years, the total annual cost of LTC in Canada will triple from approximately $69 billion in 2014 to about $188 billion in 2050. Public LTC costs are estimated to increase from around $24 billion in 2014 to approximately $71 billion by 2050 (Blomqvist & Busby, 2015).

Evidence suggests that annual per capita spending on deaths increases with age, ranging from an average of $25,000 to $30,000 for those dying between age 66 and 70 to more than $40,000 for those who die over the age of 90 (Payne et al., 2009). A 2012 report by the

Canadian Life and Health Insurance Association (CLHIA) showed that LTC residents were occupying beds in hospitals at a much higher cost, approximately $842 per day versus $126 per day in LTC facilities. Collectively, LTC residents spent close to 17,000 days in hospital in the last 180 days before death. Over one-third (36%) of these days in hospital were in the residents' last month of life (CIHI, 2007). Canadian statistics from 2018 indicate that 62 to 71% of LTC residents were transferred to hospital at some point in their last year of life (CIHI, 2019). A study from LTC facilities in Ontario showed that approximately 65% of residents visited the emergency department (ED) during their last year of life, with approximately 45% being in the last month of life and 27% in the last week of life (Kaasalainen et al., 2017). In 2007, 18% of Manitoba's LTC residents died in an acute care hospital; two-thirds of these residents were transferred to hospital in their last month of life (CIHI, 2007). Thus, statistics show that hospital use increases markedly in the months leading up to death (CIHI, 2007). In addition, 20% of total Canadian healthcare expenditures occur during the last year of patients' lives (CIHI, 2009).

The Canadian population is undergoing what Butler (2008) called the longevity revolution. As the population ages and the baby boomer generation reach advanced age, the Canadian healthcare system will be challenged with higher rates of disability and rapidly rising rates of dementia. These trends, in combination with continual advancements in medical technology, mean that the Canadian healthcare system and LTC facilities will need to provide quality care for the oldest members of the population while reducing the burden of healthcare spending, especially in EOL care.

The Organizational Structure of Long Term Care Facilities

The following sections will provide an overview of the organizational structure of LTC settings in Manitoba, along with the funding and regulations of LTC in the context of this province.

Definition of Long Term Care

According to Sanford and colleagues' (2015) international survey of 17 countries, a LTC facility or NH is defined as:

> A facility with a domestic-styled environment that provides 24-hour functional support and care for persons who require assistance with activities of daily living (ADLs) and who often have complex health needs and increased vulnerability. Residency within a nursing home may be relatively brief for respite purposes, short term (rehabilitative), or long term, and may also provide palliative/hospice and EOL care. (p. 183) .

The following terms are used interchangeably across Canada to describe this type of setting: LTC home, NH, residential care facility, and home for the aged. For the purposes of this research study, the terms LTC facility, NH, and personal care home (PCH) are used because they are consistent with terminology used within the province of Manitoba. In Manitoba, the term 'PCH' refers to a facility in which ongoing, indefinite care for individuals who can no longer fully care for themselves in their own homes. Long term care straddles the line between healthcare, in the forms of nursing/medical care, and social services, in the forms of income-supported housing, assistance with ADLs, and the provision of recreational and social programs (Banerjee, 2007).

Residents are admitted to a LTC facility in Manitoba based on a paneling process that assesses their level of dependency, need for assistance with ADLs, degree of behavioural problems, personal safety risks, and availability of informal support. The application for paneling must be completed by medical and nursing/social work professionals (Martin-Matthews, 2011). In Winnipeg, Manitoba, LTC is delivered through a mixture of not-for-profit and for-profit facilities. Currently, there are two LTC facilities in Winnipeg that are directly owned and operated by the Winnipeg Regional Heath Authority (WRHA) (J. Puchniak, personal communication, March 6, 2019). Approximately 65% of LTC facilities in Winnipeg are not-for-profit (Banerjee, 2007). Not-for-profit facilities may further be categorized as faith-based, freestanding, or connected to a healthcare facility (Fransoo et al., 2013).

A survey of NHs from 30 countries, including Canada and the US, showed that the dominant model of care is either social or nurse-led; the physician-led model is less commonly used (Tolson et al., 2013). In the social model, resident care is coordinated and led by a social worker; doctors and registered nurses (RNs) may visit residents when required, but do not have administrative responsibilities or influence over how the facility is operated. In the physician-led model of care, a doctor serves as the medical director and has concurrent administrative responsibilities. This doctor oversees the residents' care, which is supported by a team that consists of a nurse director and other staff. The nurse-led model is the dominant model of care in Winnipeg's LTC facilities. In this model, a nurse director with administrative responsibilities oversees the care of residents with the support of an interdisciplinary team. An attending physician visits the residents regularly, but does not have administrative responsibilities in the facility (Tolson et al., 2013).

Funding of Long Term Care in Manitoba

In Manitoba, the costs of LTC are shared between the province and individual residents. Provincial funding is administrated through the regional health authorities (Manitoba Health

Seniors and Active Living, 2018). Residents pay an income-based charge that is set annually; in 2022, the per diem charge ranged from $39.40 to $95.20 (Manitoba Health, 2021). The payment structure is standardized, regardless of the type of facility. All residents receive full room and board, which includes meals, assistance with ADLs, necessary nursing care, routine medical supplies, prescription drugs, additional therapies like physiotherapy and occupational therapy, and routine laundry services (Manitoba Health, 2021).

Regulation of Long Term Care in Manitoba

The Continuing Care Branch of the Manitoba Health Seniors and Active Living (MHSAL) governmental department oversees both the licensing and regulation standards of LTC facilities in Manitoba. All facilities must operate in compliance with the *Personal Care Homes Standards Regulation* (2005), as set out under *The Health Services Insurance Act C.C.S.M. c. H35* (2015). There are 26 different standards that outline quality expectations in relation to care and services, record-keeping, resident safety, staff development, and risk management. Each LTC facility is assessed for compliance with these standards on a biennial and as needed basis by a team led by MHSAL and WRHA personnel (MHSAL, 2017).

Staffing guidelines for LTC facilities in Manitoba are mandated through a government directive referred to as *Personal Care Home Staffing Guidelines* (Manitoba Nurses Union [MNU], 2018). The only staffing component governed by Manitoba's Personal Care Homes Standards Regulation is the requirement for an RN to be present 24 hours a day, seven days a week. As per provincial guidelines, LTC facilities are required to provide 3.6 paid hours of nursing care per resident per day (MNU, 2018). In general, health care aides (HCAs) provide most of the care in LTC settings yet have the least amount of formal training of all members of the healthcare team. As time and staffing are increasingly in short supply, care often ends up being a detached act between the care provider and the resident (Cammer et al., 2014). Positive interactions and engagement between staff and residents during care activities have been shown to improve quality of life, reduce agitation and depression, improve mood, and enhance residents' overall level of interest (Hartmann et al., 2018).

Complexities of Care in Long Term Care Settings

The following sections will describe the complexities of care in LTC settings, specifically with respect to clinical complexities of the residents and the complexities associated with providing timely EOL care.

Clinical Complexities of Long Term Care Residents

Clinical complexities of residents in LTC facilities include chronic illness and disability, poor prognosis and shorter length of stay, and uncertainty in diagnosing when death is near.

Chronic Illness and Disability. The Manitoba government has mandated that all LTC facilities complete the Resident Assessment Instrument Minimum Data Set (RAI-MDS 2.0) (Armstrong et al., 2016). This assessment captures the demographic, clinical, and functional characteristics of all residents. This information is publicly available via the Continuing Care Reporting System. Based on the Continuing Care Reporting System Quick Stats 2018-2019, the majority of LTC residents in Manitoba are female (70%) and over the age of 85 (60%), with 16% being over the age of 95. Nearly all residents (97.4%) have two or more chronic conditions and 60% live with dementia. Thirty percent of residents have severe cognitive impairment and about 40% suffer from some psychiatric or mood disorder(s). Half of all residents have limited to no social engagement and some indication of health instability. More than half of the residents suffer from both bowel and bladder incontinence (CIHI, 2020a). Not only do most residents suffer from multiple chronic conditions, but these conditions are often in advanced stages—a finding echoed by residents in Whitaker's (2010) ethnographic study where it was noted that life in LTC facilities was mediated by their increasingly "incapable bodies" (p. 99).

Poor Prognosis and Shorter Length of Stay. Nursing home residents have an average life expectancy of 12 to 18 months, with one-third of them dying in the first year of admission and two-thirds dying in the second year. (Frohlich et al., 2002). Close to 40% of older Canadians die in LTC facilities, with approximately one in five dying each year (Menec et al., 2009; Wickson-Griffiths et al., 2014). A 2010 WRHA report showed that the average length of stay of residents in Winnipeg NHs was about 20 months, with an average of 12 months for the most severely disabled and 18 months for moderately disabled residents (WRHA, 2010). About 1,400 LTC residents die in Manitoba each year (Menec et al., 2009). Whitaker's "*omnipresence of death and dying*" (2010, p. 99) is a major feature and notable part of daily life in LTC facilities, which provide palliative and EOL care to aging residents (Canadian Medical Association, 2016).

Uncertainty in Diagnosing When Death is Near. It can be complicated to identify when LTC residents are close to death or dying because most residents are of advanced age with multiple chronic conditions (Bern-Klug, 2009). In LTC settings, the interactions between advanced age and advanced chronic illness make it more challenging to determine when a resident is or should be considered to be dying (Lynn et al., 1995). The combination and severity of residents' comorbidities complicates their health status and prognosis as well as the process of clinical decision making. Pattison (1978) argued that LTC residents are in the "chronic living-dying interval" (as cited in Waldrop & Kusmaul, 2011, p. 768). Dying in this setting is considered a process that is extended over time (Glaser & Strauss, 1968). The "chronic living-dying interval" denotes the period of chronic morbidity that occurs prior to the active dying process (Engle et al., 1998); this period can be certain or uncertain based on the residents' prognosis and comorbid conditions (Waldrop & Kusmaul, 2011). For most LTC residents, the length and timing of this period is uncertain. As a result, this ambiguous dying syndrome (Bern-Klug, 2006) complicates the timing of EOL care and makes it difficult to reach consensus on when a resident should be considered dying (Bern-Klug, 2006). Bern-Klug (2006) captured this notion in an ethnographic study of LTC residents, where an understanding about the social construction of 'possible dying' was based on the reporting of specific triggers that may indicate death is near. These triggers include: a decline in a resident's health status; noncompliance with diet and medications; available medical interventions not being well suited for the residents; and family consideration of an out-of-town vacation (Bern-Klug, 2006). According to Bern-Klug (2009), the social interactions related to dying status and care plan goals for NH residents can be classified into five categories: (a) dying allowed; (b) dying contested; (c) mixed message dying; (d) not dying; and (e) not enough information.

Over five decades ago, Glaser and Strauss (1968) stated that in order for a patient to be treated as dying, the patient must be defined as dying. Glaser and Strauss (1965) used qualitative methods to document patterns of social interactions related to care for hospitalized patients. They described the social consequences of the expectations for prognosis and the level of certainty of patients' prognoses. In *Time for Dying*, Glaser and Strauss (1968) emphasized that the process of dying takes place over time and that the trajectory toward death has a shape that can be graphed. They described four critical junctures on the trajectory of dying: (a) when the patient is defined as dying; (b) when the patient, staff, and family make preparations for death; (c) when there is a final descent toward death; and (d) when death occurs (Glaser & Strauss, 1968). Staff and family were able to develop a sense of where in the trajectory the patient was and then react accordingly: "how a patient, a doctor, a nurse or a family member defines a dying trajectory becomes the basis for his or her behaviour in connection with treating and handling the patient" (Glaser & Strauss, 1968, p. 55). Bern-Klug (2009) argues that LTC residents who are recognized as dying have a better chance of being enrolled in hospice care, or the NHs' equivalent version of comfort care. The executive summary of the IOM document, "*Describing death in America: What we need to know*," reported that designating a period of time as the EOL is a necessary first step to improving care for people approaching the end of their lives (IOM, 1997).

Complexities of Providing End-of-life Care in Long Term Care

High quality EOL care is an important component of high quality LTC, yet many older adults receiving LTC services do not obtain optimal EOL care as they approach death (CIHI, 2018; Huskamp et al., 2012; Stall et al., 2017; Thompson & Chochinov, 2006). The following sections will describe the complexities that make it challenging to provide timely EOL care in LTC facilities. These complexities include: ineffective communication between nurses and physicians; delayed initiation of EOL/palliative care; limited physician involvement in EOL care; and inadequate conversations about EOL.

Ineffective Communication Between Nurses and Physicians. Decisions about medical care in LTC settings, including those about diagnosis, prescription medications/interventions, and hospitalization, often occur in the context of brief telephone discussions between physicians and nurses, as physicians are frequently off-site when such decisions are required (Field et al., 2011). The medical management of residents in LTC relies heavily on the quality of communication between nurses within the facility and the physicians who provide medical care to individual residents (Field et al., 2011; Kuo et al., 2013). Nurse-physician communication is described as a professional interaction that involves working together, making shared decisions around health issues, and formulating collaborative patient care plans (Hailu et al., 2016).

Studies focused on communication between physicians and nurses in LTC facilities have identified challenges in communicating all the relevant information required to make optimal clinical decisions (Cadogan et al., 1999; Kuo et al., 2013; Renz & Carrington, 2016).

Suboptimal communication between nurses and physicians is a major concern in LTC facilities and has been identified as a causative factor in the over-hospitalization of LTC residents (Buchanan et al., 2006) as well as in reduced work satisfaction among nurses and physicians (Renz et al., 2013). In a mixed methods study, Tjia and colleagues (2009) identified the following barriers to effective nurse-physician communication in LTC facilities: lack of physician openness to communication (rushed and/or not open to nurses' views), logistical challenges (including noise, lack of privacy or time, and difficulty reaching the physician), lack of professionalism (rudeness and disrespect), and language barriers (accent and use of jargon), as well as suboptimal nurse preparedness (inadequate information). Twenty-four percent of nurses reported feeling that they were bothering the physician when making a phone call regarding changes in a resident's status (Tjia et al., 2009). Similar results were reported in a study by Cadogan et al. (1999), where nurses reported that physicians were often unpleasant during phone calls and did not value their opinions. Physicians perceived nursing competence as the most significant barrier to good communication.

Renz et al. (2013) sought to describe nurses' perceptions of nurse–physician communication through the use of questionnaires and focus groups. Ninety percent of nurses interviewed (n=40) reported having difficulty communicating with a medical provider due to the provider's communication style ("rude" or "hurried"), treatment decisions (e.g., refusing hospice care for a terminally ill patient), and/or language (accent and use of jargon) (Renz et al., 2013). Other physician behaviours that commonly affected the quality of nurse-physician interactions included physicians being interrupted during calls and physicians hurrying nurses (Cadogan, et al., 1999; Tjia et al., 2009). Nurses also identified their own barriers to effective communication, including lack of skill in collecting and disseminating assessment data, time constraints, and environmental noise (Renz et al., 2013).

A combination of nurse and physician behaviours contribute to ineffective communication in LTC settings. Quality of communication in NHs has been shown to affect the quality of healthcare delivery, including decisions regarding the transfer of NH residents to a hospital as well as medical prescriptions (Renz et al., 2013; Tjia et al., 2009). Improving nurse-physician communication in LTC setting is necessary to create a culture of patient safety and improve the quality of care (Renz & Carrington, 2016).

Limited Physician Involvement in End-of-Life Care. Studies have repeatedly indicated that inadequate physician presence in NHs is a persistent issue linked to problems with communication and decision making at EOL, inappropriately high rates of hospitalization, inadequate symptom management, and general dissatisfaction with care among residents/family members (Givens et al., 2012; Shield et al., 2005; Thompson et al., 2012; Vohra et al., 2006). A qualitative meta-synthesis reported that American physicians spend little time with LTC residents and their families, have limited knowledge of the residents, rely on LTC nurses for information, and have a more deferential relationship with families than nurses (Petriwskyj et al., 2014a). Bereaved family members of LTC residents reported that physicians often insufficiently addressed the dying residents' needs and were viewed as "missing in action" from NHs (Shield et al., 2005, p. 1652). Family members who did not receive enough information about their relatives' prognosis and illness trajectories experienced uncertainty and distress with regard to EOL decision making, and had difficulty understanding the dying process of their loved ones

(Fosse et al., 2014; Hennings et al., 2010). Relatives who had negative experiences and insecurity in making EOL decisions often expressed frustration over "the missing doctor" (Fosse et al., 2014, p. 8).

Givens et al. (2012) conducted semi-structured interviews with 16 family members enrolled in the Choices, Attitudes, and Strategies for Care of Advanced Dementia at the EOL (CASCADE) study and found that almost all family members were dissatisfied with the level of physician communication. Participants also expressed that, due to the lack of communication about changes in residents' health condition, they were unable to act as patient advocates or engage in shared decision making. A large, multi-site American study of 440 family members of LTC residents investigated families' perceptions of physician communication (Biola et al., 2007). The study reported that 40% of relatives felt uninformed and 50% felt they were not given information on what to expect at EOL (Biola et al., 2007). These findings were further supported by a scoping review that identified: (a) physicians tend to focus on acute, potentially reversible illness while avoiding the terminal aspects of residents' care (Erel et al., 2017); and (b) physicians' tendency to focus on curative care provides a safe and protected climate, enabling them to avoid uncomfortable and distressing discussions regarding death (Marcus et al., 2016).

Data from the CASCADE study suggested that physicians' communication with family members be specifically focused on engaging them as equal partners in decision making. This suggestion was endorsed by Biola et al. (2007) who stated that effective communication between physicians and family members in LTC may be promoted though face-to-face meetings. In these meetings, physicians can explain the resident's prognosis and provide timely information about any changes in the residents' health status, especially when the resident is actively dying.

Fosse et al. (2014) identified that participation of physicians in EOL decision making is crucial to residents and their families. In a meta-synthesis, Fosse et al. (2014) affirmed that doctors must provide individualized information about probable trajectories to prepare residents and families for EOL. Thompson and Roger (2014) stressed that family members of people with dementia also have a need for information and decisional support. They suggested that healthcare providers discuss the trajectory of dementia and strategies for optimal clinical care with residents' family members to diminish their suffering at EOL. Families will generally choose a comfort care approach when they have adequate information and are able to acknowledge that the resident's health is not expected to improve (Levy, 2015).

Delayed Initiation of End-of-Life/Palliative Care. The Canadian Hospice Palliative Care Association (CHPCA, 2012) describes palliative care as whole person care that aims to relieve physical, social, psychological, and spiritual suffering for dying individuals and the families that support them, from the time of diagnosis and into bereavement care. The World Health Organization (WHO, 2014) further defines palliative care as a philosophy of care that should be initiated at the time of diagnosis of any life limiting illness that has no cure, and seeks to affirm life and regard death as a normal process. One could argue that most LTC is palliative in nature because almost all residents are of advanced age and suffering from multiple comorbidities for which there is no cure. As noted previously, death occurs frequently in LTC settings. National and international evidence suggests that palliative care should be integrated into the practice of LTC (CHPCA, 2012; WHO, 2014) and be the standard of care for all residents in LTC (Ersek & Carpenter, 2013; Meier et al., 2010). In spite of this, most of the care provided in LTC facilities is directed toward restoration, rehabilitation, and prolongation of life (Hill et al., 2018; Jimenez et al., 2018; Meier et al., 2016).

For many LTC residents, the dying trajectory is one of prolonged decline where the individual's functional status is already relatively low and punctuated by unpredictable episodes of decline and recovery, which decrease gradually until death (Murray et al., 2005). Limited understanding of this specific trajectory leads to unnecessary hospital admissions and aggressive interventions at EOL (Murray et al., 2005). Given the unpredictable trajectory of dying and lack of standardized procedures for assessing the terminality of a resident's prognosis (Murray et al., 2005), many LTC providers struggle to identify transitions from living to dying, shift GOC from restorative to palliative care, and initiate communication about EOL care (Cable-Williams & Wilson, 2017). Moreover, families rarely choose LTC facilities for EOL care and the majority of residents do not enter LTC with the primary goal of receiving comfort care (Hill et al., 2018). The healthcare consequences of the ambiguous dying trajectory among LTC residents can include unnecessary treatments, such as cardiopulmonary resuscitation (CPR), the insertion of feeding tubes, and the administration of intravenous antibiotics as well as unnecessary transfers to hospital, all of which can cause undue distress and suffering among residents without any tangible benefits (Forbes, 2001; Forbes-Thompson & Gessert, 2005; Murray et al., 2005).

The broad philosophy of palliative care is underutilized in LTC and often delayed until quite late in the dying process (Hill et al., 2018). This reality was supported by the findings of a Canadian study, which aimed to strengthen the palliative approach in LTC settings (SPA-LTC). Although the LTC staff, residents, and families involved in the study believed that comfort care at EOL was a central feature of palliative care in LTC, they only associated EOL comfort with those who were actively dying (Sussman et al., 2017). Evidence suggests that LTC staff that embrace a palliative care philosophy tend to view death as a normal and inevitable outcome for all residents. Furthermore, staff in LTC facilities that focus on palliative care are more likely to:

(a) actively engage in ACP and in open discussions about dying; (b) elicit residents' personal preferences regarding EOL care upon admission, at care plan meetings, and whenever a resident's condition changes; (c) be knowledgeable about and engage in active symptom management strategies; (d) integrate palliative planning and interventions, with lower rates of unnecessary hospitalizations and feeding tube insertions; (e) provide psychosocial support for dying residents and their family members; (f) employ bereavement interventions, such as memorial services for staff, other residents, and family members; and (g) provide staff with continuing education regarding palliative care (Forbes, 2001; Forbes-Thompson & Gessert, 2005; Forbes et al., 2000; Stevenson & Bramson, 2009).

Even though death is a common occurrence in LTC, the belief and practice that LTC facilities are for living has disadvantaged those who are dying, making it harder for them to access a palliative approach to care; as a result, palliative care is often only available to LTC residents very late in the EOL trajectory (Cable-Williams & Wilson, 2017; Hill et al., 2018; Meira et al., 2017). In the presence of advanced age and incurable chronic illness, living to the fullest includes an open awareness of EOL and death (Glaser & Strauss, 1965). This awareness warrants timely EOL conversations and appropriate ACP.

Inadequate End-of-Life Conversations. There is no universal consensus on the content of EOL conversations in LTC. The definition of EOL conversations in LTC varies from study to study. As a result, there is uncertainty and confusion among healthcare providers about what to include in their conversations with residents/families. Some studies suggest that EOL conversations be a "discussion" about life-sustaining treatments or care goals (Livingston et al., 2013; Morin et al., 2016) or about the risks and benefits of invasive treatments (Temkin-Greener et al., 2016). Others studies have defined EOL conversations as a way of "speaking" about life-sustaining treatments and symptom management (Vandervoort et al., 2014a; Vandervoort et al., 2014b), “receiving/providing information” about how the resident is doing, discussing the resident’s health problems, and/or outlining what to expect in the future (Liu et al., 2012; Reinhardt et al., 2014). Several authors assert that palliative care conferences at EOL can help create a structured mechanism for systematically addressing the resident’s health condition, clinical course, and prognosis while also identifying the family’s stated care goals and explaining the risks and benefits of potential treatments (Durepos et al., 2018; Parker et al., 2016; Reinhardt et al., 2017).

Regardless of the specific terminology used, EOL conversations with LTC residents and families promote less aggressive care, improve quality of life, minimize suffering (Kaasalainen et al., 2016; WHO, 2014), and enable healthcare providers to align their care with a palliative care philosophy (Jimenez et al., 2018). A systematic review and meta-analysis showed that structured EOL conversations between healthcare providers and families were positively associated with the adoption of palliative care and decisions to limit or withdraw life-sustaining treatments (Jimenez et al., 2018). In addition, families’ satisfaction with EOL care increased along with the frequency and duration of EOL conversations (Parker et al., 2016; Reinhardtet al., 2017).

Despite the positive benefits of EOL conversations, there is a tendency among healthcare providers to avoid or delay these conversations until the resident becomes terminal (Gjerberg et al., 2015). When these conversations do occur, they are often brief and infrequent (Teno et al., 2012). Evidence shows that EOL conversations should be offered from the time of admission to a LTC facility and should not be limited to the final days of life (Jimenez, et al., 2018; Reinhardt et al., 2014). Evidence also suggests that NH staff tend to avoid discussions related to EOL care due to their own fear of death (Ingelar et al., 2010) and/or discomfort to talk about death (Hill et al., 2018). In a qualitative study, Towsley et al. (2015), described EOL-related conversations in NHs as “missed conversation” (p. 421). According to residents, families, and staff from four different NHs in southeastern Pennsylvania, missed conversations occurred when: (a) no one inquired (i.e., residents or families were not asked about their preferences related to EOL; (b) assumptions were made by residents, family, or staff that EOL wishes were already known; and (c) there was no formalized process to converse about or share resident’s EOL wishes among members of the care team (Towsley et al., 2015).

Thompson and colleagues (2012) conducted a retrospective quantitative study with bereaved family members in urban Canadian LTC facilities. The family members reported problems with: (a) receiving confusing information from nursing staff about the resident’s care, including medical treatments; (b) receiving inadequate information from nursing staff; and (c) feeling that EOL care was different than they had expected. The work of Thompson et al. (2012) was supported by the findings of a systematic review of family members who had a dying relative in LTC. The review, conducted by Hennings et al. (2010), highlighted the families’ disappointment in the level of contact and communication they had with LTC staff.

A qualitative study from Ontario, Canada explored the experiences of twenty-two multidisciplinary professionals working in LTC and providing palliative care. The study reported on communication challenges between staff and families and noted that family members, especially those ill-informed about the dying process, often became more emotional, aggressive, irrational, and distressed as their loved one approached EOL. These communication challenges made collaborative care decisions more difficult (Hill et al., 2018). In addition, evidence has shown that uninformed family members can be a significant barrier to the initiation of palliative care (Durepos et al., 2018; Hill et al., 2018; Parker et al., 2016).

Staff-family communication and relationships are important in facilitating family involvement in decision making (Petriwskj et al., 2014a). Even though family members' involvement in decision making is central to implementing a palliative approach to care (Hudson et al., 2005), evidence shows that families are not consistently involved in decision making discussions nor are such discussions supported/facilitated by LTC staff (Petriwskj et al., 2014a). While NHs in the US are required by federal law to inform family members of any changes in a resident's status or care plan (Petriwskj et al., 2014a; Reid & Chappell, 2017), similar facilities in Winnipeg/Canada do not have any explicit requirements that family be informed of such changes.

In summary, the emerging trends within LTC facilities in Canada include older age of admission, higher acuity of care needs, and shorter duration of stay prior to death. About one-third of residents die each year in LTC settings. Due to the shorter length of stay and the common trajectories of decline between admission and death, residents should be offered a comfort-oriented approach to care at the time of their admission. There is a limiting belief that LTC is for living, which contributes to the failure to disclose EOL information to residents/families and accounts for the uncertain and lingering EOL trajectory experienced by most residents. For most residents, the dying process will only be acknowledged just prior to the time of their death. Failure to acknowledge impending death may compromise the quality of EOL care for LTC residents and lead to futile and aggressive interventions, such as terminal hospitalization. Although the CHPCA and WHO recommend an earlier and more comprehensive palliative approach to care, this approach is unlikely to be employed within the existing context of most LTC facilities. Unfortunately, the majority of LTC facilities provide EOL care that is deficient in quality, specifically with respect to pain and symptom management, spiritual care, ACP, EOL conversations, and family satisfaction with EOL care, especially in the context of dementia.

Inadequate communication between decision makers has been identified as a main barrier to quality EOL care and has been studied for many years. This literature review identified a need for more extensive knowledge and understanding on exactly how EOL conversations are carried out in LTC settings. Areas for potential improvement in EOL conversations and healthcare providers' actual experiences in EOL conversations have not been well-researched in LTC settings. It was evident from the literature review that there is an increased need for more extensive knowledge on how EOL conversations should be carried out in LTC settings, especially in the Canadian context. It is imperative that researchers and care providers attend to the complexities of EOL conversations and EOL decision making in LTC settings to optimize the quality of residents' EOL care.

Advance Care Planning

The following section begins with an overview of the history and legal implications of ACP in the US and Canada. This chapter also reviews literature related to the empirical and ethical understandings of ACP, outcomes of ACP, engagement in ACP by Canadians, and factors affecting the implementation of ACP at the patient/family, healthcare provider, and institutional levels. The latter part of this section provides a critical comparative analysis of the WRHA's and two other Canadian health authorities' ACP processes.

The Historical and Legal Context of Advance Care Planning

The concept of advance directives was first proposed in 1969 by Luis Kutner, a human rights lawyer (Sabatino, 2010). According to Kutner, a person of sound mind should indicate in writing the extent of treatment that she or he would like to receive at EOL, specifically in the case of terminal illness (Kutner, 1969). Kutner (1969) called this document a “living will,” which he described as a “declaration for bodily autonomy” and “a declaration determining the termination of life” (p. 551).

The pivotal 1975 case of Karen Quinlan led California to pass the Natural Death Act in 1976; this was the first law to give legal force to the living will (Brown, 2003). After a respiratory arrest and unsuccessful resuscitation, 21-year old Karen Ann Quinlan lapsed into a persistent vegetative state and was kept alive by a respirator, artificial nutrition, and intravenous hydration (Fine, 2005). Karen's parents asked that she be removed from the respirator and allowed to die. The doctors and hospital refused this request, arguing that removing life-sustaining treatment was equivalent to murder and that they had an inherent duty to protect life, and keep Ms. Quinlan alive. The case was eventually adjudicated in the New Jersey Supreme Court. In 1976, the court supported the parents in their request to remove the ventilator, based on the right to privacy. The court found that families are adequate surrogates for incapacitated patients who did not and could not make their wishes known. After removal of the respirator, Karen lived for another nine years sustained by artificial nutrition and hydration (Fine, 2005). The Quinlan decision marked a shift away from physician-controlled EOL decision making toward a shared decision making process between patient/family and healthcare providers. Thus, the Quinlan case marked the beginning of the right to die movement in the US and led California to enact laws authorizing use of the living will (Fine, 2005; Lim, 2005).

Another high-profile case was that of Nancy Cruzan. This case served as the driving force for the creation and implementation of the Patient Self Determination Act (PSDA) of 1990 in the US. This federal law mandates that, at the time of admission, all hospitals, NHs, hospices, home healthcare programs, and health maintenance organizations must give adults information about their rights to accept or refuse medical treatment; to prepare a living will, which states the individual's preferences for medical treatment under specific circumstances when the patient is not capable of making decisions; to appoint a healthcare proxy; and to document in the patient's medical record whether or not the patient has executed an advance directive (Brown, 2003; Sabatino, 2010).

Nancy Cruzan was a 33-year-old woman who was in a persistent vegetative state after an automobile accident in January 1983. After six years with no recovery, her parents asked that tube feedings be discontinued so she could die peacefully. The hospital insisted on a court order to remove the feeding tube. The court ruled that the feeding tube could not be removed unless the family had written documents, such as a living will, stating the patient's wishes. Nancy's parents did not have formal written documents but had evidence of informal conversations Nancy had with relatives and friends prior to the accident (Lo & Steinbrook, 1991). In December 1990, the court ruled that the informal conversations Nancy had with others provided clear and convincing evidence that her parents were acting on her expressed wishes. The feeding tube was removed, and Nancy died 12 days later (Lo & Steinbrook, 1991).

In Canada, healthcare directives are regulated at the provincial level, with each province or territory outlining laws and regulations specific to their own jurisdiction (Brown, 2003). Although all Canadian provinces and territories have enacted advance directive legislation, some allow for instructional directives while others (Nova Scotia and Quebec) allow only for the appointment of a proxy decision maker in the event of incapacity (Thomas & Lobo, 2011). Currently, only five provinces (British Columbia, Saskatchewan, Manitoba, Ontario, Prince Edward Island) and two territories (Yukon and the Northwest Territories) have reciprocity protocols in place, meaning that out-of-province advance directives can have legal effect if they comply with the local formal requirements (Thomas & Lobo, 2011).

Even though the recommended readability level for health documentation is set at fifth grade, the Manitoba healthcare directive readability is an 8.5 grade level. A cross-sectional study by Richard et al. (2018) reported that the readability of currently available Canadian advance directives surpassed the recommended reading level by an average of 4.5 grade levels, with Ontario, Quebec, and Alberta having the hardest to read documents. Advance care directive documents written at a high readability level present significant obstacle to both health literacy and patient autonomy (Richard, et al., 2018). As a result, there is a need to improve the health literacy and standardization of healthcare directives across Canada, including the development of a single national advance directive form to promote higher completion rates (Richard et al., 2018; Thomas & Lobo, 2011).

In Manitoba, a healthcare directive is a self-initiated legal document, governed by the Healthcare Directive Act (Manitoba Health, 1993). This act provides legal protection and support for the autonomous decision-making rights of Manitobans, and allows individuals to document, in advance, their wishes for future medical care as well as designate a proxy (or proxies) to make medical decisions on their behalf, if unable to do so for themselves (Manitoba Health, 1993). According to this act, mentally competent individuals have the right to give or refuse consent to medical treatments; this right must also be respected after individuals are no longer able to participate in decisions regarding their healthcare treatments (Manitoba Health, 1993).

Advance directives have limitations in that they do not provide instructions for specific circumstances and often include vague descriptions and information about treatment preferences that can be difficult to interpret, especially when circumstances differ from what has been identified in the living will (Cantor & Pearlman, 2003). The risk of misinterpretation by clinicians is very high with living wills (Lynn, 1991). An EOL care expert declared that she would never create a living will, stating that "a living will of the standard format attends to priorities that are not my own, addresses procedures rather than outcomes, and requires substantial interpretation without guaranteeing a reliable interpreter" (Lynn, 1991, p. 101). Evidence shows that the healthcare proxy is often unsure of what the patient would choose and has difficulty making decisions that limit care (Bollig et al., 2015; Cantor & Pearlman, 2003; van Soest-Poortvliet et al., 2015). The Senate subcommittee that updated *Of Life and Death* affirmed that:

> If loved ones and medical professionals have engaged in a process of serious communication, the problems associated with the interpretation and application of advance directives are much less likely to arise. The passage to death is eased, the level of comfort rises, and the burden of care is lightened for the substitute decision maker (Carstairs, 2000, p. 13).

The sentinel trial, known as SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), shifted the shortcomings of the legal transactional approach of the advance directive to an alternative paradigm of an ongoing communication approach, known as ACP (Sabatino, 2010). This large prospective clinical trial used nurse facilitators to undertake discussions with seriously ill hospitalized patients and their families, with the goal of documenting their preferences regarding EOL care (Connors et al. 1995). While demonstrating a significant increase in documented advance directives, the intervention did not improve communication, incidence, or timelines with respect to “do not resuscitate” orders, days spent in the intensive care unit (ICU), physician knowledge of patient preferences, or level of patients’ pain. In other words, the intervention failed to improve EOL care. The document-driven approach is severely limited by a narrow focus on specific interventions and lack of attention to the broader values and GOC that accurately predict EOL treatment preferences (Collins et al., 2006; Emanuel, 2008). Furthermore, this study demonstrated that use of an ongoing process of communication around patient preferences, treatment options, and clinical care planning, known as ACP, may be more beneficial than relying solely on advance directive documents (Teno et al., 1997).

Fueled by persistent dissatisfaction with EOL care, poor quality of care at EOL, economic consequences of aggressive futile care at EOL, and the failure of legalistic advance directives to guide EOL care, the IOM released a report profiling the state of death and dying in America. In this report, the IOM made comprehensive recommendations to address EOL care issues (Field & Cassel, 1997), and highlighted key recommendations for healthcare systems, policy, and research. These recommendations included improvements in EOL care education for providers, the designation of palliative care as a medical specialty, increasing numbers of palliative care providers, and improvements in patient-provider discussions about EOL. The IOM report defined ACP as a comprehensive rather than legalistic approach and indicated that EOL care discussions should include open discussions with patients, families, and providers about prognosis, beliefs, and preferences that will guide decision making at EOL (Field & Cassel, 1997). As Field and Cassel, stated:

> The communications approach to EOL care discussion encompasses not only preparation of legal documents but also discussions with family members and physicians about what the future may hold for people with serious illness, how patients and families want their beliefs and preferences to guide decisions…, and what steps could alleviate concerns related to finances, family matters, spiritual questions and other issues that trouble seriously ill or dying patients and their families (1997, p. 198-199).

Some countries have enacted national frameworks that guide the use of advance directives, such as the PSDA in the US, the Mental Capacity Act (MCA) in the United Kingdom (UK), and the Australian national framework for advance care directives in Australia. However, there is no federal legislation or policy regulating the use of advance directives in Canada (Martin et al., 2016). Nevertheless, a comprehensive national framework was developed in 2012 by national organizations and ACP interest groups in Canada to address and mitigate concerns. This collaborative framework sought to integrate legislative, ethical, and clinical practice considerations for the successful implementation of ACP across Canada (CHPCA, 2012). The national ACP framework focuses on four areas: (a) engagement to actively involve stakeholders in planning for and implementing ACP; (b) education to train and inform relevant stakeholders in ACP related content; (c) system infrastructure to establish and maintain formalized systems within healthcare and legislative sectors that support the connection, involvement, and immersion of stakeholders in ACP; and (d) continuous quality improvement to evaluate ACP based on structure, process, and outcome indicators (CHPCA, 2013). In addition, the ACP initiative, known as the Speak Up campaign, has been promoting April 16th as a national annual ACP day across Canada and encouraging all adults to develop an ACP even if they are well (CHPCA, 2015).

In 2011, the WRHA redeveloped a policy to standardize the region's approach to ACP. The policy was intended to strengthen communication between patients, families, and healthcare professionals to facilitate important conversations about patients' healthcare goals (WRHA, 2011). According to the policy, healthcare providers should initiate ACP whenever future treatment options or GOC need to be considered or revised, whether care is being provided in a hospital, LTC facility, or a community setting (WRHA, 2011).

Empirical Understanding of Advance Care Planning

According to a multidisciplinary panel of international ACP experts:

> ACP is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness (Sudore et al., 2017, p. 821).

Advance care planning is considered a set of inter-related health behaviours (Fried et al., 2010; Pearlman et al., 1995; Sundore & Fried, 2010). Prior research has demonstrated that people have variable readiness to engage in ACP behaviours (Fried et al., 2010; Pearlman et al., 1995; Sudore et al., 2008). This readiness can be represented and explained by constructs of the transtheoretical model, including stages of change, decisional balance (the pros and cons of behaviour change), and processes of change (Fried et al., 2012). Readiness is also explained by the construct of values/beliefs. The transtheoretical model posits that health behaviour change requires progression through six stages of change: precontemplation, contemplation, preparation, action, maintenance, and termination (Prochaska & Velicer, 1997). Evidence suggests that the most effective way to engage people in the ACP process is to tailor the information to a person's readiness for engagement (Fried et al., 2010; Fried et al., 2017). Studies confirm that the contextual factors influencing the uptake of ACP are complex and multifaceted (Ernecoff et al., 2016; Lovell & Yates, 2014; Rietze & Stajduhar, 2015). Indeed, ACP is conceptualized more as a social process rather than just the completion of a document (Brinkman-Stoppelenburg et al., 2014; Singer et al., 1998).

Prince-Paul and DiFranco (2017) and Tilden et al. (2011) stressed that ACP is a public health issue that advocates for the upstreaming of ACP conversations to a societal level with multiple stakeholders, including schools, workplaces, community-based organizations, faith-based organizations, and governmental agencies. Mitchell (2017) recommended that implementation of ACP be one of the most urgent priorities for the healthcare system, especially considering the expansion of palliative care needs in LTC facilities. In fact, ACP has become an established standard of care from the perspective of Accreditation Canada (CHPCA, 2021).

In general, ACP discussions are viewed positively from the perspectives of patients and healthcare providers. For patients, ACP is a way of ensuring that they receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness. The completion of ACP relieves families of the challenge and burden of trying to accurately make decisions on the patient's behalf (Collins et al., 2006; Sudore et al., 2017). Nurses consider ACP as a safeguard of patient autonomy that prepares them for future EOL care, whereas physicians view ACP conversations as an important part of their professional responsibility (Jimenez, et al., 2018). Accordingly, many practitioners worldwide have begun to implement various ACP tools to make the systemic changes that would embed ACP into routine healthcare practices (Heyland et al., 2013a).

Ethical Challenges and Advance Care Planning

The ethical foundation of ACP is firmly rooted in individual autonomy and the right to self-determination (Emanuel, 2008; Puchalski et al., 2000). Advance care planning is viewed as a way of extending individuals' autonomy and control over future healthcare decisions at a time when they may be unable to speak for themselves (Collins et al., 2006; Connors et al., 1995). Respect for autonomy has a central role in bioethics. People who are considered autonomous are assumed to have the freedom to accept or refuse medical treatments, while a person who is non-autonomous may have treatment decisions made without their involvement that are not in accordance with their wishes (Robins-Browne et al., 2017). This is a key problem in LTC facilities where many residents are non-autonomous and incapable of making decisions for themselves.

According to Beauchamp and Childress (2009), if there is no formal documented preference and the incompetent person has not expressed any specific preferences, then the best interests of the incompetent person should prevail. The non-autonomous person's autonomy is challenged by the notion of relational autonomy, a concept developed by feminist philosophers. Relational autonomy asserts that a comprehensive account of the autonomous individual must address not just the individual's inner self but also their social relationships with others (O'Conner, 2010). Robins-Browne et al. (2017) stressed that relational knowing is central to the understanding of ACP in those who cannot fully participate in decision making. Relational autonomy allows a shift from protecting the autonomy of a non-autonomous person to focusing on developing and maintaining the person's identity. Relational autonomy suggests that significant others might be well placed to make decisions by considering not just what they have been explicitly told, but by reflecting on what they know about the person (Robins-Browne et al., 2017).

Advance care planning and relational autonomy are essential components of person-centered care (Ells et al., 2011), and provide useful perspectives to guide ACP discussions for non-autonomous residents in LTC facilities. Research suggests that the ethical underpinnings of ACP need to shift from individual autonomy to an approach informed by relational autonomy. This approach does not deny individuals' autonomy, but supports a process that is both deeper and more complicated than what is acknowledged by traditional conceptions (Robins-Browne et al., 2017; Robinson et al., 2013).

Outcomes of Advance Care Planning

Advance care planning is fundamental to guiding medical care at EOL and can increase welfare by aligning care to the person's preferences (Ampe et al., 2015; O'Hanlon et al., 2018). Advance care planning has been associated with decreased aggressive medical interventions near EOL, increased quality of life scores, and increased utilization of palliative or hospice care resources (Detering et al., 2010; Wright et al., 2008). A study by Wright et al. (2008) sought to determine associations between EOL care discussions with physicians and medical interventions received at the EOL. The researchers reported that 123 (37%) of the 332 participants had EOL discussions with their physicians. Patients who participated in EOL discussions had lower rates of mechanical ventilation, resuscitation, ICU admission, and earlier hospice enrollment compared to those who did not engage in such discussions. Wright and his colleagues (2008) also reported that caregivers of patients who received aggressive care at the EOL had a higher risk for developing major depression. In addition, aggressive care of a loved one at the EOL had the potential to negatively impact caregivers. A randomized controlled trial in Australian NHs compared facilitated ACP versus usual care and showed greater levels of satisfaction among patients and relatives who received facilitated ACP; 86% of patients in the intervention arm felt that their EOL wishes were recognized and respected when compared to only 30% of patients in the control arm (Detering et al., 2010). Advance care planning was also associated with fewer symptoms of post-traumatic stress disorder, depression, and anxiety among family members and caregivers of the decedents (Detering et al., 2010)

A systematic review (Brinkman-Stoppelenburg et al., 2014) showed that ACP increases the rates of do not resuscitate (DNR) and do not hospitalize (DNH) orders as well as advance directives. Do not resuscitate orders were associated with decreased use of hemodialysis, ICU admission, hospitalization, and increased quality of life. In addition, the use of DNH orders among NH residents led to fewer surgeries, lower rates of feeding tube insertions, less use of antibiotics at EOL, higher uptake of hospice care, and enhanced decision making satisfaction among healthcare proxies. The presence of an ACP resulted in increased use of comfort care measures and decreased incidences of out-of-hospital death as well as lower levels of concern, stress, and learned helplessness among family members (Brinkman-Stoppelenburg at al., 2014). Most of the studies included in Brinkman-Stoppelenburg et al.'s (2014) review were observational (n=107), originated from the US (n=91) or Canada (n=5), and were performed in institutional settings, such as hospitals (n=55) or NHs (n=37). Only nine studies were performed in the community. Studies were conducted with different patient populations, such as patients with dementia or advanced cognitive impairment, patients with advanced cancer, patients hospitalized with an acute myocardial infarction, and patients who experienced physical trauma (Brinkman-Stoppelenburg at al., 2014).

A systematic review by Martin et al. (2016) showed a 9% to 26% reduction in hospitalization among LTC residents who had undergone facilitated ACP. Seven out of the thirteen studies included in their review were from the US. The one Canadian study (Molloy et al., 2000) included in the review used a randomized controlled trial to evaluate the outcomes of a facilitated ACP intervention, such as the Let Me Decide ACP. Patients who had ACP discussions were more likely to accept that their illness is terminal and more likely to choose comfort care and DNR (Wright et al., 2008). A retrospective study from the UK showed that LTC residents who completed ACP spent less time in hospital and died in a LTC facility. Advance care planning also helped to resolve family conflicts and prepared families for the death of their loved ones (Brinkman-Stoppelenburg et al., 2014).

An economic analysis by O’Hanlon et al. (2018) showed that ACP can lead to more efficient allocation of resources, especially in EOL care, where intensive treatment does not have a reasonable probability of improving quality of life. A study using a simulation model demonstrated that in-hospital ACP has the potential to save 11% of total ICU costs and 25% of ICU costs for patients with a chronic life-limiting illness (Khandelwal et al., 2016). A systematic review (Klingler et al., 2016) that evaluated the cost implications of facilitated ACP demonstrated that cost savings through ACP can range from USD 1041 to USD 64,830 per patient. For the purposes of the study, facilitated ACP was defined as at least one professionally facilitated conversation with patients/families about the patients’ preferences for future medical care. Seven studies were included in Klingler et al.’s (2016) systematic review, six of which were conducted in the US and one in Ontario, Canada (Molloy et al., 2000). Three studies were performed in hospitals, one in a NH (Molloy et al., 2000), and three in homecare. Molloy et al.

(2000) used specially trained nurses to facilitate education about advance directives (Let Me Decide advance directive) with LTC residents and their families.

The overall outcomes of ACP in LTC include lower rates of terminal hospitalization, hospital deaths, and unwanted life-sustaining treatments; higher congruence of care with patient’s and family’s wishes; fewer misunderstandings and conflicts between healthcare providers and families; higher rates of ‘good deaths’ with decreased existential distress, depression, and anxiety in family members and caregivers; higher incidences of dying in the preferred place; increased and earlier referral to hospice/palliative care (Brinkman-Stopplenburg et al., 2014; Detering et al., 2010; General Medical Council, 2016; Martin et al., 2016); and increased healthcare savings (Dixon & Knapp, 2018).

In summary, ACP is associated with better outcomes for residents, family members, healthcare providers, and healthcare systems. Successful implementation of ACP could preserve residents’ autonomy, avoid harm, and prevent suboptimal or crisis decision making to ensure fair treatment of all residents and the optimization of finite resources. The most important outcomes of ACP include healthcare actions being consistent with the patient’s wishes and the avoidance of unwanted hospitalizations and unnecessary life-sustaining treatments. The aforementioned effects of ACP on patients and caregivers are consistent with foundational themes associated with a ‘good death’ or successful dying.

Engagement in Advance Care Planning by Canadians

Despite its demonstrated benefits, a low percentage of Canadians engage in ACP, either through discussions with a healthcare provider or formal documentation of their healthcare wishes (Taxiera et al., 2015). An Ipsos-Reid study conducted in 2012 reported that 84% of Canadian respondents (n=1523) had not heard of ACP and 80% had no written plan for their

EOL wishes. Less than 55% of respondents had engaged in conversations with a family member or friend about what healthcare treatments they would and would not want if they were ill and unable to communicate (Teixeira et al., 2015). Only 10% had ever spoken to a healthcare provider about their wishes for EOL care. Twenty percent of respondents had a written ACP and 47% had designated a healthcare proxy. Thirty three percent of the survey respondents were between 45 and 54 years of age and only 21% were over the age of 65 (Teixeira et al., 2015).

Results from the multisite Canadian Advance Care Planning Evaluation in Elderly Patients (ACCEPT) study (Heyland et al., 2013a) showed that engagement of ACP was higher in hospitalized older adults than the general Canadian population. The ACCEPT study examined ACP practices in older hospitalized patients at high risk of dying and found that more than 76% of participants had thought about the care they would want in the final stages of life, 46% had completed an ACP, and more than 90% had discussed their preferences with family members (Heyland et al., 2013a). However, less than 30% had discussed their EOL care preferences with their doctors. While many older patients have thought about and expressed their preferences for care, there is insufficient communication and documentation regarding patients' preferences (Heyland et al., 2013a).

Studies have shown that there is a low prevalence of ACP engagement among older adults living in the community (Harrison et al., 2016; Martin et al., 2016; Musa et al., 2015). Harrison et al. (2016) found that older adults with dementia had a significantly lower predicted prevalence of EOL discussions (54%) and ACP (46%) when compared to those with no dementia (62% and 54%, respectively). Data from Canadian LTC facilities has shown that 76% of residents have a DNR order and 21% have a DNH order (CIHI, 2016). Evidence increasingly shows that ACP should be promoted in NHs so that staff can honour residents' preferences and underlying values in future decision making (Chan & Pange, 2010; Molloy et al., 2000; Moore et al., 2016). The process of ACP is especially relevant for NH residents as they have a high prevalence of frailty, multi-morbidity, and cognitive impairment that renders them unable to make decisions about EOL care. Research shows that only a small portion of older people actively engage in ACP and there is still a low prevalence of ACP in NHs (De Gendt et al., 2013; Martin et al., 2016; Musa et al., 2015; Vandervoort et al., 2014b).

Factors Affecting the Implementation of Advance Care Planning

Evidence shows that factors affecting the optimal implementation of ACP are complex, multifaceted, and require necessary elements or pre-conditions at the patient/family, healthcare provider, and institutional/organizational levels (Flo et al., 2016; Gilissen et al., 2017). Implementation of ACP refers to all aspects that influence the introduction of ACP, including the provision of information to patients/families, the facilitation of discussions, and the completion (recording, revising, and updating) of ACP-related documents as well as the application of this information when needed (Emanuel et al., 1995). The following sections describe the available evidence of the multiple barriers and facilitators for implementation of ACP at patient/family, healthcare provider, and institutional levels.

Patient and Family Level. Factors that can either promote or undermine engagement in ACP at the patient level include knowledge, attitudes, beliefs, personality traits, health status, and psychological factors (De Gendt et al., 2013; Fried et al, 2010; Robinson et al., 2013). Patient factors that facilitate a higher rate of ACP engagement include: advanced age (Reynolds et al., 2008), higher education (Wagner et al., 2010), tendency to exert control over EOL care, desire to avoid life prolongation and invasive interventions, lack of surrogate decision makers, the wish to relieve family members from the burden of decision making, and limited trust that family members would respect their wishes (Mignani et al., 2017; Piers et al., 2013). Patients with a cancer diagnosis are more likely to complete ACP than those with other diagnoses (De Gendt et al., 2013). Additional facilitators for ACP include expectation of death in the near future, greater levels of functional impairment, and past engagement in EOL decision making for others (Amjad et al., 2014; Froggatt et al., 2009). Collaborative and trusting relationships between healthcare providers and families were identified as one of the facilitators for ACP and a ‘good death’ (Bern-Klug, 2009; Petriwskyj et al., 2014a; 2014b; Stewart et al., 2011).

One barrier to ACP is patients’ perceptions that healthcare providers do not have time for ACP conversations (Heyland et al., 2013a; Mignani, et al., 2017). The most cited barriers to ACP were related to insufficient knowledge about the importance of ACP, the risks and benefits of life-prolonging treatments, the option of palliative care, and the role of surrogate decision-makers as well as residents’ reluctance to acknowledge their poor prognosis or EOL status (Heyland et al., 2013b; McGlade et al., 2017; Mignani et al., 2017; Piers et al., 2013). Further barriers to ACP include diminished capacity or dementia, communication difficulties (McGlade et al., 2017; Robinson et al., 2013; Stewart et al., 2011), high level of religiosity or spirituality (Carr, 2012; Garrido et al., 2013), and membership in an ethnic and/or racial minority group (Frahm et al., 2015). For instance, research has shown that Hispanics, Asians, and African Americans were less likely to engage in ACP when compared to their Caucasian counterparts (Hong et al., 2017). In addition, NH residents with severe dementia were six times less likely to have ACP than those without dementia (De Gendt et al., 2013; Froggatt et al., 2009).

Breakdown in family relationships and a lack of close family relationships, along with some family members’ desire to protect their loved ones from potentially upsetting EOL conversations were also identified as barriers to ACP (Sharp et al., 2013). Conflict between healthcare providers and family members as well as families' reluctance to talk about ACP were mainly due to the family's denial of their loved ones' terminal illness, lack of knowledge about palliative care, and lack of understanding about their loved ones' current illness trajectory as well as the importance of ACP (Ashton et al., 2016; Froggatt et al., 2009; Stewart et al., 2011).

Research examining the barriers and facilitators to ACP at the patient/family level consists mainly of observational cross-sectional studies (Ampe et al., 2015; Burgess et al., 2011; De Gendt et al., 2013; Froggatt et al., 2009; Hagen et al., 2015; Wagner at al., 2010;) or evaluations of ACP interventions (Ampe et al., 2017; Caplan et al., 2006; Detering et al., 2010; Hockley et al., 2010; McGlade et al., 2017). In these studies, the ACP intervention involved either an educational program for staff, residents, and families or the implementation of an ACP program, such as the Respecting Choices ACP (Ampe et al., 2017) or the Gold Standard Framework for care homes (Hockley et al., 2010). The main data collection methods were either a questionnaire survey or patient chart review (Ampe at al., 2015; Burgess et al., 2011; Froggatt at al., 2009; Hagen et al., 2015; Hockley et al., 2010; Livingston et al., 2013; Reynolds et al., 2008). The participants were nurses, nurse managers, family members, and patients. Some studies used a quasi-experimental pre-post-test research design with an intervention and a control group (Ampe et al., 2017) or a randomized controlled trial (Wagner at al., 2010). The survey research was completed by postal (De Gendt et al., 2013; Froggatt et al., 2009; Rietze et al., 2018) or electronic delivery methods (Burgess et al., 2011). Most questionnaires were developed by the researchers and the validity/reliability of the survey was not mentioned in most of the studies. Limitations of quantitative survey research include potential recall bias (Wagner et al., 2010), social desirability bias (Burgess et al., 2011), selection bias (De Gendt et al., 2013), and limited ethnic and geographical diversity (Detering et al., 2010; Fried et al., 2012; Livingston et al., 2013). For example, Livingston et al's. (2013) study was conducted in one Jewish home in the UK, while Fried et al. (2010) focused their study on community-dwelling Caucasians and African American older adults and their surrogate decision makers, limiting the transferability of their findings to other racial groups and settings.

A few studies used a qualitative descriptive design with older adults and their families, where experiences with ACP were captured through semi-structured interviews (Ramsbottom & Lou Kelley, 2014; Shaw et al., 2017; Stone et al., 2013). Older adults included in these studies had the cognitive capacity to express their thoughts and ideas about ACP, thereby not allowing for the transfer of the findings to those lacking cognitive capacity. Most of the studies did not provide the specific demographic characteristics of their older adult participants (Shaw et al., 2017; Stone et al., 2013). The studies were mostly conducted in the UK, US, and Australia, so the results cannot be generalized to the Canadian context. See Appendix A for details of the studies.

Healthcare Provider Level. Barriers at the healthcare provider level include lack of knowledge and limited education on ACP-related topics, lack of confidence in addressing the emotions that might emerge during ACP discussions, lack of knowledge on patients' cultural beliefs and values, discomfort in discussing death and dying, and fears of damaging relationships with patients/families and destroying patients' hope (Ke et al., 2015; Rietze & Stajduhar, 2015; Rietze et al., 2018; Stone et al., 2013). Major barriers to ACP identified by healthcare providers included poor communication skills, lack of knowledge about the importance of ACP, how and when to have appropriate ACP conversations, and uncertainty about who should initiate these conversations (Lovell & Yates, 2104; McGlade et al., 2017; Ramsbottom & Lou Kelley, 2014). Providers' lack of interest in initiating and engaging in ACP conversations has been reported as a major barrier in several studies (Mignani et al., 2017; Ramsbottom & Lou Kelley, 2014; Stewart et al., 2011). Healthcare providers may be reluctant to initiate ACP conversations due to confusion about the related legal issues and legal paperwork required for documenting ACP, along with fears of legal action from families (Dening et al., 2011; Lovell & Yates, 2014; Sharp et al., 2013).

Physicians commonly struggle to communicate with patients/families about EOL care and may have anxiety that ACP discussions will destroy residents' hope and cause discomfort (Detering et al., 2010; de Vleminck et al., 2014; Heyland et al., 2013b). Nursing staff may hesitate to initiate ACP discussions due to perceptions that conversations about death and dying will upset the residents and trigger their personal discomfort and emotions around this topic (Heyland et al., 2013b; Stewart, et al., 2011). In a study by Froggatt et al. (2009), 55% of the 213 NH managers reported some level of discomfort with initiating an ACP conversation. Navigating dysfunctional family dynamics also discouraged healthcare providers from initiating ACP discussions (Stewart, et al., 2011). Health providers' uncertainty about when to initiate EOL discussions was found to delay timely conversations about ACP. End-of-life care planning was inhibited by the need to plan for uncertain circumstances that would affect future care (i.e., unforeseen medical scenarios) and the challenges associated with making well-informed decisions before an illness occurs (Sharp et al., 2013; Stewart et al., 2011).

Studies reported differing opinions about the healthcare providers who were best suited to initiate ACP discussions. While Rhee et al. (2012) argued that general practitioners are the most appropriate professionals to initiate ACP discussions, Morrison et al. (2005) stated that outcomes of ACP were significantly improved when social workers were involved in the process. Ke et al. (2015) stated that nurses were best suited to implement ACP because they were most familiar with the patients, their families, and the families' dynamics. Ke and colleagues' (2015) assertion aligns with that of Mignani et al. (2017), who recommended that the healthcare providers who know a patient well are ideally situated to initiate ACP.

Studies that assessed the barriers and facilitators to ACP from the healthcare provider level were mainly conducted in the UK, US, or Australia (de Vleminck et al., 2014; Living et al., 2011; Pauls et al., 2001; Rhee at al., 2012; Robinson et al., 2013; Seymour et al., 2010; Stewart et al., 2011). Limited studies have been conducted in Canada (Hagen et al., 2015; Pauls et al., 2001; Ramsbottom & Lou Kelley, 2014; Rietze et al., 2018; Shaw et al., 2017). From these studies, only Rietze et al. (2018) explicitly assessed the nurses' engagement in ACP as well as the factors influencing their engagement in the ACP process. The remaining studies reported the experiences of other healthcare providers or the combined experiences of nurses and other professionals, patients, or families. The findings from these studies might not represent the nurses' own views or experiences because these aspects were not deeply explored.

For example, Ramsbottom and Lou Kelley (2014) conducted a qualitative descriptive study to understand the experiences and perspectives of ACP in two LTC facilities in Ontario. The participants were 31 family members and three LTC staff (one nurse practitioner [NP], one nurse, and one HCA). The study underrepresented nurses' views on ACP so the findings cannot be generalized to other LTC facilities. Similarly, in an interpretive descriptive research study, Shaw et al. (2017) explored factors and readiness for ACP among residents, family members, and healthcare providers at four supportive living facilities in Alberta, Canada. Although there were 27 participants in the study, only one NP and two RNs participated in the semi-structured interviews. Again, due to the small sample size of nurses as well as the context of the study, the findings cannot be generalized to LTC settings. Residents in supportive living facilities are generally in better health with higher physical and cognitive function. In addition, these facilities do not provide continuous nursing services nor weekly visits from primary care providers, like the LTC facilities in Winnipeg.

Hagen et al. (2015) conducted a quantitative survey, based on the transtheoretical model, to characterize the system-specific barriers and facilitators to ACP implementation in the province of Alberta. The participants were mainly administrative staff (41%) and physicians (33%). Nurses and the public represented less than 5% of the study participants and the research was mainly focused on a policy initiative. The respondents were mainly from Edmonton, so the survey did not represent the overall population of Alberta. Pauls et al. (2001) conducted a qualitative study to describe an ideal model for the transfer of advance directive completion from LTC facilities to EDs. Thirty-five healthcare providers from Toronto participated in seven semi-structured focus group interviews to develop an ACP form. A total of 14 nurses participated in the study, seven of whom were from LTC facilities and 70% were RNs. Due to the overrepresentation of RNs, the findings of the study cannot be utilized in Winnipeg LTC facilities, where most of the nurses are licensed practical nurses. Moreover, the main focus of the study was the development of an ACP form, rather than the actual ACP conversations between nurses and residents/families. The disciplinary lens of this study was medicine.

In comparison to the above four studies, Rietze et al. (2018) conducted a cross-sectional descriptive survey based on the theory of planned behaviour (TPB) framework. Rietze et al. (2018) sought to determine the extent to which RNs engaged in ACP with their patients and to understand the factors associated with their engagement in ACP. The participants were randomly selected from the Ontario RNs license registry. The survey questionnaire was developed by the researchers and content validity of the survey was established by nurse clinicians with expertise in ACP and EOL care. The response rate of the mailed survey was very low (12.8%) and the research did not indicate the definition of ACP used for the purposes of the study. Most of the nurse respondents were employed in acute care hospitals (67%), while the rest were employed in non-acute care settings. More than half of the nurses had a baccalaureate nursing degree. Even though this quantitative study exclusively assessed the views of nurses, the research was not focused on the actual process of ACP and it does not represent the views of LTC nurses, the majority of whom are licensed practical nurses.

Most of the qualitative studies examining ACP used exploratory descriptive designs (de Vleminck et al., 2014; Livingston et al., 2011; Ramsbottom & Lou Kelley, 2014; Stone et al., 2013). Individual semi-structured interviews and focus groups were the most common methods of data collection in these studies (Fried et al., 2010; Pauls et al., 2001; Robinson et al., 2013). Even though the aim of these studies was to understand healthcare professionals' experiences and perspectives of ACP, none of these studies were focused on the process of ACP or actual ACP conversations between nurses and families/residents. None of the qualitative studies explicitly researched nurses' views of ACP in LTC settings. All of the studies had small sample sizes of nurses and most of the studies had only head nurses/senior nurses carrying out ACP conversations (Ampe et al., 2017; McGlade et al., 2017). In general, head nurses and senior nurses have limited contact with residents and their families. In Winnipeg LTC facilities, ACP conversations are usually initiated and completed by the unit nurses. Moreover, no studies used a GT methodology design. Although two of the studies claimed to use a GT approach for data analysis (Fried et al., 2010; Pauls et al., 2001), neither of these studies followed the procedures of GT data analysis (theoretical sampling, constant comparison method, or theoretical saturation). The data analysis in these studies represented only thematic analysis and no conceptual understanding of ACP emerged from these studies. Most of the studies did not report on the trustworthiness or rigor of their qualitative research. The three available Canadian studies were conducted in Ontario (Pauls et al., 2001; Ramsbottom & Lou Kelley, 2014) and Alberta (Shaw et al., 2017); none of the studies were conducted in Manitoba. In Canada, the legislation around ACP and advance directives varies from province to province, thus findings from different provinces cannot be generalized to the Manitoba context. Moreover, the definition of ACP was missing from most of the studies and none explicitly identified the use of a theoretical framework underpinning the work. The presence of a theoretical framework gives credence that the study was not based on the personal instincts of the researcher, while also enhancing the empiricism and rigor of the research and making the findings more meaningful and generalizable (Dickson et al., 2018).

Some studies used quantitative survey research to understand healthcare providers' experiences of ACP (Ampe et al., 2015, 2017; Burgess et al., 2011; Hagen et al., 2015; Rietze et al., 2018). Rietze and Stajduhar (2015) conducted an integrative review to understand the factors that influence RNs' involvement in ACP with their patients in acute care settings. Most of the studies in the review were from the US and there were no Canadian studies. Thus, these findings cannot be generalized to other countries that have different ACP medico-legalities and nursing scopes of practice when compared to the US. Cross-sectional surveys were the most frequently used design, with only one descriptive exploratory qualitative study included in the review. The majority of studies did not have an explicit theoretical base, which may have limited the scope of the research or the researchers' understandings of the findings in clinical practice. See Appendix A for study details.

Institutional/Organizational Level. Barriers identified at the organizational/institutional level include unclear policies and procedures related to ACP roles, time constraints related to busy clinical environments, rapidly changing clinical assignments and workloads, physicians' perceptions that nurses lack the ability to carry out ACP conversations, lack of organizational leadership/collegial support, staff shortage, and a lack of appropriate ACP forms/technology for documentation (Ceccarelli et al., 2008; Dixon & Knapp, 2018; Dube et al., 2015; Ke et al., 2015; Rietze & Stajduhar, 2015; Rietze et al., 2018).

The two most prominent barriers to ACP identified by Ampe at al. (2017) and McGlade and colleagues (2017) were lack of time and workload of the staff. Physicians reported time constraints, poor reimbursements, and lack of legal familiarity in completing ACP (Ampe et al., 2017; Sharp et al., 2013) as the chief reasons for failing to broadly implement ACP. Studies also identified inadequate retention and recruitment of experienced staff in NHs as a major obstacle in ACP implementation (Hockley et al., 2010; Sankaran et al., 2010). Other administrative barriers included a lack of information flow, such as inadequate systems for monitoring, accessing, and transferring ACP records (Pauls et al., 2001). Availability of a technological infrastructure, with system-wide electronic medical records, has been found to promote consistent communication of ACP between healthcare providers across different healthcare settings (Hagen et al., 2015; Lund et al., 2015). A pre-test-post-test study by Ampe et al. (2017) reported hierarchy in the organization as a barrier to ACP, where head nurses were generally appointed to ACP completion even though the floor nurses had better rapport and contact with the residents. Other institutional/organizational barriers contributing to low rates of ACP included: lack of a centralized location for ACP documentation, lack of a standardized ACP form, inconsistent documentation habits, limited time to counsel residents and their families, and lack of recognition of team members' efforts (Burgess et al., 2011).

Facilities that adopted a culture of continued education and equal partnership with residents and families regarding ACP, and embedded person-centered ACP in everyday conversations, were able to successfully facilitate ACP implementation (Ampe, et al., 2015; Baron et al., 2015). A systematic review by Gilissen et al. (2017) advocated for a supportive community as a pre-condition to achieve desired ACP outcomes, where those involved in the process need to have a common vision and conceptualization of ACP. A study by Caplan et al. (2006) revealed that system-wide education provided to residents, families, staff, and general practitioners about the terminal nature of dementia increased the uptake of ACP. Education about ACP needs to be broad and target all members of society to promote awareness of ACP (Lunder et al., 2017). Robinson et al. (2013) recommended that ACP become an evidence-based part of routine dementia care. A systematic review by Gilissen et al. (2017) revealed that the rate of ACP engagement in LTC facilities could be increased through a supportive culture, grounded in a palliative care ideology; trusting relationships; open awareness and discussions of death and dying among staff, families, and residents; and a supportive administrative system.

Only one Canadian study explicitly assessed the barriers and facilitators to ACP at the institutional/organizational level (Hagen et al., 2015). In other studies, this level was combined with the patient/family and provider levels. Hagen et al. (2015) used a survey research design based on the transtheoretical model to characterize system-specific barriers and facilitators for the uptake of ACP. The participants in this study were administrative staff, physicians, nurses, the general public, and others. This study was focused on a policy development approach and the findings mainly reflected the views of administrative staff. Most of the barriers and facilitators affecting the institutional/organizational level were identified in systematic reviews (Gilissen et al., 2017; Ke et al., 2015; Myers et al., 2018). See Appendix A for details of the studies reviewed.

Overall, the evidence shows that factors influencing the uptake of ACP are complex and multifaceted, and reflect the diverse and often competing needs of patients, health professionals, legislation, and health systems. Therefore, it is critical to engage a multi-sector healthcare system approach to ACP, with an explicit process that promotes system-specific engagement. Myers et al. (2018) concluded that a comprehensive approach to ACP includes community engagement, professional education, development of standardized practices, and the monitoring of these practices through quality improvement initiatives, policies, practices, and technology infrastructure.

This literature review highlighted that ACP can be a challenging and laborious process in LTC settings. Although several elements can influence the ACP process, the literature has provided a variety of interventions that could support successful, effective, and sustainable ACP implementation in LTC. Effective ACP discussions can support EOL care as well as quality of life throughout the illness trajectory, including the period before death is imminent. Moreover, effective ACP could open lines of communication and enhance peace of mind for all involved in EOL care. The value of ACP is evident and healthcare providers' lack of involvement in this process can jeopardize the patient-centered approach to clinical care. Unfortunately, the existing literature did not provide a conceptual understanding of ACP from a nurse's perspective. Therefore, the proposed CGT methodology aimed to empirically generate this much needed understanding.

A Critical Comparative Analysis of WRHA's Advance Care Planning-Goals of Care

As part of the national Speak Up ACP initiative, several Canadian health authorities instituted a medical order framework to better reflect the provision of medical care that is aligned with patient values. Some examples of these frameworks include: the ACP-goals of care designations (GCD) order in Alberta (Alberta Health Services, 2014), the medical orders for scope of treatment (MOST) and ACP in Fraser Health Authority (FHA) (Fraser Health Services, 2012), and the ACP-goals of care (ACP-GOC) in the WRHA (2011). Alberta Health Services and the FHA in British Columbia have been leaders in Canada with their streamlined ACP and GOC documentation. These two health authorities incorporated engagement, education, system infrastructure and tools, and continuous quality improvement as the four basic building blocks (CHPCA, 2013) for the successful implementation of ACP. Building on experiences from the Physician Orders of Life-Sustaining Treatment (POLST) program, they adopted mechanisms for providers to elicit patient preferences and translate them into a set of medical orders that address high probability interventions (Detering et al., 2010). Documentation on a highly visible form ensures portability between facilities and assists healthcare professionals with EOL decision making across care settings (Detering et al., 2010). While ACP conversations guide decision making, a GOC designation guides the healthcare team during medical emergencies to ensure their care best reflects the patient's health circumstances, wishes, and values (Alberta Health Services, 2014).

The POLST is an ACP developed in 1991 in Oregon, US to avoid societal default toward CPR, hospitalization, and other unwanted life support treatments for seriously ill patients (Moore et al., 2016). The relevant population for POLST are patients who have advanced chronic progressive illness and frailty or those who wish to further define their preferences of care

(Moore et al., 2016). The POLST form is completed by a physician or NP based on conversations with the patient and/or surrogate decision maker about the provision of orders for CPR, antibiotics, artificial nutrition/hydration, and hospitalization (The POLST California, 2016).

The WRHA's ACP-GOC policy is applicable to all WRHA-governed sites and facilities, including hospitals and LTC facilities (WRHA, 2011). The intended aim of this policy is to promote an ongoing collaborative process for ACP to ensure that residents' GOC are addressed and identified. Goals of care are defined as the healthcare interventions recognized by the resident/healthcare proxy and the healthcare team, and documented in an ACP-GOC form (WRHA, 2011). This form contains three general foci of care that have been labeled comfort care (C), medical care (M), and resuscitative care (R) (WRHA, 2011) (See Appendix B). The ACP-GOC policy also ensures that healthcare teams provide the resident/healthcare proxy with complete information about the nature of the resident's condition, prognosis, and available treatment/investigation options, ranging from the least recommended to the most recommended. The healthcare team must review the expected benefits and burdens of treatment/investigation options prior to completing or revising the ACP-GOC form. The healthcare team consists of the healthcare professionals directly involved in the resident's care. The overall goal of the ACP-GOC process is to achieve consensus among the healthcare team and resident/healthcare proxy. It is recommended that the ACP-GOC process be a routine practice on admission to LTC facilities and that the information on these forms be reviewed at least annually. In addition, ACP-GOC can be completed at the request of the healthcare team/resident/substitute decision maker or whenever unexpected/significant changes occur in the resident's clinical status (WRHA, 2011). The WRHA ACP-GOC form and policy does not provide specific guidance about medical care and interventions. While the WRHA's policy indicates that the healthcare team should initiate ACP discussions, no single discipline is identified as being the leader of this activity or being responsible for documenting decisions on the ACP-GOC form.

In contrast, Alberta's GCD order provides more clarification on specific interventions (see Appendix C). While the GCD policy states that any member of a patient's healthcare team may initiate ACP conversations, the most responsible health practitioner is ultimately responsible for ensuring that a clinically indicated GCD order has been discussed, established, and documented. The most responsible health practitioner is the provider who has responsibility and accountability for the specific treatment/procedure(s) provided to the patient, and who is authorized by Alberta Health Services to perform the duties required to fulfill the delivery of such a treatment/procedure(s), within the scope of his/her practice (Alberta Health Services, 2014).

The FHA's MOST-ACP is a physician order that provides a code status (CPR or DNR) and a designation regarding the scope of desired medical interventions, which are documented as a MOST designation of either medical treatment (M1, M2 and M3, but excluding critical care interventions and resuscitation) or critical care intervention (C1 and C2) (see Appendix D). The MOST-ACP policy states that the most responsible physician is ultimately responsible for initiating the discussion and completing the MOST form; most responsible physician means the physician who initiates the admission of the resident to LTC, and who coordinates the resident's care of the resident while in the facility (Fraser Health Services, 2012). The MOST-ACP discussions and documentation must be initiated and completed within sixty days of admission to a LTC facility, and must be reviewed at least annually by the resident's physician (Fraser Health Services, 2012).

In contrast to the GCD and MOST, the ACP-GOC form does not provide clear specification of the three GOC categories and broadly labels them as comfort care, medical care, and resuscitative care. For example, ‘medical care’ could be any life-prolonging treatment, other than CPR, and does not account for cases where patients would not want to be defibrillated or receive chest compressions for a cardiac arrest but would want to be intubated for respiratory distress. Residents’ wishes, regardless of how they are communicated, must be methodically factored or translated into specific medical orders that clearly outline acceptable/desired interventions. Currently, the WRHA has no formal guidelines concerning which disciplines should be involved in the ACP process. From this researcher’s experience, nurses often initiate ACP discussions and complete the GOC form without any input from the attending physician/ NP about the resident’s medical status or prognosis. According to the WRHA policy, nurses are engaging in this process incorrectly; the WRHA policy recommends a review of the resident’s condition, prognosis, and available treatment/investigation options, including the expected benefits and burdens, prior to completion or revision of the ACP-GOC form. This policy recommendation is challenging to fulfill in WRHA LTC facilities due to the nurses’ limited education and knowledge about individual residents’ prognosis and available treatments. Moreover, it is difficult for the healthcare team to initiate ACP on the first day of admission, with limited available information on the resident’s condition and prognosis.

The WRHA’s ACP process does not currently reflect a geriatric palliative care ideology in LTC settings, where most of the residents are at the EOL. Discussions pertaining to ACP and GOC in LTC settings should seek to prepare for death and dying rather than for possible incapacitation. The WRHA’s current ACP policy and GOC form fail to address the complex clinical and communication challenges in LTC settings. The WRHA’s ‘one size fits all’ ACP approach is in urgent need of modification to ensure successful implementation of ACP in LTC settings.

Nurses' Role in Advance Care Planning

While there is no real consensus in the literature about who should conduct ACP (i.e., nurses, physicians, social workers, or chaplains), most studies concur that it should be a healthcare provider with good communication skills and/or the best rapport with the patient (Con, 2008; Mignani et al., 2017; Myers et al., 2018). Studies have indicated that patients and healthcare professionals perceive that EOL care issues are often broached less tactfully by physicians when compared to other healthcare professionals (Arnett et al., 2017; Scott et al., 2013). Similarly, a Delphi consensus process with an international expert panel yielded a high level of agreement that ACP should be initiated by a non-physician healthcare provider (Rietjens et al., 2017).

Black (2006) and Ke et al. (2015) claimed that nurses are the most suitable professionals to implement ACP because they know the patients, their families, and the patient/family dynamics, and possess the necessary medical expertise to describe specific details of clinical situations. Izumi (2017) argued that nurses are well positioned to initiate ACP because they have more frequent and regular contact with patients and family members (especially in hospitals and LTC facilities) and often act as the hub of communication within the multidisciplinary team. Nurses are the largest group of healthcare professionals in the world, working in all geographical areas and domains of healthcare. Nursing is a major component of the interdisciplinary team and provides most of the direct clinical care that patients require (Canadian Nurses Association, 2008). Nurses are at the patient's bedside 24 hours a day, seven days a week, and are optimally positioned to contribute to meeting the ACP needs of various patient populations (Baughman et al., 2012).

Nurses' roles in EOL care and decision making are well outlined by the CNA, the CHPCA, and the Canadian Hospice Palliative Care Nurses Group's (CHPC-NG) (2015) position statement entitled, '*The Palliative Approach to Care and the Role of the Nurse.'* These roles include advocacy for patients in their experience of living and dying, honoring patients' values and healthcare wishes, and advocating for resources that support patients and families in their choice of environment for a peaceful and dignified death (CHPC-NG, 2015).

Even though nurses are well placed and supported by the mandates of professional bodies to play an important role in ACP discussions, current literature depicts nurses as having variable or limited involvement in ACP practices (Baughman et al., 2012; Boyd et al., 2011; Ceccarelli et al., 2008; Duke & Thompson, 2007; Ke et al., 2015; Rietze et al., 2018; Reitez & Stajduhar, 2015; Shepherd et al., 2018; Yee et al., 2011). Nurses' limited involvement in ACP conversations may partially explain why only 8% of older Canadians reported engaging in ACP with a nurse during their hospital admission (Heyland et al., 2013a).

An integrative review by Reitze and Stajduhar (2015) reported that a large percentage of acute care nurses were not engaging in ACP discussions with their patients and there was no consensus among these nurses about their role in ACP. Duke and Thompson (2007) found that 44% of acute care nurses had never assisted their patients with any aspect of ACP. Shepherd et al. (2018) conducted a survey-based cross-sectional study with 181 RNs from critical care and acute care wards of three metropolitan hospitals in Australia and found that 15% of nurses never engaged in any ACP discussions.

Similar findings were reported in a study conducted in residential aged care facilities in Australia (Silvester et al., 2013). The study reported that nurses were minimally engaged in ACP; more specifically, 35.8% of nurses had not conducted an ACP discussion in the last six months and 40% had ACP discussions with “very few/no residents” in the last six months (p. 354). Furthermore, study participants identified having “little or no experience in holding such discussions” (p. 353) and 53% stated that ACP was ‘poorly’ or ‘very poorly’ executed in their care facility (Silvester et al., 2013). A quality indicator project from the US (Izumi, 2017) reported that over 40% of nurses were ‘never’ or ‘rarely involved’ in ACP, with only 20% stating they were ‘often involved.’ Overall, the evidence indicates that nurses have varying degrees of participation in ACP, which is similar to findings from the general population (Shepherd et al., 2018; Yee et al., 2011).

A Canadian cross-sectional descriptive study (Reitze et al., 2018) with 125 nurses from Ontario identified that nurses who worked in acute care settings were more often engaged in ACP than their non-acute counterparts. More than half of these acute care nurses reported engaging ‘often’ or ‘very often’ in ACP. Davidson et al. (2013) reported that New Zealand nurses working in a primary healthcare setting (n=13) felt they were well positioned to successfully engage in ACP with their patients. These nurses believed that the therapeutic relationships that developed over time in the community setting provided an effective foundation for “such sensitive discussions” (p. 30). The nurses also believed that “involvement in ACP was part of their professional obligation” (p. 30) and valued teamwork in ACP, seeking physician involvement and collaboration. An American quantitative non-experimental study (Dube et al., 2015) showed that NPs working in LTC, community, or inpatient settings (n=130) frequently engaged in ACP discussions.

Nurses themselves seem to hold divergent perspectives about their role in ACP (Black, 2006; Rietze & Stajduhar, 2015; Rietze et al., 2018). While some nurses view ACP as being within their scope of professional practice, others are less confident about engaging in this activity as part of their regular duties (Black, 2006; Rietze et al., 2018). While some nurses perceive ACP to be part of their scope of practice, the literature suggests that nurses do not place a high priority on ACP (Baughman et al., 2012). Furthermore, in Yee et al.'s (2011) study, nurses reported participating in ACP-related discussions less frequently than physicians and social workers. Nurses often deferred ACP-related discussions to physicians or other healthcare team members and did not believe ACP communication was part of their clinical scope of practice. According to Izumi's (2017) quality indicator project, nurses were hesitant to engage in ACP because they perceived that it was not designated as a nursing responsibility in the organization and that physicians had concerns about nurses fulfilling that role. This notion was further supported in an exploratory qualitative study by Dixon and Knapp (2018), where physicians believed that nurses should not discuss prognosis or treatment decisions with patients. The physicians were consequently reluctant to refer patients to nurses for ACP conversations (Dixon and Knapp, 2018).

Most of the reviewed articles showed that nurses played a crucial role in ACP, as educators, initiators, facilitators, advocates, information providers, communicators, brokers, assessors, and liaisons with family and/or the healthcare team (Black, 2006; Duba et al., 2015; Izumi, 2017; Ke et al., 2015; Rietze & Stajduhar, 2015). Nurses fulfill these roles by assessing patients' needs, preparing them for discussions about ACP, and identifying the patients' wishes for EOL care during admissions and routine care (Black, 2006; Seymour et al., 2010). Nurses have reported that their primary role in ACP is to serve as an educator (Black, 2006), where they educate and inform patients/families about advance directives and surrogate decision makers, and tailor information to patients' specific needs, diseases, and treatments (Black, 2006, Ke et al., 2015). Research has shown that nurses' ACP communication tends to focus on pragmatic information, providing an abundance of medical information to patients and families in "everyday language" and reviewing the expectations of different medical interventions. These discussions provide patients with a realistic description of the intervention and help them envision their possible experience (Black, 2006). In the advocacy role, nurses advocate for the patient's and family's rights, inform them of the intended positive outcomes of advance directives, and document their wishes. Nurses also advocate on the patient's behalf to other healthcare providers and to the patient's family (Black, 2006; Seymour et al., 2010). In addition, nurses play a role in facilitating patients' (and their families') transition from curative to palliative care (Seymour et al., 2011; Thompson et al., 2006). Nurses function as brokers in facilitating ACP in chronic care settings, where they act as an intermediary between families and physicians to ensure that ACP decisions are honoured (Ceccarelli et al., 2008; Dixon & Knapp, 2018). Baughman et al. (2012) used focus groups in one mid-western American state to explore community-based care managers' roles in the ACP process. Managers preferred to limit their role in ACP to that of educator or coach, whereby they would provide information to clients regarding the ACP process and leave physicians in charge of conducting ACP-related discussions with patients.

In summary, nurses are well positioned to implement ACP in LTC facilities because they know the patients, families, and the patient/family dynamics and are continuously available to be present at the bedside. In spite of this, the literature shows that nurses are minimally engaged in ACP discussions and there is no uniform consensus about the nurse's role in ACP. Currently, there is a paucity of literature that investigates the ACP practices of nurses in Canada, especially in LTC facilities. This gap in Canadian research leads to a reliance on international sources to represent or depict the ACP practices of Canadian nurses. Extrapolation of international data could be problematic given the differences in legislation, especially in terms of healthcare directives and healthcare systems, and possible differences in nurses' scope of practice between countries (Brown, 2003; CHPCA, 2012).

Summary of the Literature Review

In alignment with the CGT methodology, a preliminary literature review was undertaken on a broad range of topics to contextualize the background information, identify knowledge gaps, and provide rationale for this thesis research. The first section of this review discussed the impact of the aging population on the Canadian healthcare system. Advances in medical sciences, combined with an aging population, have resulted in an increasing number of older adults with multiple chronic incurable illnesses, including dementia. The growing population of Canadian older adults with varying levels of disease burden and frailty will place increased demands on the healthcare system for formal care services, including LTC facilities. Healthcare expenditures are generally higher in aging populations. In addition, the costs of dementia care and LTC have been projected to increase astronomically over the next two decades. Many older adults are transferred to hospital during EOL; these transfers are inappropriate, invasive, and associated with significantly greater costs when compared to remaining in LTC. Evidence shows that the Canadian healthcare system will be strained by the growing population of older people. Therefore, LTC facilities need to optimize their ACP processes so they can continue to provide cost effective quality care for years to come.

In order to provide the background for this research, this review examined the organizational structure of LTC and the complexities of the LTC context, and identified a variety of challenges. The provision of care in LTC settings is challenged by factors at the resident/family, healthcare provider, and wider healthcare system levels. It can be challenging for healthcare providers to isolate the EOL period among LTC residents, as they are in an ambiguous chronic living-dying phase with chronic frailty and multiple comorbidities. Even though death and dying are major features in LTC settings, studies have repeatedly identified inadequate EOL care in these settings, with high rates of terminal hospitalizations and futile aggressive interventions, inadequate symptom management, minimal physician presence, suboptimal communication, and poor EOL care planning/ACP. Evidence suggests that a palliative approach to care should be integrated into the practice of LTC and be the standard of care for all residents upon admission. In most facilities, the broad philosophy of palliative care is underutilized and its implementation is delayed until late in the dying process. Studies indicated that structured EOL conversations between healthcare providers and families are positively associated with the adoption of a palliative care approach as well as the family's decision to limit or withdraw life-sustaining treatments. In practice, healthcare providers tend to avoid or delay these conversations until the resident is deemed to be terminal. When these conversations do occur, they are often infrequent and brief in nature.

Various research studies have been conducted in an attempt to improve and understand EOL care in these settings. These studies examined communication issues, staff and families' experiences with EOL care, and obstacles in providing quality EOL care. Most of these studies identified inadequate communication between decision makers as a main barrier to quality EOL care. This literature review identified the need for more extensive knowledge on exactly how

EOL conversations are being carried out in these settings. Attending to the complexities of EOL conversations and EOL decision making in LTC is imperative to providing high quality EOL care in these settings.

This review examined theoretical literature on ACP to provide a philosophical grounding for the communication approaches used in EOL care discussions. In general, ACP is an interactional multi-stage process between a resident and/or surrogate decision maker and the healthcare provider(s) that seeks to achieve shared decision making of the residents' future goals and preferences, particularly in the event of loss of competence. Through this review, ACP emerged as a complex intervention, health behaviour, social process, and public health issue. Although several research studies have acknowledged the potential benefits of ACP in LTC settings, there is a lack of empirical work examining ACP from the perspective of healthcare providers—perhaps due in part to the complexity of the process. Research conducted to date provides some information about when and how ACP conversations should take place and who should initiate them. Additional research is needed to generate theoretical frameworks and provide various strategies and approaches for implementing ACP in patient care.

The last part of the literature review focused on nurses' roles in ACP. The evidence strongly supported that nurses play a crucial role in ACP conversations, more so than any other healthcare providers, but revealed that nurses have limited involvement in ACP practices across all settings, both nationally and internationally. Barriers identified at different levels served to impede nurses' engagement in ACP. The evidence also suggested that nurses hold divergent views about their role in these discussions. Although nurses are well positioned to facilitate ACP conversations, especially in LTC settings where physician presence is limited, no research has been conducted to understand nurses' involvement or their perceived role in ACP discussions in the Canadian context, especially in the Manitoba healthcare system. This could be problematic given the differences in funding, staffing regulations, and nurses’ scope of practice between countries.

There has been considerable research focused on the benefits of ACP, the barriers and facilitators of ACP from the perspectives of residents/families and healthcare providers, and the outcomes of ACP. A significant gap in the existing ACP literature concerns the lack of attention being given to theoretical understandings of ACP conversations in LTC settings. Such understandings are important because they help to describe nursing care, guide nursing practice, and provide a basis for clinical decision making. This missing piece is vital in promoting the understanding, development, and advancement of ACP. A study that develops substantive theory would be the next logical step in advancing the understanding of ACP in nursing practice and EOL care.

Some compelling qualitative studies have shown that current ACP processes have been disappointing, ineffective and inconsistent across all healthcare settings in Canada. The only way to improve the ACP process is to study it using rigorous qualitative research. Furthermore, this understanding could be the basis for future quantitative studies about ACP in nursing practice, as the development of a substantive theory is highly valued as the basis for quantitative investigations.

Chapter 3: Research Framework

Creswell (2013) described three components that researchers should include within a research framework: (a) the paradigm; (b) the research strategy; and (c) the research methods. This chapter explores and describes these three components as they relate to this study.

Research Paradigm

Kuhn (1970) first used the term paradigm to describe the theoretical and methodological basis that guides research. To ensure a strong research design, the researcher must choose a research paradigm that is congruent with his/her belief about the nature of reality (Denzin & Lincoln, 1998). A paradigm refers to the basic belief systems, the metaphysics, or a view of the world that guides the choice of methods as they relate to the underlying ontology and epistemology of that view (Denzin & Lincoln, 1998; Guba, 1990). Crotty (1998) suggested that, once the research questions and aim of the study have been identified, it is important to explore the ontological and epistemological stance that fits with the research. According to Crotty (1998), the four elements of a research paradigm are ontology and epistemology, theoretical perspectives, methodology, and methods (see Appendix E). The following sections use the scaffolding process outlined by Crotty (1998) to provide detailed explorations of each element of the research paradigm as they relate to this study. The research method used in this study will be described in detail in chapter four.

Ontology and Epistemology

The first step in creating the research scaffolding is to clarify the ontological stance that aligns with one's philosophy of science (Crotty, 1998). Ontology is the study of "being" (Crotty, 1998, p. 10) and raises basic questions about the "nature of reality" (Denzin & Lincoln, 2005, p. 183), such as: what is the nature of reality? Is reality of an objective nature, or the result of individual cognition? What is the nature of the situation being studied? (Kivunja & Kuyini, 2017; Mackenzie & Knipe, 2006). Social constructivists reject the realism of positivism and embrace a relativist position, acknowledging the construction of multiple realities (Charmaz, 2014; Crotty, 1998).

This study assumed a relativist stance in that the theoretical analyses were the interpretive rendering of the process of ACP, rather than focusing on objective reporting. The understanding of ACP was constructed with the nurses through the researcher's interpretive understanding -- an emic perspective that assumed a relativist and reflective stance toward the data (Charmaz, 2006). The objective of this study was to understand the process of ACP rather than objectively test hypotheses about it. The researcher believes that reality cannot be objectively grasped; as such, the aim of this study was to seek multiple realities from the nurses then examine these realities within the local context, specifically within nature and the sociocultural backgrounds of the nurses holding these constructions. The subjectivity of the knowable was valued in this research, and quotes from the nurses were used to provide evidence of multiple subjective perspectives.

Crotty (1998) defined epistemology, or the study of knowledge, as "a way of understanding and explaining how we know what we know" (p. 3). Therefore, when considering the epistemology of one's research, one should ask questions such as: (a) is knowledge something that can be acquired? (b) is it something which has to be personally experienced? (c) what is the nature of knowledge and the relationship between the knower and the would-be known? (Kivunja & Kuyini, 2017; Mackenzie & Knipe, 2006). The aim of this research was to explicate an in-depth understanding of nurses' experiences with the ACP process, which can be best accomplished using a qualitative research design (Creswell & Poth, 2018). The knowledge acquired in this study was not objective knowledge to be discovered, but subjective knowledge that was co-constructed by the nurses and researcher. This approach to developing knowledge is congruent with the core tenets of social constructivism and its subjective epistemology (Charmaz, 2014; Crotty, 1998).

Constructivists believe that truth exists only through interaction with the realities of the world; thus, meaning is constructed rather than discovered (Mills et al., 2006). Creswell (2007) explained that constructivist researchers believe that reality is a construction created in an effort to understand the world. This stance has implications for the ontology-epistemology relationship, as reality changes with each new viewing (Bryant & Charmaz, 2007a). Guba (1990) held a similar view of the ontology-epistemology relationship of constructivism. Guba (1990) believed that the 'relativists' ontology of constructivism results in a 'subjectivist' epistemology, meaning that reality is always represented from the perspective of the viewer, and there is no objective 'truth' to be found. Therefore, constructivists seek to represent what is happening rather than produce universally applicable laws or theories (Creswell, 2007). Importantly, constructivists acknowledge that their own understandings and experiences influence the outcomes of their research. As a result, constructivists become participants in their own research as well as interpreters of the data (Bryant & Charmaz, 2007a).

Congruent with the ontological stance of relativism, the relationship between the knower and the known is acknowledged as a fundamental part of knowledge development and is valued for the production of knowledge. This co-construction of knowledge is viewed as occurring within a particular context that influences the construction of reality (Lincoln & Guba, 2013). Therefore, knowledge is situated within a certain time frame, and its development is influenced by many contextual and individual factors (Lincoln & Guba, 2013). The knowledge developed is context-led, with meaning being applied in relation to the situation; as a result, constructivists provide detailed descriptions of context (Charmaz, 2000). In this study, this approach allowed the exploration of each nurse's views and comprehension within their own context, recognizing that each nurse has had different experiences in the process of ACP. Knowledge was constructed in this study using a process of social interchange between the nurses and researcher in an interactive interview process; data from the interviews reflected the nurses' voices, views, and experiences. The GT that emerged was based on the researcher's own understandings and interpretations of the nurses' views.

In summary, the assumptions of social constructivism have implications for research. First, the described reality of a particular population is considered in context, and rich descriptions of the context need to be provided. Second, findings are viewed as the creation of an interactive process. Third, subjectivity is desirable and values need to be acknowledged. Finally, research procedures are emergent, and holistic aspects of human life are emphasized (Creswell, 2007; Weaver & Olson, 2006).

Theoretical Perspectives

A theoretical perspective is defined as "the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria" (Crotty, 1998, p. 3). In this study, theory was not utilized for deducing research hypotheses, as it would be in a quantitative study, but for theoretically guiding and situating the study (Charmaz, 2006). In classic GT (Glaser & Strauss, 1967), the researcher did not need an initial research question or guiding theoretical perspective, as these preconceived ideas could foster unwanted researcher influence (Glaser & Holton, 2007). In contrast, Charmaz (2006, 2014) argued that theoretical frameworks can guide the research and interview questions, help develop sensitizing concepts, inspire theoretical questions about one's data, inform data analysis, and enhance theoretical depth of the findings. However, if a researcher uses a theoretical framework, it is important to ensure that data is not forced into a pre-specified theory; it is essential to employ reflexivity and transparency regarding its influence on the research process (Charmaz, 2006).

Symbolic interactionism (SI) (Blumer, 1969; Mead, 1934) and the socio-ecological model (SEM) by Simons-Morton et al. (2012), were the two theoretical perspectives that provided the sensitizing concepts for this study. Charmaz (2003) has referred to sensitizing concepts as “those background ideas that inform the overall research problem” (p.259) and further stated, “sensitizing concepts offer ways of seeing, organizing, and understanding experience” (p. 259). Although sensitizing concepts can guide the research project, Charmaz (2006, 2014) noted that they should be points of departure to develop new ideas rather than limiting data into preconceived ideas. Potential sensitizing concepts can be developed from guiding interests, extant theories, and disciplinary perspectives (Charmaz, 2014). Despite their utility, the researcher must remain cautious and prudent in the use of sensitizing concepts (Bowen, 2006). The researcher will use sensitizing concepts to lay the foundation for the analysis of research data and might also use these concepts when examining substantive codes, with the intention of developing thematic categories from the data (Bowen, 2006).

Advance care planning has been conceptualized as a health behaviour with multifactorial influences (Fried et al., 2012; Gilissen et al., 2017); therefore, it can be studied using multiple theoretical perspectives. Symbolic interactionism provides an understanding of the operation of society from the micro-level processes that emerge during face-to-face encounters of human actors. According to SI, humans are viewed as agentic, autonomous, and integral in creating their social world (Carter & Fuller, 2015). Alternatively, SEM offers a framework for addressing theoretical perspectives, targeting multiple levels of influences on health-related behaviours

(Simons-Morton et al., 2012). The SEM also focuses attention on broader organizational, cultural, social, and contextual factors rather than exclusively focusing on individual factors, as is the case with SI. The following sections introduce the key concepts and ideas from SI and SEM that are relevant to this study.

Symbolic Interactionism

Symbolic interactionism was developed in the early 20th century at the University of Chicago (Charmaz, 2014) and has roots in social psychology (Charon, 2010). Philosopher George Herbert Mead's ideas formed the foundation for SI; he postulated that humans come to understand reality through a social process and active interpretation of their world (Benzies & Allen, 2001; Crooks, 2001). Mead was influenced by Darwin's ideas on evolution and believed that the mind and intelligence evolved as a result of human interaction with others, through both time and self (Blumer, 1969; Strauss, 1965). Herbert Blumer was one of Mead's students and was credited with interpreting his work. Blumer coined the term 'symbolic interactionism' in 1937 (Charon, 2010).

Symbolic interactionism is a dynamic micro-level theoretical perspective that addresses how society is created and maintained through repeated interactions among individuals. According to SI, human actions are viewed as constructions of the self, situation, and society (Carter & Fuller, 2015; Charmaz, 2014). Symbolic interactionism focuses on the interpretations of subjective viewpoints, such as how individuals make sense of their world from their unique perspectives and how repeated, meaningful interactions among individuals come to define the makeup of society (Carter & Fuller, 2015; Crotty, 1998). Symbolic interactionism views society as a framework for interactions rather than a determining structure, and is less concerned with the structure of society than the subjective meaning individuals ascribe to it (Milliken & Schreiber, 2012).

The main concepts of SI used in this study were Mead's idea of self and role-taking (Mead, 1934) and Blumer's (1969) three premises. The self is defined from the SI perspective as a complex interpretive process that involves a continuous communication between the "I" and the "Me"; in other words, the "I" acts and the "Me" defends, evaluates, and interprets the self as reflected by others (Mead, 1934). Mead (1934) considered the "I" as a human subject and the "Me" as the social self and human object that arises through interactions with others. The "Me" is the organized set of attitudes, definitions, understandings, and expectations of others. From the viewpoint of SI, the "Me" is the generalized other that controls or directs human behaviours (Mead, 1934). According to Mead (1934), "a generalized other could be individuals, social groups or sub-groups, the organized community, or social class" (p. 154). Generalized others are those who influence perceptions of human beings, specifically their attitudes and behaviours (Charon, 2010). Generalized others arise out of social interaction. The concept is complex because human beings have more than one single generalized other and the attitude of each generalized other is similar to the attitudes of the community. As a result, the generalized other is considered "Me" because human beings are able to control their behaviours from the standpoint of generalized others (Charon, 2010; Mead, 1934).

From the perspective of SI, the process of interaction in which a human becomes an object himself or herself is called "role taking" (Mead, 1934). As indicated by Mead, role taking involves imagining oneself as one is seen by others. Therefore, role taking involves seeing oneself from the standpoint of the generalized other (Mead, 1934). Taking the role of the other is an active process whereby the actor is able to take control of the situation in response to the act of the other, and allow more intelligent decisions for achieving goals (Charon, 2010).

Blumer (1969) identified three central premises of SI as they apply to the meaning of being human. These premises were: (a) human beings act toward things on the basis of the meaning the things have for them; (b) the meaning of things is derived from, or arises out of, social interactions one has with others; and (c) these meanings are handled in and modified through an interpretive process used by the person when dealing with things he or she encounters (Blumer, 1969). According to Blumer (1969), there are three types of objects; physical objects, such as a hospital or bed; social objects, such as a patient or nurse; and abstract objects, such as moral principles and ideas. Meanings of objects are the product of social interactions between human beings. In other words, human beings interact socially with each other based on the social meaning of various objects (Charon, 2010). According to Charon (2010), meanings are interpreted through shared language and communication. As stated by Crotty (1998), any situation must be seen from the actor's perspective, and the meaning of objects and actions must be determined in relation to the actor's definitions.

In the second premise, Blumer claimed that meanings arise through the process of interaction between and among individuals, which involves an interpretative process. This interpretative process has two distinctive steps: indicating and communicating. Initially, the individual who possesses a self must indicate or comprehend what she or he is acting toward. This involves considering its relevance or importance to their line of action and then communicating as the actor "selects, checks, suspends, regroups and transforms the meanings in light of the situation in which he is placed and the direction of his action" (Blumer, 1969, p. 5). Through social interaction, human beings become aware of what others are doing or what they are willing to do. In turn, humans fashion their behaviour according to the behaviours of others with whom they interact in a process called “joint action” (Blumer, 1969, p. 17).

Blumer’s (1969) third premise is that these meanings are handled in and modified through an interpretive process. There are no permanent meanings to social objects; instead, these meanings are constantly changing as they are defined and redefined through human interactions (Charon, 2010). As a result, the definition of an object varies from one social group to another, depending on their use of the object. Blumer (1969) stated that the meaning of an object arises from the way that human beings prepare themselves to act toward symbols; moreover, human beings define objects based on the type of action they are planning to take toward themselves in particular situations to accomplish goals. Humans may change the objects according to their changing goals (Charon, 2010). Therefore, meaning is not inherent to the object (Blumer, 1969); the meaning of objects change because individuals change their definition of the object, not because the object itself has changed (Charon, 2010). Thus, SI provides a mechanism through which we can understand the basis of meaning, how this meaning is handled by humans through internal communication processes, and how meaning plays a central role in the processes of self-interpretation and interpretation of others.

The implications of the aforementioned key concepts of SI are exemplified in Charon’s (2010) five central ideas of SI, which state that: (a) the human actor is a social being in ongoing and lifelong interactions with others and their world; (b) the human actor is a thinking being involved in constant conversation with oneself as they interact with others and their world; (c) the human actor defines the situation they are in through ongoing social interaction and thinking; (d) human action is a product of what is occurring in the present situation; (e) the human actor is an active being in the environment. It is necessary to account for an individual’s social context when studying the meaning that they attribute to their thoughts and actions, as meaning is constructed, maintained, modified, and challenged in a “localized process of social interaction” (Blumer, 1969, p. 19). As Charon (2010) states, “symbolic communication between actors is obviously most successful when both the communicator and the receiver have the exact meaning” (p. 52). Blumer and Mead’s ideas reflect the complex nature of social reality in which individuals piece together their activities as they engage in daily social interactions. These conceptualizations highlight some of the theoretical perspectives that guided this research and its methodology.

Symbolic Interactionism in Understanding ACP. This study was inspired by the central principle of SI, whereby “we can understand what is going on only if we understand what the actors themselves believe about their world” (Charon, 2010, p. 187). Blumer (1969) supported this point in stating that:

> The contention that people act on the basis of the meaning of their objects has profound methodological implications. It signifies immediately that if the scholar wishes to understand the actions of people, it is necessary to see their objects as they see them. Failure to see their objects as they see them or a substitution of his or her meaning of the objects for their meanings, is the gravest kind of error that the social scientist can commit (p. 51).

Denzin (1971) indicated that, in order to understand how others define reality, it is necessary to interpret the acts of others from their perspective rather than our own; that is, not according to our own scholarly interpretation but from the others’ own socially based interpretation. It is important to understand the definitions actors give to their actions, even if doing so means simply asking them for “retrospective accounts of past actions” (Denzin, 1971, p. 167).

These perspectives of SI were utilized in the current research to explore the nurse's individual views and comprehension of ACP, using intensive individual interviews. This process served to acknowledge each nurse's unique experiences with ACP. Knowledge was constructed in a process of social interchange between the nurses and researcher during the interactive interview process. The nurses' individual voices, views, and experiences are reflected in the data. In this study, theoretical understanding of the ACP process was achieved by understanding the nurses' beliefs, feelings, and experiences about ACP.

Blumer's (1969) three premises, along with Mead's (1934) concept of self and taking the role of the other, were well suited for exploring and understanding ACP on a micro-level; in this study, the micro-level was the individual nurse. Advance care planning is a social process based on communication and interaction between the nurse, the resident/family, and other members of the healthcare team (Brinkman-Stoppelenburg et al., 2014). The use of SI allowed the current research to explore how the process of action and interaction occur among these actors through their symbols. In SI, individuals are viewed as agents of change who create meaning through their interactions, rather than as passive recipients of sociocultural determinants and values (Charon, 2010). According to Crotty (1998), the central notion of SI is "the putting of oneself in the place of the other" (p. 75).

Mead (1934) referred to the interaction between individuals as a social process. He described communication as the act of making a declaration, through the use of symbols or words that have common meaning to another individual or group of individuals. Mead (1934) and Blumer (1969) believed that human beings respond to a particular situation based on their interpretation of the situation rather than how the situation is objectively presented to them. Therefore, understanding how humans define a particular situation can allow us to more fully comprehend why they behave as they do in that situation. Symbolic interactionism provides a perspective for studying how individuals interpret objects and other people in their lives, and how this process of interpretation guides behaviour specific situations (see Appendix F).

Symbolic interactionism assumes that realities exist for human beings in a world of shared symbolic meanings. In this qualitative study, individual nurses were interactively linked with the researcher in a mutual relationship to understand the nurses' perspectives of the ACP process in the natural field (Aldiabat & Le Navenec, 2011; Charmaz, 2014). Symbolic interactionism served as a guiding framework to collect data about the meaning of a particular type of behavior (in this case, ACP) and the contextual sources of such meaning from the nurses' own experiences (Aldiabat & Le Navenec, 2011).

Research questions from the SI perspective emphasize process rather than structure. Researchers who utilize this perspective are not only concerned with knowing the individual's point of view, but seek to understand the processes by which the points of view develop (Benzies & Allen, 2001; Burbank & Martins, 2010). These processes are significant because symbolic interactionists view human behaviour as a dynamic process in which individuals are continuously defining and interpreting each other's acts. To understand human behaviour, such as engagement in ACP, it is important to understand how behaviour is redirected and transformed by the process of definition and interpretation. In this study, SI assisted the researcher to focus on how nurses ascribe meaning to ACP and engage in the process of ACP, which occurs within a dynamic relationship of various factors, including knowledge of ACP, understanding of disease processes, and quality of the nurse-resident/family relationship. The use of SI allowed the researcher to focus on understanding nurses' points of view about ACP, while also examining the process through which they developed these perspectives. Symbolic interactionism also allowed the researcher to attend to nurses' individual experiences and understandings of situations, thereby facilitating an understanding of the meaning that nurses ascribe to ACP (Aldiabat & Le Navenec, 2011; Charmaz, 2014).

Symbolic interactionists view interpersonal interactions as a key component of developing personal meaning about situations and constructs of reality (Charon, 2010). Although SI can be useful when trying to understand the social process of ACP (Oliver, 2012), it is important to acknowledge that no one can really understand what is happening in the mind of another, except through that person's vocal and physical behaviour (Strauss, 1965). As stated by Crotty (1998), "for qualitative research SI is a diversified and enriching matrix" (p. 78).

Although SI focuses on the individual's interpersonal interactions with other human beings, it does not address the structural or cultural factors that shape those interactions. As a result, SI has been criticized as a micro-perspective that focuses mostly on the individual level and fails to recognize the objective restraints of social actions placed on individuals, such as power and culture. In this perspective, society is defined as a thing that exists only in the minds of people, and is largely deprived of real social vision (Aksan et al., 2009; Burbank & Martins, 2010). Symbolic interactionism sees society as a framework for interactions rather than as a determining structure, and is less concerned with the structure of society than its subjective meaning (Milliken & Schreiber, 2012). This perspective does not help to address the macro issues of ACP, such as organizational culture, that may influence the nurses' experiences with ACP.

Socio-Ecological Model

The SEM was first introduced in the 1970s as a conceptual model and was later formalized as a theory in the 1980s by Urie Bronfenbrenner (Stokols, 1992). Bronfenbrenner's

(1994) systems theory incorporates three levels of environmental influences on human behaviour: (a) the microsystem, or interactions among family members and work groups; (b) the mesosystem, including the physical family, school, and work settings; and (c) the exosystem which is the larger social system of economics, culture, and politics. McLeroy et al. (1988) built on the work of Bronfenbrenner and offered five levels of influence specific to health behaviour: intrapersonal, interpersonal, institutional, community, and policy/societal. Simons-Morton et al. (2012) added two additional levels of influence: culture and physical environment.

The SEM is a set of theoretical principles for understanding, exploring, and addressing the determinants of health at many levels as well as for understanding the dynamic interrelationships between personal and environmental factors. This model encourages shifting the focus beyond individual behaviour toward an understanding of the wide range of factors that influence health outcomes. This model assumes that, not only do multiple levels of societal influence exist, but that these levels are interactive and reinforcing (McLeroy et al., 1988; Simons-Morton et al., 2012). The SEM is usually conceptualized as concentric circles or layers that reflect direct and indirect effects on people's behaviours. The innermost section is the individual or intrapersonal level, which is surrounded by the interpersonal, organizational, community, public policy, culture, and physical environment levels (Simons-Morton et al., 2012) (see Appendix G).

The intrapersonal level is the most specific level of influence on health and health-related choices, and includes individual attitudes, beliefs, knowledge, behaviour, and skills (McLeroy et al., 1988). The interpersonal level refers to the influence of formal and informal social networks and social support systems, including family, colleagues, and friendship networks, on health and health-related choices. The organizational level refers to social institutions with organizational characteristics, along with the formal/informal rules and regulations that govern their operation; examples include organizational culture and structure as well as management styles and communication networks. Community refers to the mediating structures or primary face-to-face groups to which an individual belongs, and incorporates the various relationships that exist among institutions/organizations (McLeroy et al., 1988). Public policy is not technically a societal level of influence but a social structure that includes policies and laws at the local, state, and federal levels. When policies are developed, an essential outcome may be an increase in public awareness of community health issues (McLeroy et. al., 1988; Simons-Morton et al., 2012).

Culture is significant to individual health-related choices, and can affect health and health practices in a variety of ways. For instance, culture can influence how individuals think and talk about health problems and how a person takes actions to address health issues (Simons-Morton et al., 2012). Bronfenbrenner (1994) argued that the larger social system can affect individuals and settings through shared cultural norms, values, and religious beliefs. The larger social system refers to the overall patterns of ideology and organization that characterize a given society or social group. Similarly to public policy, physical environment is not a societal level of influence but an important factor that can be addressed at many societal levels (Simons-Morton et al., 2012).

Socio Ecological Model for Understanding ACP. The theoretical perspectives of SEM can aid in the understanding of ACP as a health behaviour, determined by a set of interconnected individual and contextual factors. In this study, SEM helped identify future interventions that could be targeted at different levels of influence to ensure successful engagement in ACP. This model recognizes that ACP practices are influenced by multiple levels and that these levels are interactive and reinforcing. By identifying the barriers and facilitators of ACP at different levels, the researcher was able to focus her attention on the levels that should be targeted in future interventions. In addition, SEM has a broader focus than SI, and includes organizational, cultural, social, and contextual factors rather than exclusively focusing on individual factors.

In order to understand the barriers and facilitators of ACP in the context of LTC, it is critical to examine the joint influence and interactive effects of societal factors on ACP. According to Stokols (1992), health promotion strategies must be tailored to the unique sociocultural and environmental contexts of particular groups and communities. Stokols recommended SEM for researchers who are interested in understanding the influence of cultural, social, and contextual factors on ACP in any population. Stokols (1992) also indicated that SEM can be used as a framework to guide research and development of appropriate strategies that promote ACP at each societal level. Therefore, knowledge of each societal level of influence can be used to develop socially and culturally appropriate policies and strategies that may improve the uptake of ACP in LTC.

According to McLeroy et al. (1988), there are significant ethical concerns related to applying the SEM approach to behaviour change. Policy approaches, such as mandating discussions of ACP with residents and families upon admission to LTC, may be viewed as restricting individuals' rights and freedoms. Programs that reimburse or incentivize healthcare providers to engage in discussions about ACP with residents/families or attend ACP education sessions could be viewed as coercive. Mass media approaches or educational materials that promote ACP could also be considered coercive, especially if they appeal to people's emotions. Organizational support for ACP from professional associations could be viewed through a paternalistic ideology lens. This is especially true in physician-dominant care settings, where the notion is that healthcare providers know what is best for the patients, thereby diminishing the patients' autonomy and self-determination (Sullivan & Dickerson, 2016). McLeroy et al. (1988) indicated that the appearance of coercion and paternalism could be minimized by promoting consensus building and actively involving the target group in the intervention planning stage.

In summary, the micro perspective of SI explains how social interactions influence human behaviour (Charon, 2010). Conversely, the macro perspective of SEM seeks to understand the multifaceted and interactive effects of personal and environmental factors on human behaviour (Bronfenbrenner, 1994). This research used a broadened philosophical framework and dual lens of SEM and SI to examine key concepts and ideas. This dual lens allowed the researcher to view nurses' perspectives and experiences about ACP from both a micro and macro perspective.

Methodology

Methodology is defined as "the strategy, plan of action, process or design laying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes" (Crotty, 1998, p. 3). As noted in chapter one, this qualitative research aimed to develop an understanding of the process of ACP undertaken by nurses working in LTC facilities. Qualitative research seeks to describe and understand participants' experiences, attitudes, opinions, and social interactions (Denzin & Lincoln, 2005). Broadly speaking, qualitative research endeavors to study phenomena in their natural settings, using a range of strategies. Qualitative research strategies are most appropriate when endeavoring to understand social behaviour and the underlying explanations of that behaviour (Creswell, 2007). Parahoo (2006) supported this view by stating that "qualitative research is appropriate when studying the experiences and perceptions of participants and it is inductive, interactive and holistic" (p. 63).

Gaining new understandings through interactions with the research participants was at the heart of this research from the outset.

The aim of this study was to develop a GT to provide insight and understanding of nurses' experiences with ACP. As a result, emphasis was placed on the processes and patterns of behaviours/actions involved in ACP experiences. A qualitative strategy was best suited for this research, as it sought to develop a conceptual understanding of the ACP process from the perspective of the nurses. Since there are many qualitative methodologies available, the challenge was to choose the most appropriate methodology (Farrelly, 2013). After exploring various modes of research inquiry, GT was chosen over other qualitative methodologies as the best means of achieving the objectives of this study. The following sections describe the origin and evolution of GT methodology, the various approaches to GT research, the respective strengths and limitations of each approach, and the rationale for selecting the particular GT methodology used in this study.

Origin and Evolution of Grounded Theory Methodology

Grounded theory methodology was originally developed in the 1960s by American sociologists Barney Glaser and Anselm Strauss as an alternative to the hypothetical-deductive tradition of that time (Charmaz, 2006, 2014; Glaser & Strauss, 1967). This methodology was derived from a melding of Glaser's quantitative research at Columbia University and Strauss' pragmatism and field research at the University of Chicago (Charmaz, 2006; Glaser & Strauss, 1967). In 1965, while Glaser and Strauss were working as sociology professors at the University of California, they collaborated on a research study on dying hospital patients and published their first GT study: *Awareness of Dying* (Glaser & Strauss, 1965). Based on this study, Glaser and Strauss published their first book on the GT method in 1967, titled *The Discovery of Grounded*

Theory. This book emphasized the notion of generating new theory from data as opposed to testing existing theory. Glaser and Strauss (1967) posited that the researcher interacts with participants and strives to interpret their social world, and provided the structure for the first GT methodology (Kenny & Fourie, 2015; Schreiber & Stern, 2001).

Following the initial methodology developed in 1967, Glaser and Strauss independently expanded GT in their own ways. The divergence of the original GT led to the formation of Classic GT (CLGT), based on Glaser's original and subsequent work. Strauss reformulated the methodological procedures of the original GT and incorporated new analytical tools. In 1990, Strauss co-authored the textbook *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* with Juliet Corbin and, subsequently, developed the Straussian grounded theory (SGT). Cathy Charmaz, a sociologist and former student of both Glaser and Strauss, developed CGT a decade after the birth of SGT. She published her first book in 2006, titled *Constructing grounded theory: A practical guide through qualitative analysis* (Charmaz, 2006).

General Features and Central Concepts of Grounded Theory Methodology

Grounded theory provides guidelines for the simultaneous collection and analysis of data to develop theories grounded in real life experiences (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1994). Creswell (2013) expanded on this idea by stating that the data from the participants are grounded "especially in the actions, interactions and social processes of people" (p. 83). As a result, the researcher generates a "general explanation (a theory) of a process, an action or an interaction shaped by the views of the participants" (Creswell, 2013, p. 83). Corbin and Strauss (2008) claimed that GT provides a "unified theoretical explanation for a process" (p. 107). In this methodology, theories are derived from the data instead of testing extant theories

(Bryant & Charmaz, 2007a; Charmaz, 2006). Thus, GT enables researchers to achieve an abstraction without completely sacrificing context and complexity (Bryant & Charmaz, 2007a; Hunter et al., 2010). The main tenet of GT is the process of iterative conceptualization rather than description (Bryant & Charmaz, 2007a). Grounded theory incorporates proven principles and procedures, such as inductive and abductive reasoning, constant comparative analysis, theoretical sampling, theoretical saturation, theoretical sensitivity, and theoretical memo writing (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1994).

Constructivist Grounded Theory (CGT) is the first GT approach to clearly describe abductive reasoning, which is the iterative process of the researcher moving back and forth between data and conceptualization, as a key part of data analysis (Charmaz, 2009). Abductive inference entails “considering all possible theoretical explanations for the data, forming hypotheses for each possible explanation, checking them empirically by examining data, and pursuing the most plausible explanation” (Charmaz, 2006, p. 104). Timmermans and Tavory (2012) referred to “abduction as an inferential creative process of producing new hypotheses and theories based on surprising research evidence” (p. 170). With abductive analysis, a researcher is led from old to new theoretical insights (Timmermans & Tavory, 2012), which can be seen in the GT strategies of theoretical sampling and constant comparison.

Constant comparative analysis is a fundamental technique of GT. When using the constant comparative method of analysis, data collection, coding, and analysis occur simultaneously (Glaser & Strauss, 1967). This method allows the researcher to move back and forth within the data, and change focus to pursue new leads as they are revealed through ongoing data analysis (Glaser & Strauss, 1967). According to Creswell (2013), data analysis in GT is a “zigzag process: out to the field to gather information, analyze the data, back to the field to gather more information, analyze the data, and so forth" (p. 86). Each round of data collection is conditioned by what has been learned in the preceding round of data analysis. This "data dance" (Strass & Corbin, 1998, p. 22) proceeds recursively so that theory is progressively refined until a point of theory saturation is reached. The concurrent data collection, analysis, and emergence of theory in GT gives clear direction for further data collection and exploration of the research phenomena (Glaser, 1978; Glaser & Strauss, 1967). If there are gaps in the evolving theory, these are identified and addressed through a further round of data collection; if not, a point of theoretical saturation is said to have been reached. At this point, normal practice is to state the theory produced and position it within the literature.

Constant comparative analysis continues for the duration of the GT research. Constant comparison develops ideas that are successively more abstract (Charmaz, 2009; Glaser, 1978; Polit & Beck, 2012) by comparing "data with data, data with category, category with category, and category to concept" (Bryant & Charmaz, 2007b, p. 607). Constant comparative methods rely on both inductive and abductive logic (Birks & Mills, 2011). Abductive logic is increasingly used in the comparisons as they become more abstract, such as when the researcher compares categories to data or categories to categories during theoretical coding (Birks & Mills, 2011). The researcher begins with the coding of incidents that lead to the emergence of categories and their properties, and finishes with the theoretical codes that connect the categories. This means that all data collected over the course of the research has been compared and analyzed, and that the theory that emerges is a true reflection of the data and study participants (Glaser, 1978, 1992).

The constant comparative method and theoretical sampling are inextricably linked in GT (Glaser & Strass, 1967); constant comparison requires theoretical sampling to enable comparison of factors and explication of their relationship to the process being investigated (Dey, 2007). Theoretical sampling is concerned with deciding what data to collect next and where to find the required data. The term theoretical sampling "means sampling for development of a theoretical category, not sampling for population representation" (Charmaz, 2012, p. 3). In this method of data collection, the data is led by the emergent theory. Theoretical sampling saturates categories and establishes relationships between categories in the later phases of data collection (Glaser & Strass, 1967). Glaser (1978) defined theoretical sampling as:

> The process of data collection for generating theory whereby the analyst jointly collects, codes and analyses the data and decides what data to collect next and where to find it in order to develop the theory as it emerges; this process of data collection is controlled by the emerging theory (p. 36).

Therefore, theoretical sampling only seeks out relevant data that will advance and add density to the emergent theory. Theoretical sampling is concept driven and enables researchers to discover the concepts relevant to the participants' problem, so researchers can explore these concepts in more depth. Theoretical sampling occurs after the initial data collection and analysis has been completed (Charmaz, 2014; Corbin & Strauss, 2008; Glaser & Strauss, 1967).

Theoretical saturation means that no additional data are being found whereby the researcher can develop properties of the category (Glaser & Strass, 1967). Strauss and Corbin (1998) noted that "saturation is more a matter of reaching the point in the research where collecting additional data seems counter-productive; the 'new' that is uncovered does not add that which more to the explanation at this time" (p. 136). Theoretical saturation is achieved through constant comparison of incidents in the data until further coding and comparison produces no new properties or dimensions (Dey, 2007). Theoretical saturation occurs in data collection when: (a) no new or relevant data seem to emerge regarding a category; (b) the category is well developed in terms of its properties and dimensions, with demonstrated variations; and (c) the relationships among categories are well established and validated (Glaser, 1978; Strauss & Corbin, 1998).

Theoretical sensitivity is initially used to sensitize the researcher and involves entering the field with an awareness of the subtleties of the data (Glaser, 1978). Theoretical sensitivity relates to the ability to have insight, understand, and give meaning to the data, while detaching the relevant from the irrelevant (Strass & Corbin, 1998). Charmaz (2014) defined theoretical sensitivity is the "ability to understand and define phenomena in abstract terms and to demonstrate abstracts relationship between studied phenomena" (p. 161). Although guiding interest, extant theories, personal experiences, and disciplinary perspectives can develop theoretical sensitivity in GT (Charmaz, 2006), this contribution needs to be balanced with reflexivity to ensure that the researcher is not forcing the data with preconceived ideas (Kelle, 2005).

The use of memos is fundamental to GT. Theoretical memos are the building blocks for theory generation and serve as a reflective process that enables the researcher to analyze and make meaning of the data (Mills et al., 2006). Memos allow the researcher to document their ideas, thoughts, hunches, questions, emergency hypotheses, and analytical schemata in real time (Glaser, 1978), so the researcher can keep track of the emerging theory.

Brief Review of the Different Schools of Grounded Theory Methodology

Epistemology and Ontology. Glaser and Strauss's seminal classic GT textbook was mainly focused on methods and virtually silent on the questions of epistemology and ontology. As a result, CLGT's philosophical positions have remained ambiguous (Kenny & Fourie, 2015;

Urquhart, 2002). Charmaz (2000) addressed this ambiguity and argued that Glaser and Strauss's title '*The Discovery of Grounded Theory'* had an epistemological orientation, which assumes reality can be discovered, explored, and understood. As such, CLGT is closely related to the positivist realist ontology, which assumes that an external reality exists independent of the human mind (Crotty, 1998). The features of CLGT are consistent with objectivist epistemology, such as separating the data and the observer, valuing a neutral expert observer, giving priority to researcher's analytic categories and voice, developing context-free generalizations, and parsimonious abstractions from a particular time, place and situation (Charmaz, 2014; Glaser & Strauss, 1967; Mills et al., 2006). Charmaz (2000) placed CLGT at the objectivist pole of the objectivist-constructivist continuum.

Strauss and Corbin located their SGT with pragmatism and SI and favored post-positivism (Kenny & Fourie, 2015). They took a middle ground in terms of objectivity and acknowledged that the researcher cannot possibly explore a problem without any pre-conceptions. They advised that the researcher try to stay as objective as possible in their interpretations (Mills et al., 2006). Numerous evolutions have occurred in SGT over the years, from post-positivist (Strauss & Corbin, 1994) to constructivist (Corbin & Strauss, 2015).

In contrast to CLGT and SGT, Chramaz (2000) positioned CGT explicitly with the constructivist relativist ontology. Constructivists believe that truth exists only through interactions with the realities of the world, whereby meaning is constructed rather than discovered (Crotty, 1998). The features of CGT are consistent with subjectivism epistemology, including the notions that subjectivity is used throughout data analysis; knowledge is co-created; the researcher is not separate from the research; the research needs to take a reflexive stance toward the research process and products; participants' meanings and actions need to be located;

and the connections between micro and macro levels of analysis can be shown by linking the subjective and the social (Charmaz, 2014). Mills et al. (2006) argued that all variations of GT exist on a methodological spiral and reflect their epistemological underpinnings. Along with Charmaz (2014), Mills et al. (2006) positioned CGT at the opposite end of the objectivist-constructivist continuum when compared to CLGT.

Role of the Researcher. The classic GT approach requires that the researcher be objectively detached and argues that the researcher must prevent any preconceived theories from dictating the research process (Glaser & Strauss, 1967). Conversely, SGT sees the researcher as being actively engaged with the research in an attempt to better describe and understand the world through the participants' perceptions (Corbin & Strauss, 2008). In the CGT approach, the researcher is a co-creator of knowledge and influences the research by interacting with the participants and data. However, Charmaz asserted that the researcher must remain reflective and not force their preconceived ideas on the data (Charmaz, 2006, 2014).

Rationale for Selecting Grounded Theory Methodology

Glaser (1992) stated that GT is well suited to discover participants' problems and generate an appropriate theory to process the problem. Over two decades ago, Singer et al. (1998) conceptualized ACP as a social process rather than just the completion of a document. Moreover, Prince-Paul and DiFranco (2017) stated that ACP is a public health issue, while Jong-Wook (2005) labelled public health as a social issue. A social issue or social problem refers to an issue that influences a considerable number of individuals within a society (Bryant, 2009). While ACP is a social issue that affects everyone in the healthcare sector, it is of particular importance to residents in LTC settings (Cantor & Pearlman, 2003; Prince-Paul & DiFranco, 2017; Robinson et al., 2013).

The decision to adopt GT as a methodology for this study was based on a number of factors. First, a literature review suggested that there was a dearth of information on ACP from nurses' perspectives, especially in the Canadian context. Grounded theory methodology is appropriate to use when there is little knowledge of a theory or when an existing theory offers no solution to the problem (Charmaz, 2006). Second, the main goal of this study was to develop a theoretical understanding of the patterns and processes of ACP undertaken by the nurses. This goal could only be achieved through GT methodology, which generates an inductive theory grounded in empirical data (Glaser & Strauss, 1967). Third, GT was a useful methodology to study the interpersonal activities between nurses, patients, and others, especially given that social interaction is at the heart of the caring process in nursing (McCann & Clark, 2003). Last, but extremely significant, GT methodology provides tools that reveal the links between concrete experiences of social structure, culture, and social practices or policies (Charmaz, 2000; Glaser & Strauss, 1965). The GT methodology was well placed to address the micro and macro dimensions of a social problem (Simmons & Gregory, 2003). The focus of this research was to understand the actions and interactions of social factors that affect ACP in LTC. Grounded theory captures the complexities of the context in which action unfolds, enabling the researcher to better understand all that may be involved in a particular substantive area (Hunter et al., 2010).

Of the three existing versions of GT methodology, CGT was the chosen approach for this study. First, the purpose of this study was to develop a theoretical understanding of the ACP process, based on the interpretations of the researcher and the nurse participants (Charmaz 2014). Second, the process of ACP is complex and multifaceted, so theoretical understanding should incorporate multiple diverse realities (Charmaz, 2014). Nurses working in LTC settings have diverse and heterogeneous perspectives and, thus, may have different constructions of realities when engaging in ACP. Third, CGT assumes that new knowledge is socially and culturally produced through interactions among participants, and the researcher engages in an inquiry process that creates knowledge through interpreted constructions (Barnett, 2012). The researcher's background in constructivist epistemology and relativist ontology (i.e. the social construction of knowledge with multiple realities) are well aligned with CGT. Fourth, CLGT characterizes the researcher as a tabula rasa who constructs inquiry without prior views and values (Dunne, 2011). By contrast, CGT acknowledges the researcher's prior experience, privileges, positions, professional knowledge, and theoretical knowledge on the research topic (Charmaz, 2014). The researcher in this study worked as an NP in LTC, meaning that she had a high degree of familiarity with the socio-political context of LTC and the processes and practices around ACP. She had daily involvement in ACP while working in LTC and had developed strong relationships with other nurses in the facility. The CGT approach allowed the researcher to incorporate her prior experiences in both the data collection and analysis phases of this study. It would have been an unattainable task for the researcher to avoid preconceived ideas or influences in the research process. The researcher embraced Charmaz's (2014) position that "the theory depends on researcher's view; it does not and cannot stand outside of it" (p. 239). Moreover, Charmaz (2006) stated that "neither data nor theories are discovered. Rather we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices" (p. 10).

Fifth, CGT facilitates reciprocity with the participants through partnership and reflexivity. The flexibility of CGT procedures facilitates the researcher's creativity so they can properly elucidate participants' voices (Charmaz, 2014). In the current study, this feature of CGT afforded the researcher with the opportunity to partake in the interpretation of realties constructed by the nurses and act as a “passionate participant” (Lincoln & Guba, 1985, p. 17). As such, the researcher was able to more authentically engage with the nurses and gain a richer understanding of their worlds. The CGT approach requires that the researcher establish relationships with participants to explicate and attempt to modify power imbalances (Hussein et al., 2014). Finally, the flexible guidelines of this approach facilitated the flow of the researcher’s imagination, which may have been impeded by more prescriptive approaches to GT work.

Summary

This chapter provided a description of each element of the research paradigm used in this study, specifically in relation to ontology and epistemology, theoretical perspectives, and methodology. This section also provided justification for the selection of a CGT methodology for this study. The constructivist epistemology and relativist ontology were well aligned for understanding the nurses’ subjective experiences of undertaking ACP in LTC. In addition, the synergistic theoretical approaches of SEM and SI helped facilitate a broader perspective and understanding of ACP at the micro-and macro-levels. The next chapter provides a detailed discussion of the research method used in this study.

Chapter 4: Research Methods

Methods are the “techniques used to gather and analyze data” (Crotty, 1998, p. 3) that flow from and are congruent with the researcher’s choice of epistemology, ontology, theoretical perspectives, and methodology; in this study, these are constructivism, relativist, SI and SEM, and CGT, respectively. Constructivist grounded theory has unique, flexible, and well-defined methods that were utilized in this study (Charmaz, 2006, 2014). This chapter provides a discussion of the research method in terms of: (a) study setting; (b) sample, sampling strategies, and recruitment procedures; (c) data collection and analysis; (d) ethical considerations needed for the study; and (e) measures taken to enhance the trustworthiness of the study.

Study Setting

The study was carried out in one regional health authority in the province of Manitoba: the Winnipeg Regional Health Authority (WHRA). This particular regional health authority was selected because, for more than two decades, it has had a very active policy addressing the process of ACP. According to the policy, healthcare providers should initiate ACP whenever future treatment options or GOC need to be considered or revised, whether care is being provided in a hospital, LTC facility, or in the community (WRHA, 2011). There are 39 LTC facilities in Winnipeg that provide personal care/health services to more than 5,700 individuals (WRHA, n.d). The average age of a Winnipeg LTC resident is 85 years old. According to the CIHI (2020a), more than 60% of LTC residents have dementia and one in three have some form of aggressive behaviour. The sizes of Winnipeg’s LTC facilities range from 50 to 400 beds. The nursing staff in these facilities include RNs and licensed practical nurses. Most of the medical care is provided by general practitioners who specialize in family medicine; in a few facilities, medical care is provided by NPs. General practitioners visit the facilities for about one to two hours once a week. If medical care is required at any other time, nursing staff contact the physician or NP; most of the time, interventions that direct residents' care are provided through phone communication without direct assessment by the general practitioner (J. Puchniak, personal communication, March 6, 2019).

Study Sample and Sampling Strategy

The sampling strategies used in this study included nonprobability, purposive, maximum variation, and theoretical sampling techniques (Strauss & Corbin, 1998). The sample was composed of RNs and licensed practical nurses employed in LTC facilities in Winnipeg. As suggested by Davoudi et al. (2016), purposive sampling can be used to locate a setting and a person who can provide a rich source of information. Polit and Beck (2014) further noted that purposive sampling can be used to obtain multiple views from participants who have different backgrounds and experiences. According to Charmaz (2006), sampling for GT begins with purposive sampling so that the researcher can interview participants with specific characteristics.

During the purposive sampling process, nurses were recruited and eligible to participate in the study if they: (a) had at least three months of experience working as a nurse in the LTC facility being sampled; (b) were able to speak and understand English; (c) had participated in ACP at the facility being sampled at the time of data collection and/or within the six months prior to data collection; and (d) were willing to volunteer and consent to participate in the study. The rationale for including only those with three months of experience as a nurse in LTC was based on the assumption that this time frame would have enabled them to become familiar with ACP protocols. It was assumed that nurses who worked at least three months in LTC would have experience engaging in ACP and providing ACP support to residents/families. To achieve maximum variation, nurses were recruited from LTC facilities with different characteristics, such as: faith-based or secular; for-profit or not-for-profit; board of directors or WRHA management; standalone or attached to a healthcare facility; and those with varied bed numbers. This variation in the sample provided rich sources of information that contributed to and challenged the emerging conceptual categories (Charmaz, 2006; Charmaz, 2014; Polit & Beck, 2012). During data collection and analysis, casual nurses' challenges with ACP emerged; unfortunately, it was not possible to recruit casual nurses to affirm this assertion due to the single-site staffing model in place for the COVID-19 pandemic.

Maximum variation sampling entails seeking out and examining cases that vary from what has been observed. This technique ensures that the emerging theory is sufficiently robust and up to the task of explaining variant findings. Collecting a rich variety of accounts helps to create a more robust and complete explanatory theory, as does the confirmation of one finding by another (Creswell, 2013). Using maximum variation sampling, nurses from facilities with different characteristics were confirmed and the initial categories of performing CPR were further elaborated. Provision of CPR varies from facility to facility. For example, facilities that were for-profit, faith-based, or attached to health centres allowed facility staff to provide CPR on-site, whereas other facilities required staff to call 911 for the provision of CPR and had policies that prevented nursing staff from performing CPR on residents who were resuscitative level advance care plan (ACP-R). Nurses were recruited from a variety of settings to understand their experiences of CPR on residents who chose ACP-R.

Although initial sampling for this CGT study was purposive, there was a need to illuminate, elaborate, and/or confirm the developing categories through theoretical sampling. Theoretical sampling involves the recruitment of additional people or other sources of data to define and develop the emerging theoretical ideas (Charmaz, 2006, 2014). Theoretical sampling was used in both the early and late stages of this research study to initially develop preliminary categories and later demonstrate links between categories (Charmaz, 2006). Based on the initial interviews with nurses, the researcher noticed differences in the ACP practices of experienced, new, and internationally educated nurses. Nurses who could provide insight into that particular part of the experience were recruited to define the categories from the initial interviews.

Further theoretical sampling occurred when the theory started to take shape, at the stage when the researcher began to take coding to a more abstract and conceptual level (Charmaz, 2006). For example, when the analytic diagram that describes nurses' actions and processes started to take shape, the researcher had some niggling questions. According to Charmaz (2006), these questions represent the gaps in the research that still need to be addressed. One such question in this study was the nurses' experiences in conducting ACP with residents under the Public Guardian and Trustee (PGT); theoretical sampling was used to identify nurses who could provide more robust answers to this question.

Theoretical sampling strategies were also used to narrow the focus of data collection to the emerging categories, to saturate their properties, and define gaps in the data to identify the full range of nurses' experiences with the ACP process. In order to develop and saturate the properties of emergent categories, the researcher explored the nurses' views on multiple issues that elaborated the theoretical components of ACP, including: their perspectives on other healthcare providers' engagement in ACP; the cultural and religious factors that impact ACP engagement; and the support from management toward ACP discussions. All nurses who were approached to participate in the study were interviewed; a total of 25 nurses were interviewed through initial purposeful and then theoretical sampling. The participants consisted of: unit nurses (n=10); resident care managers (RCM) (n=9); directors of care (n=2); assistant directors of care (n=1); and clinical resource nurses (n=3).

In GT, sample size cannot be calculated at the beginning of the study. The sample size is determined by the concept of theoretical saturation (Charmaz, 2006; Strauss & Corbin, 1998). Multiple authors have suggested different sample sizes to reach saturation. However, Morse (2007) and Creswell (2007) suggested that a GT sample often involves 20 to 30 interviews. Furthermore, Charmaz (2014) wrote that “a study of 25 interviews can suffice for certain small projects but invites skepticism when the author’s claims are about, say, human nature or contradict established research” (p. 214). She also asserted that reaching saturation depends more on quality of data than on sample size (Charmaz, 2014). A review of GT studies on ACP decision making indicated that sample sizes for reaching saturation ranged from 10 to 26 (Macpherson et al., 2013; O’Hare, 2016; Rhee et al., 2013; Ryan & McKeown, 2020; Taneja, et.al, 2019). Guest et al. (2006) added that high levels of homogeneity allow for saturation to be achieved at sample sizes as low as six participants. In this study, the researcher noted that no new issues were emerging after interviewing 25 participants. In consultation with academic advisors, the researcher judged that theoretical saturation had been achieved. Throughout the analysis, the researcher recorded field notes and memos of her reflections regarding whether or not new properties of the category were emerging. This allowed the researcher to track when new issues ceased to emerge and saturation had been achieved.

Recruitment Procedure

After obtaining ethical approval from the University of Manitoba Research Ethics Board (see Appendix H) and the WRHA Research Access and Approval Committee (see Appendix I), the researcher arranged an initial meeting with the WRHA PCH director to discuss the nature and purpose of the study. In order to optimize the nurses' participation at different facilities, the researcher sought permission from the director to present a concise overview of the study as well as the nature of the nurses' involvement at one of their monthly Directors of Care (DOC) meetings. After obtaining permission from the WRHA and PCH director, study details were presented at a monthly DOC meeting (see Appendix J). The researcher used this opportunity to collect contact information from DOCs who were supportive of the study being conducted at their facilities; recruitment posters (see Appendix K) were provided to these DOCs to post at their facilities to recruit nurses for the study. With permission from the PCH director, LTC administrative personnel were tasked with sending the study details to the DOCs who were absent from the meeting, with a request to contact the researcher if interested. Directors of Care from 18 LTC facilities contacted the researcher with their interest in the study. The study details were subsequently presented at three LTC facilities (see Appendix L) to solicit nurse participation. At these meetings, it was explained to the nurses that participation would include an individual 60 to 90 minute, in-depth, semi-structured, face-to-face, audiotaped interview, along with the completion of a brief demographic questionnaire. Nurses who were interested in participating in the study were asked to fill out a form (see Appendix M) on which they recorded their telephone number, as well as a date and time they could accommodate the interview. Nurses were given the option of handing the form back to the researcher at the end of the information meeting or emailing the scanned sheet within a week to set up a mutually convenient date, time, and location for the interview. Nurses who agreed to participate in the study were asked to provide written informed consent (see Appendix N) and complete a socio-demographic questionnaire (see Appendix O) prior to commencement of the face-to-face interview.

Recruitment and data collection began in November 2019 and concluded in August 2020. There was a three month pause in face-to-face recruitment and data collection due to the COVID-19 pandemic. An amendment from the University of Manitoba Research Ethics Broad was sought to modify the recruitment procedure and data collection methods (see Appendix P), whereby DOCs were asked to post the study poster in their facilities' staff rooms so that nurses had access to study information; if interested, the nurses could contact the researcher as described on the poster. A total of 20 nurses were recruited this way. The researcher contacted all interested nurses to ensure they met the inclusion criteria. The researcher emailed the nurses a study package that included a form to obtain informed consent and a sheet asking for details to set up a telephone interview (see Appendix Q). Participants were also asked to provide their choice of electronic gift card.

Recruitment and sampling ended when theoretical saturation was noted, which is the criterion for stopping data collection in CGT (Charmaz, 2014). As the final interviews and analysis progressed, the categories identified in the data became more substantial, clear, and refined; at that point, it was deemed appropriate to stop the sampling, based on a variety of signals. As the researcher became increasingly certain about the central focused codes, the data was reexamined to find all available insights regarding those codes. Next, diagrams were drawn and were aided by the researcher's memos. The researcher endeavored to look for events or accounts not explained by the emerging theory, with the goal of developing it further and explaining all of the data. A pivotal point was reached when the researcher presented the developing theory to nurses who were not part of the study, but working in LTC, and found that it was accepted by and resonated with them. Dey (2007) suggested that the longer researchers examine, familiarize themselves with, and analyze their data, there will always be the potential for "the new to emerge" (p. 176). As a result, saturation should be more concerned with reaching the point where it becomes "counter-productive," and when "the new" (p. 176) data is not necessarily adding anything to the overall story, model, theory, or framework. Following Dey's (2007) advice, the researcher ceased sampling when theoretical saturation was deemed adequate.

Data Collection

According to Charmaz (2014), generating quality data often involves using multiple sources of data that can reveal interesting disparities, which can then be compared and contrasted to develop nuanced theoretical ideas. In order to generate GTs, Charmaz (2006) stressed the importance of gathering rich data that are detailed, focused, and full of the participants' views, feelings, interactions, and actions as well as the structures and contexts of their lives. This research study utilized four sources of data collection: a socio-demographic questionnaire; in-depth, semi-structured, audiotaped, individual face-to-face or telephone interviews; field notes; and memos. Socio-demographic information was collected to describe participants' characteristics, which enabled a rich description of the sample to promote transferability of the research findings (Polit & Beck, 2012).

Interviews are often a primary method for data collection in CGT (Charmaz, 2014). Furthermore, a social process encompasses a beginning and an end; this temporal data may be best collected through a narrative form that lets participants share events as they unfold (Morse, 2009). Therefore, this research used intensive interview methods for data collection. Charmaz (2006) described intensive interviews as "an in depth exploration of a topic with a person who has had the relevant experience" (p. 26). This approach enables participants to set their own agenda and talk about their own priorities on their own terms. Unlike a formally structured interview, the intensive interview possesses a more conversation-like quality and is purported to yield richer data that can be analyzed for tacit meanings. In an intensive interview, the interviewee talks to the interviewer; what they decide to share with the interviewer as they talk about relevant phenomena provides valuable insight into their values and assumptions, which may be more tacit in nature (Charmaz, 2006). Intensive interviewing involves attending very closely to what the interviewee is expressing, then formulating successive questions in response. Such intensity is only possible through a lengthy interview lasting about an hour, though it is incumbent on the interviewer to create an atmosphere conducive to divulging that which is personally meaningful (Charmaz, 2006).

In order to gather rich narrative descriptions of the ACP process, semi-structured interviews were conducted with consenting participants. A suitable date and time were negotiated with each participant for the face-to-face or telephone interview. Nurses were given the option to choose the location of their face-face interview; this was one way of limiting the possibility of a hierarchal relationship between the researcher and the nurses. Four nurses opted to have the interview at their workplace, during working hours, and one chose to be interviewed in the researcher's office. Due to the COVID-19 pandemic and public health orders, the remaining 20 interviews were conducted via telephone. All interviews were digitally recorded.

It has been argued that establishing rapport in the interview is crucial to enhancing the quality of information that emerges from the data. Charmaz (2006) stated "the interviewer is there to listen, to observe with sensitivity, and to encourage the person to respond" (p. 25). The researcher took the following steps to establish good rapport with the nurses: (a) prior to commencement of the interview, the researcher provided the nurses with background information about herself, explaining that she worked as an NP in LTC and often engaged in ACP discussions with residents/families; and (b) all participants were given the opportunity to raise any queries they had about the study and have any questions answered prior to commencing the interview. This sharing of information about the researcher’s background and the purpose of the interview served as ‘icebreakers.’ The researcher felt this background information was important to ensure honest and transparent communication with the nurses throughout the study. The nurses appeared more comfortable after this disclosure of information, which eased the transition into the interview.

In light of the COVID-19 pandemic and social distancing guidelines, telephone interviews were more practical for this study. According to Edwards and Holland (2013), telephone interviews are associated with lower costs, easier access, fewer ecological dilemmas, and less challenges when compared to face-to-face interactions. The main advantage of the telephone interview was flexibility; the location/time of the interview could be moved to ensure privacy of the conversation or for the convenience of either the nurse or researcher. Telephone interviews also reduced travel time for both the nurses and researcher. One problem with the telephone interviews was that there seemed to be a tendency to get to the interview topic quickly, which made the process seem less social and more formal. Other issues with telephone interviews were that interruptions were more common and it was not possible to read non-verbal cues; as a result, the researcher inadvertently spoke over the nurses when they occasionally paused for longer silences and had not yet finished speaking. To ensure the nurses knew the researcher was still present and listening, the researcher used a lot of filler sounds and words, including ‘um’, ‘ah,’ and ‘yes’. Overall, the quality of the telephone connection was good, and the researcher found the telephone interviews were generally shorter than those conducted face-to-face. The interviews lasted an average of 55 to 65 minutes.

Charmaz (2006) noted that novice researchers may benefit from using an interview guide, with thoughtful open-ended questions. She also recommended that questions should be chosen to foster participants' reflections on the specific phenomenon or process being studied (Charmaz, 2006). Thus, the researcher formulated a preliminary interview guide (see Appendix R) for this study. Initial interview questions were informed by CGT procedures (Charmaz, 2014), concepts from SI (Charon, 2010; Blumer, 1969), the SEM (Simons-Morton et al., 2012), ideas that emerged from the literature, and the researcher's own experiences with ACP in LTC facilities. As per Charmaz's (2006) recommendations, the questions were open-ended and designed to encourage participants to speak freely about what is pertinent in their minds at the time of the interview. Indeed, one of the reasons researchers use the inductive method is to avoid imposing prior ideas and, instead, focus on learning about participants' concerns. It is also important to take leads from the participant. In the interviews, nurses were given the freedom to speak about their concerns rather than having them simply respond to preset questions based on the researcher's prior concepts. The researcher opened the interview with the following broad statement to commence the discourse, '*I would like to know about your understanding of advance care planning,'* followed by the broad question: *In your role, how are you using ACP in your workplace?'*

The first five interviews were less focused, and the researcher relied more heavily on the interview guide for prompts during these interviews. Since this was a GT study, data collection and analysis were undertaken simultaneously. In GT research, questions evolve in subsequent interviews to reflect the emerging themes and categories in an ongoing analysis of the data (Glaser, 1992; Charmaz, 2014). In addition to the preliminary questions in this study, the researcher asked more explorative questions related to specific issues in the emerging themes. As the interview process progressed, interviews were conducted with other nurses. During subsequent interviews, the researcher used prompts and tentative categories identified in earlier interviews and initial data analysis to explore the tentative codes and categories in more depth. For example, subsequent interviews explored nurses' views regarding the involvement of other team members in ACP; support for newly hired nurses in ACP engagement; management support in ACP; and ACP discussions for residents under PGT. As the research progressed, the researcher became more comfortable allowing nurses to lead the interviews and discuss their experiences in their own ways. As a result, participants were able to freely share their own stories, even if this led to frequent divergence into other aspects of their lives. Sometimes this digression did not appear to be immediately relevant to the study questions, but later enhanced overall meaning. By letting participants describe their experiences at their own pace, and using subtle prompts to guide them, the researcher was able to gain a greater understanding of the meanings nurses associated with their experiences of ACP.

After each interview, nurses were given time for debriefing and were encouraged to talk about their feelings during the interview and ask any questions they had about the study/interview process. The researcher took this opportunity to ensure the nurses were fully informed about the study. The researcher thanked the nurses for their participation and ensured they had the appropriate contact information for the researcher, her advisors, and the ethics review board. Each interview was closed by asking if the nurses wished to add anything to what they had already shared; no additional information was received at the end of the interviews.

All individual interviews were audiotaped with two digital recorders. The recording with the best sound quality was retained and downloaded into a secure data system for confidential storage (i.e. University of Manitoba Dataverse), while the recording of lesser quality was permanently destroyed. A professional transcriber was hired for transcription of the interviews. The transcriber signed the confidentiality agreement for transcriptionists (see Appendix S) prior to receiving any data. After comparing the transcribed data to the audiotaped recording and confirming that it was an accurate account of what had been recorded, the recording used to transcribe the interview was deleted from the digital recorder. The transcription for each interview, with the participant's code, was uploaded and stored as a dataset within this thesis project's Dataverse.

Descriptive field notes were documented after each interview and included in the data collection. Descriptive field notes are "objective descriptions of observed events and conversations; information about actions, dialogue, and context are recorded as completely and objectively as possible" (Polit & Beck, 2012, p. 549). Field notes were kept throughout the data collection process. These field notes were written immediately after the interviews, while the details were still fresh in the researcher's mind. Field notes from the individual interviews were coded with the same number as appeared on the participant's demographic form. Field notes from each interview included the date of the interview, information about the nurse's worksite, and the researcher's observations about the nurse's response to the interview process. Field notes were fully completed once the researcher had listened to the audiotape. The duration of each interview (in minutes) was later added to the field notes. Field notes were used to record observations and reflections on the interview process itself and the data; they also contributed to the reflexive approach and ongoing analytical process. The researcher found that listening to the audio recordings and reviewing these field notes were particularly useful to identify salient points from the interview as well as any emotions that had emerged. The researcher found that these tools helped her gauge the nurses’ responses to questions and facilitated reflection of her own emotions during the interview process.

Memos form the core of GT (Charmaz, 2006) and serve as an important step between data collection and draft writing. Memos provide a record of the research and analytic process, including the interviewers’ thoughts and feelings about the interview as well as their ideas about the emerging theory and research process, such as questions, gaps, and the analytic progress of the research (Charmaz, 2006). Glaser (1978) has suggested that the four goals of memo writing are: to theoretically develop ideas; to do so with complete freedom; to store them in a format that enables later searching; and that also allows sorting. Memos offer the researcher a place to formulate, move around, and expand ideas while developing ways of knowing and proceeding through the research process (Lempert, 2007). Memos are used to note the researchers’ reflections about the data and compile questions to build upon and further explore ideas (Charmaz 2006). When recording memos, the researcher pauses to analyze their own ideas about the codes and emerging categories. In this study, the researcher used memos to record her thoughts and feelings on key issues. Memo writing was an ongoing process that was critical to the data collection process. During early data analysis, the memos were valuable in explaining the properties and dimensions of the emerging categories; as the analysis proceeded, the memos became more theoretical in nature. The memos captured and explored the researcher’s thoughts and feelings in relation to what was being seen in the data, including the similarities, differences, and connections. Ongoing memo writing throughout the study enabled the researcher to analyze ideas as they arose and challenge her own preconceived ideas in comparison to those emerging from the data. This allowed the researcher to remain grounded in what was unfolding from the nurses’ perspectives, enabling an open, candid account of the codes and categories that were emerging. Memo writing undertaken throughout the interviewing, transcribing, coding, and writing processes provided an opportunity to step outside the coding process and further explore the ideas being identified during the analytic process. As data collection progressed, coding produced more analytical material and the nature of the memos changed from descriptive to more theoretical or abstract. Memo writing also led to theoretical sampling. The researcher noticed that the form of the memos varied greatly, from short notes and a few dot points to several pages in length, and that proper syntax was frequently lacking. Memo writing allowed the researcher to record immediate thoughts and impressions before moving on to another perspective or idea. For the duration of this study, the researcher wrote most memos by hand in a notebook, which was kept close by at all times; these memos were later transcribed into a Microsoft Word document.

Data Analysis

Data analysis consisted of analyzing the socio-demographic data with descriptive statistics using the Statistical Package for the Social Sciences (SPSS). Interview transcripts, field notes, and memos were analyzed using CGT methods. Data collection, data analysis, and conceptual theorizing occurred simultaneously and continued until the theory emerged. Analysis of the study data began with coding the interview transcripts, which was undertaken as soon as possible after the interview.

Constructivist grounded theory methodology involves the development of a theory by conceptualizing empirical data into a more abstract form that explains what is happening in the data. This is achieved by coding data, which Charmaz (2006) has described as, “the pivotal link between collecting data and developing an emergent theory to explain these data” (p. 46). Coding is “naming segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data" (Charmaz, 2014, p. 111). These codes provide analytic handles and are the first step toward the analytical interpretation of the data and the beginning of the GT (Charmaz, 2006). Charmaz (2014) explained that data coding serves as a tool to draw a logical conclusion or extract meaning from the data; it assists the researcher in condensing and breaking up data into manageable units to enable further analysis. Codes can be attached to words, sentences, phrases, or entire paragraphs (Berthelsen et al., 2014). In GT, coding is a means to link raw data with emerging categories and explain how the categories are drawn from the raw data, which increases the rigor of the study (Charmaz, 2014). This study used Charmaz's (2006, 2014) three-stage CGT coding process, which consists of initial, focused, and theoretical coding. The following sections describe the coding processes used in this study in more detail.

Initial Coding

Initial coding is the first step in the coding process and aims to "remain open to exploring the data" (Charmaz, 2006, p. 47). Charmaz (2006) advised that the researcher keep the code "simple, short, active and analytic" (p. 50). Charmaz (2006) further claimed that the labels attached during this stage are only provisional and can be changed as the analysis progresses. The most important element of this stage is to develop in vivo codes. These are the "codes of participants" (Charmaz, 2006, p. 55) and are particularly important because they directly convey the participants' views and actions. Initial coding assists the researcher to understand the hidden meaning of the data by interpreting these codes and directing further data collection and analysis (Charmaz, 2006). Initial coding involves studying fragments of data and labeling them with codes (Charmaz, 2006); fragments can be words, lines, or incidences.

This initial coding assisted in analysis of the data from the ground up, based on the participants actions and statements, and reduced the likelihood of superimposing the researcher's own preconceived notions on the data (Charmaz, 2006). During the initial coding process, each interview transcript was analyzed line-by-line, breaking the data into discreet incidents, events, actions, and interactions. Charmaz's (2006) approach to line-by-line coding was used in this study and revealed codes that originated from the nurses' own words (in vivo codes). Using the nurses' own words helped the researcher stay close to the data and provided a way of viewing the nurses' experiences from their perspectives, in their own language. These in vivo codes originated from the data and provided symbolic markers of the nurses' own language and meanings.

Charmaz (2006) stated that "if you can focus your coding on analyzing actions, you have ready grist for seeing sequences and making connections" (p. 136). During the line-by-line coding, the researcher adopted the strategy of coding for actions rather than themes, to move away from static topics into enacted processes. The researcher achieved this by coding for gerunds (words ending in 'ing'), which indicated processes as opposed to themes. A variety of in vivo and gerund codes emerged through the line-by-line coding. Some codes were both in vivo and gerunds; one such code that emerged was *'keeping fully in loop,'* which described a strategy that nurses used to build trust and rapport with families by giving regular updates on residents' health and functional status. In this way, coding for gerunds allowed nurses' sense of action in preparing families for the progression of their loved ones' illnesses to be retained during the coding process. Examples of in vivo and gerund codes that emerged from the line-by-line coding are presented below.

Table 1

Examples of In Vivo and Gerund Codes

Codes	Examples
In vivo	Family dynamics, experience, seeing changes, rapport, trust, deteriorate, open up conversation, living back in time, keeping fully in loop, sentencing to death, frail, knowledge, empathy, end-of-life, not ready, let go, communication.
Gerund	Willing to listen, seeing the reality, keeping fully in loop, educating, making comfortable, sending to hospital, changing the condition, planning ahead, accepting, fading away, keeping updated, getting worse, going downhill.

The ongoing data collection sought to pursue gaps that emerged in the data and develop the properties of the categories that had emerged through line-by-line coding. During line-by-line coding of each interview, categories were further developed and their properties and dimensions were more fully described. This led to some categories being collapsed while others were expanded into further categories.

Focused Coding

Focused coding was the next step in the coding process. Focused coding is more directed, selective, and conceptual than the initial line-by-line coding process. Charmaz (2014) has defined focused coding as:

> A sequel to initial coding in which the researchers concentrate on the most frequent and/or significant codes among their initial codes and test these codes against large batches of data. Researchers can then take those codes demonstrating analytical strength and raise them to tentative categories to develop. (p. 343)

Focused coding involved extracting the most frequently used key codes from initial coding and grouping them together. During focused coding, the researcher moved between interviews to compare the nurses’ experiences, actions, and interpretations of what was happening. For example, in relation to the initial in vivo code, *'seeing the reality,'* the researcher examined all the transcripts to see what led the nurses to talk about this code. The researcher compared what each nurse said about '*seeing the reality*,' which helped refine the code. The researcher looked at the causes, effects, and responses of '*seeing the reality*'; the nurses' responses to it, the strategies they used, and the supportive actions they adopted. After completion of the focused coding stage and through analysis of the data, the researcher was able to refine the provisional code of '*seeing the reality'* into the category of *'seeing the big picture.'* .

Theoretical Coding

Theoretical coding is the highest level of data analysis that moves toward a higher level of abstraction (Glaser, 1992). It conceptualizes the possible ways that the categories developed during focused coding relate to each other to explain a theory (Charmaz, 2006). Glaser (1978) argued that the purpose of theoretical coding is to "weave the fractured story back together again" (p. 72). The process of theoretical coding involved an examination of the relationship between categories of the data. As part of this coding process, the researcher analyzed the focused codes and specified the relationships between the categories. The categories were integrated and organized into major categories to aid the development of the core category. As the data collection continued, new categories were compared with other examples of the same category to fully describe and challenge interpretations and, thus, improve the explanatory power (Strauss & Corbin, 1990). This was achieved through the constant comparative method described below.

Constant Comparative Analysis

Constant comparative analysis is central to a GT study. It enables constant comparison between the data and the ideas being generated by data analysis and the emerging theory to "check that the ideas are well grounded in the data" (Gibbs, 2002, p. 240). Constant comparative analysis enables the accuracy of the initial evidence to be verified to fully describe concepts and categories; improve the descriptive power of categories in order to make generalizations; specify a concept; analyze; and verify and generate a theory (Glaser & Holton, 2007).

The constant comparative process was applied throughout all phases of data collection and analysis in this study. The researcher continuously revisited the data and words of the nurses, using the previous data and analysis to influence future data collection and analysis as part of this comparative process. Each interview was coded and, as more interviews were undertaken, data with similar codes were compared. Descriptions of the codes were developed and used to delineate some of the earlier codes and group others into categories. Data collection became more focused as the study progressed, and constant comparison continued by comparing incidents to other incidents to establish uniformities; comparing concepts to more incidents for the purpose of theoretical elaboration, saturation, and densification; and comparing emerging concepts with each other. Charmaz (2006) stated that "making comparison between data, codes and categories advance your conceptual understanding because you define analytic properties of your categories" (p. 179).

The researcher compared and contrasted concepts that emerged from the data and that were relevant in nurses' undertaking of ACP to optimize residents' comfort. The researcher also explored how the nurses made sense of their experiences. The memos written during this stage of analysis captured the researcher's interpretations and reflections. The memos and field notes were compared to the interviews during the data coding process and throughout the theorizing process. The sorting of categories that emerged from the processes of coding, diagramming, and integrating memos was an interconnected process throughout this study. As Charmaz (2016) has explained, “when you theorize, you reach down to fundamentals, up to abstraction and probe into experience.” (p.135).

Theoretical Memo Writing

Memo writing is a component of analysis and theory construction. Although memos can take many forms, they share the common purpose of tracing how a theory was developed (Willig, 2001). Memo writing starts from the beginning of the research process and is particularly important in the focused coding stage, when the researcher is seeking analytical directions. Memos serve a variety of purposes: to note the reflections that have taken place concerning the data, to compile questions in order to build upon and explore ideas (Charmaz, 2014), to shed light on the direction of the data analysis, to help with the formation of new ideas for a code, to identify and elaborate on the relationships between categories, and to identify gaps for integrative discussion (Charmaz, 1999). Memo writing also captures and explores the researcher’s thoughts in regard to the data, including similarities and differences. Memos aided the analysis of data in this study by facilitating reflexivity and reflection on data collection methods, interpreting the interview accounts, clarifying the relationships among codes and categories, developing final categories, and interfacing wider academic literature into the analysis. The researcher found that sorting the memos helped generate the theoretical outline or conceptual framework for the study, by looking for similarities and connections within the data, locating codes and categories, and identifying higher order theoretical conceptualizations. As suggested by Charmaz (2006), memo writing forced the researcher to stop and engage with different categories, and encouraged exploration and discovery of what had been “seen, sensed, heard and coded” (p. 82).

Diagramming

Charmaz (2014) has argued that “diagrams can enable you to see the relative power, scope and direction of the categories in your analysis as well as the connections among them” (p. 218). Beginning in the early stages of data analysis, visual representations were used to make sense of the codes and indicate their potential relationships. This started by accumulating codes in the form of clusters on single sheets of paper, based on the underlying ideas. Through memo writing and constant comparative analysis, these clusters were converted into more refined diagrams that represented potential categories, with properties and concepts of direction, location, and movement. There was an ongoing process of expanding, collapsing, removing, introducing, and rearranging codes throughout the analysis. A series of visual diagrams were collated to help visualize and explore the relationships between codes and categories. Diagramming aided in the interpretation of the emerging data and the discovery of potential relationships within and between the categories.

Use of Literature as a Source of Data

Another source of data for this study was the relevant literature. Consistent with Charmaz’s perspective (2006, 2014), literature was used before and during the study to stimulate theoretical sensitivity and direct theoretical sampling. An initial broad literature review was completed to set out the parameters of this research. A more focused literature review was conducted during the data analysis phase to further increase understanding of the developing theoretical concepts. When most of the data analysis was completed, the literature was revisited and reviewed to draw conclusions and situate the study findings within the existing literature.

Researcher's Reflexivity and Theoretical Sensitivity

Reflexivity has been conceptualized and defined in many ways, but often refers to the generalized practice in which researchers strive to make their influences on the research explicit (Guba & Lincoln, 2005). Within GT research, reflexivity involves showing how decisions were made and how the researcher's own assumptions and personal interests were managed (Birks & Mills, 2015; Doyle, 2007). The original CLGT discouraged reflexivity because Glaser (2001) deemed it to be "paralyzing, self-destructive and stifling productivity" (p. 47). On the other hand, CGT explicitly encourages researchers to engage in this practice. Consistent with Charmaz's position on reflexivity, this study was based on contemplations about "what I brought to the scene, what I saw, and how I saw it" (Charmaz 2006, p. 15). Consistent with the CGT approach, the researcher needed to remain transparent about her subjective approach and the interpretations she made throughout the research process. Reflexivity started at the outset of this study, with the acknowledgement of the researcher's background in LTC and ACP and identification of her own values, beliefs, and attitudes, including how these may have influenced the study. The researcher shared her background with the study participants and was aware of her own biases and assumptions that could have influenced data collection, analysis, and interpretation (Charmaz, 2014). As reported by Charmaz (2014), researchers treat their data as facts and construct data in ways that are influenced by individual backgrounds, assumptions, and disciplinary perspectives. Therefore, researchers need to be aware of how and to what extent they draw on such assumptions and perspectives. By following a CGT approach, this research study embraced reflexivity with the acknowledgement that the researcher's background, experience, and exposure to the research topic positively contributed to theoretical sensitivity. The researcher's reflexivity was supported by the use of a research diary to record decisions and reflections as well as discussions with academic advisors. During data analysis, the use of in vivo codes, memo writing, line-by-line coding, constant comparative analysis, and frequent meetings with academic advisors increased reflexivity and safeguarded the analysis from the researcher's preconceptions and assumptions.

Consequently, the researcher's role in this study was not neutral but, rather, her perspectives were integral to the data analysis and emerging data. Throughout the study, nurses' perspectives were privileged over the influence of the researcher's own experiences and personal views. The nurses' voices were made visible through the use of quotes, to ensure the reader could see the connections between the study findings and the data. In this way, this research honored the nurses' contributions by keeping their words intact throughout the data analysis process.

Ethical Considerations

Ethical considerations for this qualitative study were based upon ethical principles, such as respect for human dignity, beneficence, and justice (Polit & Beck, 2014). These principles provided protection for the study participants and formed the basis for the ethics protocol of this study, which was approved by the University of Manitoba Research Ethics Review Board.

Respect for Human Dignity

The ethical principle of respect for human dignity is expressed through three core principles: respect for persons, concern for welfare, and justice (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014). Respect for human dignity encompasses participants' rights to self-determination and full disclosure (Polit & Beck, 2014). The principle of respect for persons is the recognition of participants' rights, including the right to be informed about a study, the right to freely decide whether to participate in a study, and the right to withdraw at any time without penalty (Orb et al., 2000). In a research study, this principle is honored through informed consent. Informed consent exists when a participant has adequate information about the study, comprehends the information, and has the power of free choice to voluntarily consent or decline to participate in the study (Polit & Beck, 2014). It also means that participants exercise their rights as autonomous persons to voluntarily accept or refuse to participate in the study.

The nurses who decided to take part in this study were fully informed about the study in a way that was easy to understand. During on-site recruitment, the researcher explained the nature and purpose of the study; provided a detailed description of the risks, benefits, and confidentiality procedures associated with the study; explained what was expected of participants; emphasized that participation was voluntary, and that consent could be withdrawn at any time; explained they had the right to refuse answering any of the study questions; and indicated there would be no repercussions if they chose not to participate in the study. During offsite recruitment, nurses who expressed an interest in volunteering for the study were emailed recruitment documents explaining the above-mentioned information. They were asked to review the inclusion criteria and the study information sheet. The nurses were encouraged to contact the researcher if they had any questions about the study, or their involvement in it, before signing the informed consent form. There was a minimum of 48 hours between when the nurses volunteered for the study and their initial interview, to allow them sufficient time to consider all aspects of the study. Informed consent was verbally reconfirmed prior to each interview. All nurses signed the informed consent form before the commencement of either a face-to-face or telephone interview. A copy of the consent form was given to all nurses to keep for their records. Additionally, research participants were notified that a summary of the study findings would be available to them if interested. In order to facilitate this communication, the participants were asked during the informed consent procedure whether or not they wished to receive the study findings and, if so, their preferred format for this information (i.e., email or standard mail). The researcher's contact information was also provided, in case they wanted further information about the study results.

Beneficence

The ethical principle of beneficence requires that the researcher protect participants' welfare and ensure they are not exposed to unnecessary risks (Canadian Institutes of Health Research et al., 2014). This ethical principle underscores the researcher's responsibility to minimize harm and maximize benefits for all participants, while honouring the participants' rights to freedom from harm, discomfort, and exploitation (Polit & Beck, 2012). This study posed minimal risks to participants. 'Minimal risk research' is defined as research in which the probability and magnitude of possible harms implied by participation in the research is no greater than those encountered by participants in aspects of their everyday life, such as cost of time and the emotional discomfort that may arise (Canadian Institutes of Health Research et al., 2014). The main burden to the nurses in this study was the cost of their time to participate in the interview. In order to offset this potential burden, each nurse was provided with a small honorarium ($25 gift card) as compensation for his or her participation. Nurses who participated in the face-to-face interviews received the gift card at the beginning of the interview, after the consenting process. For nurses who participated in telephone interviews, an electronic gift card was sent before the interview; receipt of the gift card was confirmed with each nurse prior to commencement of the interview. The nurses were informed that they could keep the gift card regardless of whether or not they decided to complete their full interview.

The provision of any kind of monetary reward for research participation must be considered within the context of possible coercion. The *Belmont Report* described coercion as involving "an overt threat of harm…to obtain compliance, and offer of excessive, unwarranted, inappropriate reward" (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, p. 15). The $25 gift card was judged to be a reasonable value to compensate participants for their time and not of a significant enough value to be a coercive monetary reward for participation (Erlen et al., 1999; Grady, 2001; Ulrich & Grady, 2004).

There were some potential benefits of participation for nurses in this study. The in-depth interviews elicited personal stories and encouraged nurses to tell their whole story. Storytelling is the primary way that humans make sense of their experiences, and has the capacity to heal both the teller and the listener (Sandelowski, 1991). Telling one's story and feeling heard can be empowering for interview participants; this type of empowerment involves movement and change. Narratives can help to move people beyond text to the possibilities of action (Hutchinson et al., 1994). The nurses could have gained new perspectives of their own ACP experiences during the interview process. For some participants, interviews can be cathartic and self-acknowledging (Hutchinson et al., 1994). Catharsis involves the expression of personal feelings, thoughts, and problems that provides a sense of relief and healing. Self-acknowledgment is a person's feeling of being validated as an individual who has integrity and worth (Hutchinson et al., 1994). As stated by Morse (2009), "participation in qualitative research is undoubtedly a therapeutic process" (p. 215). During the interviews, nurses often expressed feelings of relief while sharing about their own efforts to keep residents comfortable and improve the ACP process. The nurses' stories were respected for their inherent value and varied meanings. The transformative power of storytelling was also recognized throughout the interview process, along with the potential benefits accrued by the participants.

Justice

According to Polit and Beck (2014), the core principle of justice means that study participants have the right to fair treatment, privacy, confidentiality, and/or anonymity. According to the *Tri-Council Policy Statement (TCPS)*, confidentiality is the “obligation of an individual or organization to safeguard entrusted information … [and] includes obligations to protect information from unauthorized access, use, disclosure, modification, loss or theft” (Canadian Institutes of Health Research et al., 2014, p. 58). Participants’ information remained confidential throughout the study.

To protect the confidentiality of the participants, interviews were conducted in a private location where the conversations could not be seen or heard by others. Immediately after each interview, the audio recording was uploaded to a secure data system for confidential storage (i.e. the University of Manitoba’s Dataverse). Interviews were erased from the recording devices as soon as the audio files were inputted into the secure data system. The participants’ contact details, the list linking each participant with their unique participant number, and the consent forms were kept separately from the rest of the research documents, on a password-protected USB stick and were backed up on a second password-protected USB stick. All electronic files were encrypted and stored on the secure Dataverse system. Electronic files were kept in separate electronic folders with different passwords. After the participants’ socio-demographic data was entered into the statistical program, the paper-based data was scanned, uploaded, and stored as a dataset within the thesis project’s Dataverse. All hand-written research materials, such as field notes, memos, and printed transcripts, were stored in separate locked cabinets. The confidentiality procedures were explained to the transcriptionist, who was asked to sign a confidentiality pledge that outlined their responsibility for protecting electronic files (see Appendix S). To allow the transfer of files between the transcriptionist and researcher, each audio interview file was encrypted and sent electronically to the transcriptionist; the password for each file was sent in a separate email. The transcriptionist followed the same procedure for sending the transcript back to the researcher. The laptop used for data analysis in this study was secured with a firewall and password protection, and its screen was locked when not in use.

There is the potential for this study data to be used for secondary data analysis. The consent form clearly stated that electronic data may be retained for use in future studies. All recordings, transcriptions, demographic forms, memos, electronic records, and field notes will be destroyed after seven years, or once the secondary data analysis has been completed. Paper records will be shredded and treated as confidential waste. Records stored in the computer hard drive will be erased using commercial software applications designed to remove all data from the storage device after seven years. The researcher will personally delete all remaining project data on Dataverse seven years after completion of the study. After publication of the study results, the encrypted memory sticks with audio files will be taken to the University of Manitoba Information Services and Technology (IST) department for permanent destruction.

The TCPS has defined anonymous information as that which “never had identifiers associated with it and the risk of identification of individuals is low or very low” (Canadian Institutes of Health Research et al., 2014, p. 59). The collected data were anonymized during the transcription process. The transcriptionist was asked to assign a pseudonym for each participant and remove all identifying information about each participant from the verbatim. All participants were assigned a numeric code that was linked to their pseudonym on a separate document and stored in a locked cupboard. The transcriber, researcher, and academic advisors were the only people who had access to the raw data. In any publications or presentations arising from the study, all identifying information about the participants will be removed and findings will not be reported in any way that identifies the individual nurses.

The researcher–participant relationship has the potential to be a reciprocal relationship in which each contributes something the other needs or desires. Participants devote their time, effort, experience, and wisdom to inform and shape the researcher's study (Trainor & Bouchard, 2013). In return, the participants were promised that at the end of the study the researcher would provide a presentation at the monthly DOC meeting and that each participant would receive a report of the study's findings, if interested. The researcher also advised DOCs of the participating facilities that they could request a copy of the study findings and that the researcher could present the study results to their staff in person.

In summary, procedures to protect participants in this study included securing ethical approval from the University of Manitoba Research Ethics Board and necessary approvals from the WRHA Research Access and Approval Committee. These practices ensured that this study honoured the protocols for informed consent, confidentiality, and communication of research findings to participants at the end of the study. Through careful consideration and planning, this study addressed the core ethical principles for human research, including human dignity, concern for welfare, and justice for all study participants.

Trustworthiness of the Study

Attention to scientific rigor in qualitative research provides assurance to the reader that the work is empirically sound. A variety of approaches to assess the rigor of qualitative work have been described in the literature. It is incumbent on the researcher to find the most appropriate means by which to assess rigor in their own interpretive research, ensuring that these measures are a true reflection of the methodological assumptions underpinning their work. This assertion is reflected by Koch (1996) who noted, “the responsibility lies with the writer to show the way in which the study attempts to address the issue of rigor. It is for the reader to decide if the study is believable” (p. 178).

Charmaz (2006, 2014) identified the four specific indicators for CGT, which were used to enhance the quality of the current study: credibility, originality, resonance, and usefulness (see Appendix T). The following section discusses each of Charmaz’s criterion for rigor as they relate to this study.

Credibility

Credibility is the criterion to evaluate whether the findings of the qualitative research represent a credible and believable interpretation of the data, drawn from the participants’ perspectives (Charmaz, 2006). Credibility concerns the links between theory and data, including the logical links between the empirical data, the main argument of the study, and the analysis (Charmaz, 2014). According to Bryman (2008), credibility is concerned with both the quality of the research process and confirmation of the research findings.

In this study, credibility was addressed in the following ways: (a) the research methodology and methods were discussed in detail in the earlier chapters of this dissertation to allow the reader to evaluate the credibility of the study; (b) the researcher carefully listened to the audio-recordings and read and re-read the transcribed text to get closer to the data; (c) the researcher stayed close to the data during analysis through line-by-line initialing and in vivo coding; and (d) the raw data, field notes, and memos provided an audit trail of the various steps, from the raw data collection to analysis and, ultimately, generation of the theoretical model.

Other strategies employed to enhance the credibility of this study included: (a) using theoretical saturation as the indication for stopping data collection (Polit & Beck, 2012, 2014) and (b) using the nurses' actual words. By means of constant comparison, the credibility of emergent concepts and their meanings was consistently verified throughout the coding process and in conversations with the researcher's academic advisors.

A member checking process (Bryman, 2008) further supported the credibility of these research findings. Member checking is the process of sharing interview data and/or preliminary findings with research participants to verify the trustworthiness of the data (Doyle, 2007). When the theoretical model was developed, a summary of the findings was sent to four participants: an RCM, a DOC, a unit nurse, and a clinical resource nurse. These participants were asked to provide their feedback about whether or not the theoretical model reflected their experienced reality; the participants did not suggest any revisions to the model. Additionally, the researcher discussed the emerging codes and categories with her academic advisors throughout the processes of data collection and analysis. These frequent meetings and discussions offered great insights and different views on the development of the theoretical categories, and the final theoretical model.

As discussed earlier, the researcher's background as an NP and the knowledge gained through her own experiences of discussing ACP with residents/families in LTC, were found to increase the researcher's theoretical sensitivity. In order to retain openness to the data, memos and discussions with academic advisors were used to help the researcher reflect on her own background assumptions during data analysis.

Originality

The criterion of originality refers to an assessment of the originality generated by the research findings, including new insights about categories identified in the work, the generation of new conceptual framework(s), and the social and theoretical significance of the research (Charmaz, 2014). Since nurses' perspectives and experiences of undertaking ACP in LTC have not previously been examined empirically, this study generated previously unpublished insights. These new insights have social and theoretical significance that challenge and extend current ideas, concepts, and practices. In this study, originality was evaluated by comparing the research findings with existing knowledge in this particular field of research.

Resonance

The criterion of resonance assesses whether or not the GT developed from the data relate to the studied experiences of participants and if the categories make sense to them (Charmaz, 2014). It is a measure of how well the theoretical model can "speak specifically for the population from which it was derived and to apply back to them" (Strauss & Corbin 1998, p. 267). The resonance of the developed theoretical model was tested by bringing the raw data into the model as well as through a member checking process (Bryman, 2008), described previously. The member checking process confirmed that the findings were a clear representation of the nurses' experienced reality of engaging in ACP.

Resonance was also attained by fully saturating the categories, which revealed the meaning and contextual links of participants' experiences with ACP. The emerging theory was confirmed through theoretical sampling and the use of constant comparison in the data analysis. Further connections were made between participants' individual experiences and the wider literature that relates to the experiences of undertaking ACP, including recommendations to improve ACP processes. There were similarities between the findings of this study and previous theoretical constructs in the literature, highlighting the potential transferability of the study findings to other healthcare contexts.

Usefulness

The criterion of usefulness refers to the extent to which study findings are related to individuals' day to day lives and the utility of these findings in the everyday world. Useful study findings contribute to knowledge and spark ideas for further research (Charmaz, 2014). The current study findings met the criterion of usefulness to the extent that they can help guide ACP processes in geriatric nursing practice, especially in terms of making decisions that pertain to comfort care and EOL. The usefulness of this study will be enhanced during dissemination of its findings by incorporating an end of grant knowledge translation strategy, including thick descriptions of the context and participants, and through the use of visual diagramming to illustrate the GT. This research also provided suggestions for further study, specifically related to improving the processes of ACP and quality of EOL care. Further research is required to develop a more formal GT that would be transferable to other clinical areas, such as ACP in hospitalized adults and children.

Summary

This chapter provided an overview of the methods used for conducting this study. Ethical considerations and measures used to ensure trustworthiness of the research were also presented. The following chapters detail the findings of the study.

Chapter 5: Study Findings - Orchestrating Comfort: Getting Everyone on the Same Page

Introduction

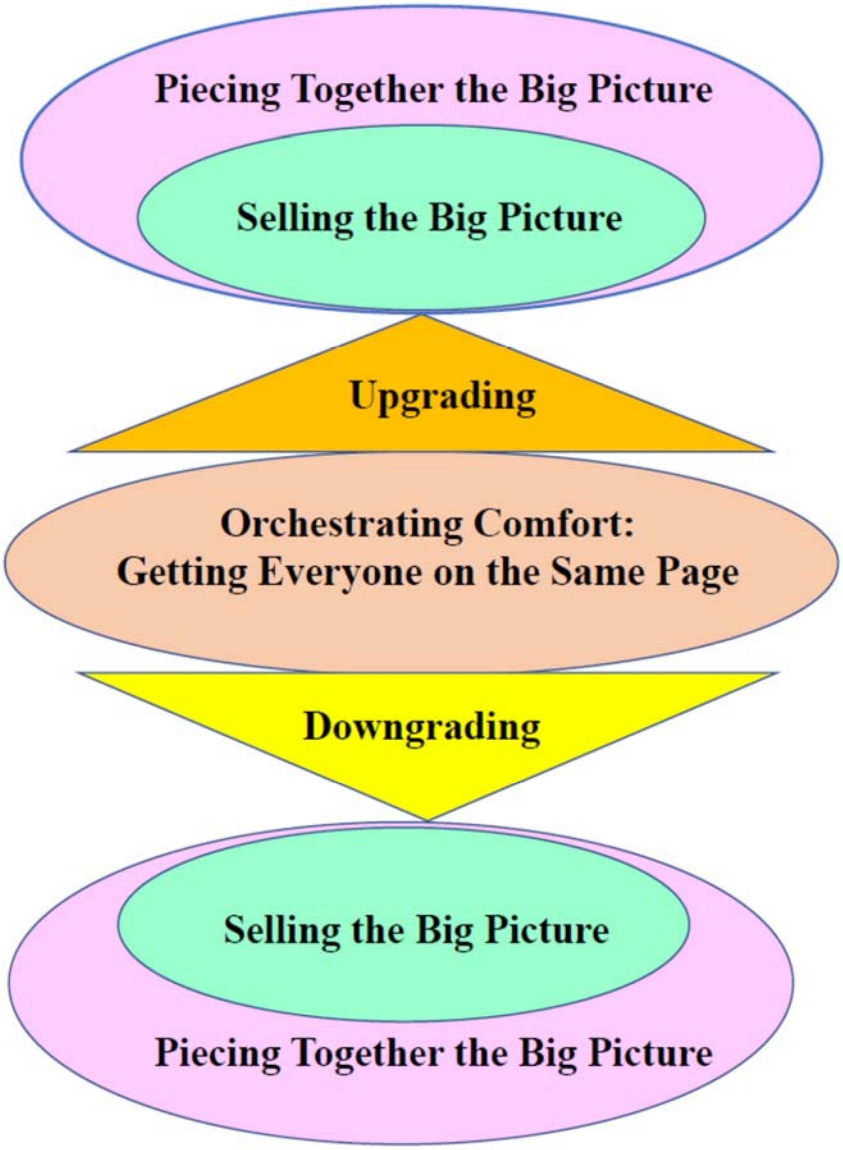
This chapter presents an overview of the theoretical model that emerged from the data. This model serves to describe the process nurses engaged in to maximize comfort for residents in LTC facilities. This chapter also describes characteristics of the sample, study settings and impact of the COVID-19 pandemic on study protocol. Chapter six and seven provide more thorough detailing of the components of the model.

An Overview of the Model

The basic social problem experienced by the nurses in this study was that of ensuring the crafting and implementation of ACP, which would promote comfort for residents in LTC facilities at EOL as well as during acute events. Since most LTC residents are of advanced age and suffer from progressive chronic conditions, the nurses in this study acknowledged that LTC facilities were often their last place of residence. The nurses believed that, in most circumstances, life-prolonging aggressive interventions neither promoted comfort nor improved quality of life for LTC residents. Exceptions included instances where aggressive interventions were needed to ensure the residents' comfort, such as: hospital transfers for surgical repair of a fractured hip; suturing an active bleeding wound; and treating a painful infection at the LTC facility with oral antibiotics. The empirically derived theoretical model that captures the experiences, processes, and strategies the nurses used to address the identified social problem was *orchestrating comfort: getting everyone on the same page*. An overview of the main components of the model is presented in Figure 1 below. The model's dynamic nature is captured in the schematic. The concentric circles illustrate the nature of the relationships between the pre-conditions that culminate in *orchestrating comfort: getting everyone on the same page*.

Figure 1

Orchestrating Comfort: Getting Everyone on the Same Page



The road to getting everyone on the same page required that two pre-conditions be met. First, nurses needed to fully understand the resident's big picture—the totality of their medical and psychosocial state of well-being. This big picture was an overall gestalt, including a sense of what was currently happening and what was likely to happen to the resident. Nurses also needed to understand the resident's family and their awareness of the resident's big picture. This understanding provided the basis from which nurses could determine the optimal ACP level that would ensure comfort, and the strategies needed to secure that level for the resident.

Second, in order to get everyone on the same page, the nurse needed to successfully sell his/her assessment of the resident's big picture to the resident's family and other members of the healthcare team. Nurses assumed a variety of roles and employed different strategies to piece together and sell the big picture. These details are discussed in greater detail in the subsequent chapters of this thesis.

The theoretical model *Orchestrating Comfort: Getting Everyone on the Same Page* encompassed two main processes: downgrading and upgrading ACP levels. In this study, the process of downgrading was defined as nursing actions that were used to shift a family's goals and treatments to comfort care ACP level in order to ensure resident comfort, to avoid aggressive painful interventions, and to improve end of life care. In contrast, the process of upgrading was defined as nursing actions that shifted family goals and treatments to ACP M (medical) or ACP M with no hospital transfers to ensure that treatment/intervention were aimed at maximizing comfort in the face of an acute medical event of a resident who had the designation of a comfort care ACP level (ACP C) in place.

The process of downgrading includes the actions taken by nurses to shift the goals and treatments of families and physicians to an ACP level that the nurse deems to be more realistic.

Downgrading often helps enhance the resident's comfort, avoid aggressive painful interventions, and improve EOL care. The process of upgrading encompasses nursing actions that shift the goals and treatments of families, paramedics, physicians, and healthcare providers in acute care settings to an ACP level that the nurse deems to be more realistic. Upgrading ensures that treatments/interventions are aimed at maximizing comfort in the face of an acute medical event in residents with ACP-C.

Several facilitators and barriers influenced the nurses' ability to engage in downgrading or upgrading of ACP levels. A barrier was a factor that hindered the fulfillment of pre-conditions, whereas a facilitator was a factor that promoted the fulfillment of pre-conditions. Facilitators and barriers were identified to exist at the resident/family, healthcare provider, and/or institutional/organizational levels; these factors are discussed in further detail in the subsequent chapters.

There were positive and negative consequences/outcomes associated with the processes of downgrading and upgrading ACP at the resident, family, and healthcare provider levels. When downgrading of the ACP level was completed in a smooth and timely manner, the outcomes were noted to be positive. For residents and their families, positive outcomes included a smooth transition to EOL care, a dignified death, increased satisfaction with care, and reduced stress. Nurses regarded downgrading residents to ACP-C as the most rewarding part of their job. Conversely, negative outcomes were more common when downgrading was not completed in a smooth or timely manner. Negative outcomes for residents included increased suffering and potential disregard of their stated wishes, including those in a living will. Negative consequences of the downgrading process for nurses included: increased emotional toll; conflict between personal and professional values; witnessing suffering while feeling a moral obligation to reduce suffering; and the feeling of being resented by physicians.

Outcomes for the upgrading process were noted to be positive when nurses were able to provide care that maximized residents' comfort. Conversely, outcomes were noted to be negative when residents were sent to the hospital without first upgrading their ACP level, as there is a lack of standardized understanding of ACP-C between these settings. A positive outcome at the family level was their enhanced overall satisfaction with the care provided in LTC. The positive outcomes of the upgrading process for nurses included feelings of competence and confidence about their clinical decision making. The negative consequences of the upgrading process at the resident level were discriminatory treatment from hospital staff due to ageism and a devaluation of the LTC sector. For nurses, the negative outcomes associated with upgrading ACP included: feelings of frustration; feeling impotent; feeling judged on clinical competence; and being treated disrespectfully by acute care staff and paramedics.

Description of the Study Sample

The study sample consisted of 25 nurses working in 18 different LTC facilities. Ninety-two percent (n= 23) of participants were female, ranging from 31 to 50 years of age. With regard to education, 52% had completed a baccalaureate nursing degree while 32% were diploma-prepared licensed practical nurses. Most nurses worked as either a unit nurse (40%) or a resident care manager (RCM) (36%). Sixty-eight percent of the nurses worked full time and 32% worked part time; none were casually employed. All nurses worked in only one facility and 36% had been engaged in ACP discussions more than 10 times in the last six months. Twenty-eight percent of those interviewed held CNA certification in gerontology. None of the nurse participants had received any formal education/training about ACP as part of their nursing education or their job. Years of experience as a nurse ranged from three to 44 years, with a mean of 18.7 years (SD= 10.3). The average years of experience as a nurse in LTC was 12.6 (SD=7.5). The average length of time working in the same LTC facility was 6.6 years, with a range from six months to 30 years (SD= 7.8). Fifty-six percent of the participants did not endorse a spiritual or religious affiliation. Demographic information describing the study sample is presented in Table 2.

Table 2

Demographic Characteristics of the Study Sample

Variables	Total N=25
Age (years), n (%)	
18-30	2 (4)
31-50	15 (60)
51-65	9 (36)
Over 65	0 (0)
Gender, n (%)	
Female	23 (92)
Male	2 (8)
Current Position, n (%)	
Unit Nurse	10 (40)
Resident Care Manger (RCM)	9 (36)
Clinical Resource Nurse (CRN)	3 (12)
Director of Care (DOC)	2 (8)
Other (Assistant DOC)	1 (4)
Highest Education Attained, n (%)	
Licensed Practical Nursing Diploma	8 (32)
Registered Nursing Diploma	3 (12)
Baccalaureate Nursing Degree	13 (52)
Registered Psychiatric Nursing Degree	0 (0)
Master of Nursing	1 (4)

Special Education/Certification in Gerontology/Long Term Care/Palliative Care, n (%)	
No	18 (72)
Yes	7 (28)
Work Status, n (%)	
Full-time	17 (68)
Part-time	8 (32)
Causal	0 (0)
Engagement in ACP in the Last Six Months, n (%)	
Less than 5 times	9 (36)
Between 5 to 10 times	7 (28)
More than 10 times	9 (36)
Formal Education on ACP, n (%)	
Yes	0 (0)
No	25 (100)
Working at More than One LTC Facility, n (%)	
Yes	0 (0)
No	25 (100)
Affiliation with Spiritual/Religious Community, n (%)	
Yes	11 (44)
No	14 (56)
Years of experience Working as a nurse, *M* (*SD*)	18.7 (10.3)
Duration of Time Worked in LTC (years), *M* (*SD*)	12.6 (7.5)
Duration of Time Worked in current LTC, (years), *M* (*SD*)	6.6 (7.8)

Characteristics of the Participating LTC Facilities

Nurses who participated in the study worked in 18 of the total 39 LTC facilities in Winnipeg. More than half of the facilities had between 100 to 200 beds for residents and functioned as not-for-profit organizations. One facility was attached to a hospital, while three facilities provided specialized dementia care. Two facilities were attached to health centres with multiple programs. One of the facilities was owned and operated by the WRHA. One in three facilities provided on-site CPR by staff. Six facilities had some religious affiliation, while four had a faith-based orientation. Characteristics of the participating LTC facilities are presented in Table 3.

Table 3

Characteristics of the Participating LTC Facilities

Variables	Total N=18
Number of Beds, n (%)	
Less than 100	3 (17)
100-200	11 (61)
More than 200	4 (22)
WRHA Owned and Operated, n (%)	1 (6)
Attached to Hospital, n (%)	1 (6)
For-profit, n (%)	7 (39)
Not-for-profit, n (%)	11 (61)
Faith-based, n (%)	4 (22)
Religiously Affiliated, n (%)	6 (33)
Specialized Units, n (%)	3 (17)
Attached to Health Centre with Other Programs, n (%)	2 (11)
On-site CPR	6 (33)

Impact of the COVID-19 Pandemic on the Study Protocol

A three month pause in recruitment and data collection occurred from March 2020 to May 2020, due to the unprecedented COVID-19 pandemic and the resulting public health orders. The researcher was forced to seek alternative participant recruitment and data collection methods due to the implementation of visitor restrictions in LTC facilities, recommendations to avoid non-essential trips from home, and recommendations to implement physical distancing to reduce the spread of COVID-19. Therefore, amended approval from the University of Manitoba Research Ethics Board (see Appendix P) was obtained to modify participant recruitment and data collection. With the amendment, in-person recruitment was modified and data collection was achieved through phone interviews, as opposed to the pre-pandemic face-to-face, in-person interviews. More details regarding participant recruitment and data collection, as well as the challenges associated with phone interviews, were described in chapter four. Data collection continued from June 2020 to August 2020 and proceeded smoothly, while upholding the public health orders.

Summary

This chapter provided an overview of the theoretical model *Orchestrating Comfort: Getting everyone on the same page*. The main processes of the model were identified, including downgrading and upgrading of ACP levels and their attendant pre-conditions, strategies, and consequences. The barriers and facilitators that influence nurses' ability to orchestrate comfort care were considered from a socio-ecological perspective. Demographic characteristics of the study sample and characteristics of the participating LTC facilities, along with the impact of pandemic on the study protocol were also provided. Subsequent chapters present a more in-depth analysis of each component of the model.

Chapter 6: The Process of Downgrading

Introduction

The process of downgrading was the cornerstone of crafting ACP levels that optimized comfort and quality of life in LTC residents. The nurses' perceptions of the necessity of downgrading ACP levels, along with the pre-conditions, strategies, barriers, facilitators, and consequences of this process are discussed in detail in the following sections. The schematic representation of the downgrading process; the barriers and facilitators to this process, as analyzed from a socio-ecological perspective; and the consequences of the process are presented in Figures 2, 3, 4, and 5. The downgrading process is summarized in Table 4, on page 279. The nurses accomplished the process of downgrading by meeting two pre-conditions: piecing together the big picture and selling the big picture.

Piecing Together the Big Picture

The pre-condition 'piecing together the big picture' refers to the process that nurses used to gain a clear and fulsome understanding of the resident's medical condition and GOC as well as the family's understanding and perspectives of these issues. Nurses believed this understanding was a prerequisite to adequately identifying an ACP level that promoted comfort for residents. In order to piece together the big picture, nurses conducted ongoing assessments and collaborated with other members of the healthcare team to gather information about the resident's overall condition, diagnoses, and functional abilities. Nurses also considered the resident's tolerance for being transferred to the hospital for diagnostic procedures and aggressive interventions.

To piece together an understanding of the family's perceptions of the big picture, nurses assessed the family's knowledge of the resident's health status, their readiness to engage in ACP discussions, and other relevant family characteristics. Nurses were then able to engage with families to shift their perspectives, making them more congruent with the resident's big picture. This allowed the nurses to shift the family's focus from life-prolonging aggressive interventions/treatments to those that actively pursued comfort at the facility, without the need for hospital transfers.

Assessments to Piece Together the Resident's Big Picture

The process of piecing together the resident's big picture required nurses to seek an understanding of the resident's underlying chronic illnesses, associated symptoms, prognosis, and baseline functional status. This information was gleaned from a variety of sources and is discussed below.

Sources of Information Guiding Assessment

Healthcare Records and Interview upon Admission to the Long Term Care Facility

Nurses reported that during the admission process, they tried to learn about a resident's comorbidities, diagnoses, and GOC, as documented on their health records. They also sought to gather information about the resident's life prior to the LTC admission. They gleaned this information from the resident's chart and/or by talking to the resident/family about the family's background as well as the resident's hobbies, work history, and involvement in faith-based activities. Nurses believed that knowing a resident's background helped them build a trusting relationship. According to one CRN participant:

> Sometimes the nurses will take the time to look through the admission package before they [the resident] even get there, and the admission package usually will have a little bit about their life history. So looking up on those things like their hobbies, work, their involvement with church and who is their family etc. And then, when you're meeting them saying, oh I've heard that you worked at Eaton's, or you did this. So they know that

> you're actually putting in some effort to get to know them. And it builds that rapport quickly. (Interview: 15)

Nursing Assessment Findings

As part of routine professional practice and the provision of safe and appropriate nursing care, nurses completed daily assessment and monitoring of the residents' baseline functional status, specifically looking for evidence of changes in or progression of their chronic illnesses. They took note of the following salient indicators, described below.

Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) Scale. Nurses reported that they used one of the outcome scales from the minimum data set (MDS) to understand residents' health status. This scale is known as the Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) scale (Hirdes et al., 2014). The CHESS scale detects health instability and is designed to identify residents at risk of serious decline. Higher scores indicate increased risk for mortality, hospitalization, and poor health. Nurses stated that the score was formulated through various indicators, such as a change in the resident's activity level and symptoms, including weight loss, dehydration, breathing problems, and edema. Nurses reported that when a resident had a high CHESS score, there was a sense of urgency to have ACP conversations with the family. One of the DOC participants stated:

> When we see somebody changing. One of the things I want to get us in the habit of, is using the CHESS scores, the health stability score and it can get it from the MDS data…as a trigger point to sort of say, okay, let's look at this. And so I'm using them now to trigger how urgently do I need to have those ACP discussions, where somebody's got a resuscitation or Medical ACP directive. If they've got a high CHESS score and a resuscitation directive, then it goes to the top of my list to have that conversation with

> family. I think the score is related to change in the resident's ADLs, along with presence of weight loss, food intake, dehydration, shortness of breath and edema. We don't usually use it, I wish we use it in our ACP discussions with family. (Interview: 02)

In line with the MDS data collection requirements, CHESS scores are collected by the nurses on a quarterly basis for every resident. While nurses acknowledged that this scale was useful in identifying residents with poor prognosis, there was no policy or direction from management in LTC facilities to use this information in routine practice or during ACP conversations. The participants believed that many nurses might not even be aware of this scale and its potential clinical uses;

> I know the CHESS score is part of the MDS assessment, which we do quarterly. I think it is very good in identifying residents with poor health and I first heard about its uses in a conference. There is no direction to use it in our practice and I am sure many nurses are not aware of it. It is good tool and we should use it to guide our ACP decisions. (RCM; Interview: 25)

Reduced Oral Intake. Nurses reported being concerned when there was a decline in a resident's oral intake because decreased appetite generally indicated that the resident was moving toward EOL. They noted that dehydration and weight loss were more common among residents who refused to eat and/or open their mouth for feeding or who had swallowing problems related to dementia. These issues also made the administration of oral medication difficult. According to one of the unit nurses, "Well, if we see that the resident is not eating, they're not taking their medications, there's a complete decline and everything" (Interview: 09).

Diminished Energy Reserves. Nurses also attended to signs related to decreased energy reserves, such as a resident sleeping most of the time, becoming fatigued quickly during activities of daily life, withdrawing from social activities, exhibiting low mood, and having decreased mobility when compared to their baseline:

> I see the decline because she's no longer interested in coming to recreational activities, and the dietician sees it, because she is sleeping most of the mealtime and losing weight every month, you know, so different people can share different perspectives and we uses these clues to put the whole picture. (Assistant DOC; Interview: 03)

Sudden Decline Related to Progressive Illness. Nurses reported that a resident's condition could change suddenly due to an exacerbation of their underlying chronic illness(es). In cases where there was no new identifiable or treatable cause for the decline and prognosis was poor, nurses signalled to families that the focus of care needed to shift and the ACP level needed to be downgraded:

> If the situation changes suddenly, from their chronic conditions and the recovery is not possible sometimes due to several diagnoses. So at that time sometimes when there are a lot of tests, after doing a lot of investigations there is no prognosis. So then if the resident is on resuscitation or medical then we have to change it to comfort care based on their decision, so we discuss all these with family and educate them about the big picture and what is best for the resident, so they can downgrade to comfort care. (Unit nurse; Interview: 16)

Increase in Pain Level. Nurses reported that an increase in pain from the resident's baseline level was often an indication of a decline in health status. For some residents, every movement caused pain and providing effective pain management was a challenge because analgesics were associated with side effects of excessive sleepiness and decreased oral intake. Nurses noted that functional decline often sent residents on a downward spiral toward further health complications, including weight loss, falls, and constipation. According to the participants, efforts to prolong life in the presence of increased pain inflicted suffering on residents. In addition, most families wanted their loved ones to be pain free. The following exemplar illustrates how one nurse articulated the big picture of a resident with increasing pain: "When the residents are in more pain than from their usual pain, then we know they are going down. The pain can be from their other illness or they are moving to end of their life" (RCM; Interview: 25). Another nurse also stated, "Just getting up is harder and they are in pain each time they move because you – you know what I mean? Everything hurts and it gives you an overall picture of where they are heading to" (RCM; Interview: 06).

Failure to Respond to Curative Treatments. The examples of residents failing to respond to curative treatments that were most commonly cited by the nurses included residents' non-response to antibiotic treatment for aspiration pneumonia as well as to the administration of artificial rehydration. Residents with dementia were often transferred from LTC to the hospital for recurring issues with dehydration and aspiration pneumonia. Nurses noted that, in the long run, these types of curative treatments were not effective to promote residents' comfort, as they had no effect on the underlying cause of the aspiration pneumonia and/or dehydration; no treatment or intervention could address the underlying dementia that predisposed residents to these issues.

One of the RCMs assessed the ongoing signs and symptoms of aspiration pneumonia and the failure of antibiotic treatment for a resident with dementia and swallowing problems. The RCM signalled to the resident's wife that the ACP needed to be shifted toward comfort care:

> The person kept having aspiration pneumonia from his dementia, and so we noticed that this person can't eat. When you put even just one thing in his mouth, he can't swallow, and then he'd start having, like, infections, like, pneumonia, like, temperature,

> congestion, wheezing and everything. You could see that this is aspiration pneumonia signs. The same thing happened again. Like, he just got antibiotics – as soon as he finished that, he just got bad infection, temperature rising, wheezy, coughing at every swallow, every little thing that's fluid, so I communicated my assessment to his wife and started the ACP conversations to make him comfortable. (RCM; Interview: 14)

The following quote from an RCM described a resident with dementia who was sent to the hospital several times for the treatment of dehydration related to poor oral intake. The RCM believed that each trip to the hospital caused an increase in the resident's suffering and that ongoing rehydration was not a permanent solution for reduced oral intake. The RCM pieced together the resident's big picture from an analysis of her reduced oral intake, failure of curative treatments, and burden of hospital transfers. Using the resident's big picture, she was able to indicate to the family that there was a need to shift the ACP level to comfort care:

> When we see a decline to residents' condition, you know the whole picture of their status, you know with the dementia they decline, they stop eating or drinking, refusing care, refusing food and pills. I remember we had one resident and the resident had declined by the time. She stopped eating and drinking, refusing care, so her advanced care planning was medical, so we were sending her to the hospital. We sent her to the hospital every time we see that she is not eating, drinking enough, so she is dehydrated. So for rehydration we sent her to the hospital for a few times. But sending to hospital only rehydration purpose, like it's a temporary, it's not a permanent solution and it is not helping her. Each trip to the hospital causes more problems for her, So we arranged a meeting with the family to bring up the big picture and changing her ACP to comfort care. (RCM; Interview: 10)

Nurses' Subjective Opinions about Hospital Transfers

In addition to their objective assessments, the nurses in this study drew upon their subjective opinions to piece together the resident's big picture. They were of the opinion that burdensome interventions, such as hospital transfers and other out-patient diagnostic assessments and consults, would have a negative impact on residents and cause undue discomfort and suffering. The nurses also believed that aggressive interventions, like CPR, had the potential to increase pain. In addition, ambulance transfers to the hospital were associated with increased stress for the residents. Nurses felt that residents' quality of life could be enhanced by maintaining an ACP level of comfort care and providing treatments at the LTC facility for pain and infections that were amenable to antibiotic therapy, such as urinary tract infections.

According to a unit nurse, frequent hospital transfers for artificial hydration were not helpful for residents who refused to eat or drink. She believed that the repeated rollercoaster ride between LTC and hospital increased the residents' suffering. She used the failure of hydration treatments and the subsequent burden on the residents' comfort level to piece together their big picture:

> If you have somebody who has stopped eating and drinking, but according to current ACP level M we, have to send them to hospital to put IVs in them and get hydrated. Well, that's going to be the same thing, we've done that they (residents) come back, they refuse to eat and drink again, like we going *[sic]* to keep sending them back for this rollercoaster ride, because it's hard on the resident, so. And then you have to sensitively bring up this big picture to the family that maybe your parent is telling you, this is their way of telling you that they don't want anything anymore. (Unit nurse; Interview: 17)

The following exemplar from an RCM showed how she pieced together the resident's big picture by incorporating her subjective opinion of the resident's inability to tolerate hospital transfers and off-site tests. She then used the resident's big picture to downgrade the ACP level to comfort care:

> A lot of times, you know, we have someone who has many comorbidities, you know, something like even if it's just dementia's just starting to progress, if they would not be able to tolerate going out for tests or being in an emergency room or, in a stretcher on a hallway or, just with people they don't know, if they couldn't tolerate those things then it would be just awful for that resident to have to experience those things. And it should be something considered medical no transfer or comfort care instead of ACP M. (RCM; Interview: 25)

One of the unit nurses believed that residents should be treated at the LTC facility, without transferring them to the hospital, in order to improve their quality of life:

> You know you put them (residents) in a nursing home and they're old and have so many comorbidities, so I think at least keep them comfortable at the facility so they're like providing oxygen or oral antibiotics but you're not putting the stress of having to transfer them through an ambulance to get them to the hospital, right? It's like you want them to live like what a quality of life, right. They say in long-term care quality of life, it's like, you know, they've lived a life, so I think it is better to put them on comfort care, I think it should just be more like providing them comfort that's for the best for them but you're still doing the treatments of like giving them antibiotics for infections and treating their pain but you're not, making their life very unbearable because of the CPR and the transfer out, you know, those things that shouldn't be necessary you know, because you

> can still do it in the facility and make the resident's life comfortable. (Unit nurse; Interview: 18)

Members of the Healthcare Team

Nurses collaborated with other members of the healthcare team, such as speech language pathologists (SLP), physicians, and HCAs, in an effort to piece together an understanding of the resident's big picture. The following exemplars demonstrate how nurses collaborated with other team members to develop the big picture and more accurately detect changes in the residents' health status.

Nurses consulted SLP when residents with dementia suffered from swallowing difficulties and used the SLP's assessment and subsequent report to piece together the big picture and facilitate a downgrade to ACP-C:

> If there's a huge change in swallowing and we contact SLP then as nurses we already know – we would use their report as back-up if we needed it, so we facilitate the SLP assessment and use that to get the ACP changed to comfort care, you know most of the residents with dementia develop swallowing problems and they get aspiration pneumonia. (Unit nurse; Interview: 23)

Nurses relied on the physician's assessment and opinions about a resident's health status/prognosis to piece together the big picture and facilitate ACP discussions with families:

> I can think of someone with Parkinson's, and the family were saying, well, you know, she's probably got another ten years, and I'm thinking to myself, I don't think so. I think we're sort of in the last year of life, but they needed to hear that from a physician, you know, because they were thinking they have lots of time to plan for this. And I was pretty sure, so I checked and the physician said, no, no, no. I said, okay, well, then let's plan the

> advance care planning discussion when you can be there too, so that they can get the same message. (DOC; Interview: 02)

Nurses relied on HCAs to notify them of changes in a resident's status. Nurses reported that, due to their frequent contact with the residents, HCAs were often the first members of the team to notice subtle changes in a resident's functional status. Nurses described HCAs as their *eyes and ears,* and believed their input was valuable in piecing together the resident's big picture:

> I rely on the HCAs, they're my eyes and ears a lot and they see changes sometimes a lot sooner than I do, they'll say, you know what, the last three days they (residents) haven't been doing this and they have, but you know, maybe they're eating a bit less and I haven't noticed, but they (HCAs) have noticed, maybe they're more lethargic or they' re in more pain. They (HCAs) help the nurses to see the changes in residents. (Unit nurse; Interview: 17)

Another participant commented on the value of information provided by HCAs:

> Sometimes they (HCAs) are the one to inform the nurses about the changes in a resident. Like, they (residents) are lethargic, they've not been eating, their condition has deteriorated. Maybe they used to participate in their care, but right now they can't even stand, they are so weak. So they (HCAs) are the front people to see all those changes. And when they bring it to the notice of the nurses, that's when we go to assess them and see what's going on with them. And I think the health care aids are very good at picking up on, you know, when they're working with the resident, what's causing pain or, you know, what kind of quality if they're trying to engage with the resident. (RCM; Interview:14)

Outcomes of Collecting Information

The piecing together of the resident's big picture required the collection of data from several sources, as described above. The outcomes of collecting this information included: (a) early detection of decline in the resident's health status; (b) gauging alignment of the healthcare team regarding the resident's condition; (c) identifying discrepancies in documentation/GOC between the healthcare directive and ACP forms; and (d) generating the content of ACP and decision making conversations with the resident's family.

Early Detection of Decline in the Resident's Health Status

Being familiar with the resident's medical history and baseline functional status enabled nurses to more quickly detect deterioration in a resident's functional status from his/her baseline. Participants in the study believed that the nurses who looked after the residents on a continual versus casual basis were best positioned to detect changes in their status and, thus, construct their big picture most accurately. Participants believed that casual nurses were unable to recognize the changes in residents due to a lack of familiarity with them. Therefore, they believed that casual nurses were unable to communicate the big picture to the family or facilitate a downgrade of ACP to comfort care. These opinions were voiced by one of the unit nurses:

> The continuous or the regular nurse that's been looking after the resident can only see the big picture. Then she's the only person that could accurately know the changes. A casual would not be able to see that, but a casual won't be able to discuss the changes with the family like what changed over the few months. Because if you're casual then you don't know, you see what's there today or what's there the other time that you were there. Like you don't have a good picture of the decline, so it has to be the person, the nurse who knows the resident very well. (Interview: 09)

Gauging Alignment of the Healthcare Team Regarding the Resident's Condition

Gathering information from the healthcare team helped nurses complete a more thorough assessment of the resident's condition, and enabled them to identify the extent to which members of the team were in agreement about the resident's condition. Nurses believed that agreement within the team about the resident's condition, as well as consistent messaging to their family members, helped get the family on the same page as the healthcare team and assisted them to choose appropriate treatments and realistic ACP levels. One of the CRN participants made the following observation:

> Within the disciplinary team, it's easier if everybody knows the health condition, and also if everybody is on the same page, like, is the patient benefitting from more, like, further investigation, or more aggressive treatment, or would the patient benefit from comfort care? So the interdisciplinary team will also give their input, like, okay, you know what, the patient might even be in discomfort if we still continue to give her meals that she cannot fully awake to eat, then there is a possibility of aspiration. So yeah, what we do is, even when there's a change in level and the patient is not eating anymore, that then we have to send a consult to SLP to make sure that there's a proper assessment as well. And also, of course the dietician, yeah, this understanding from the team helps us in communicating with the families. (Interview: 07)

Identifying Discrepancies in Documentation/GOC between the Healthcare Directive and ACP Forms

Information collected from reviewing the chart and interviewing the resident on admission helped nurses identify discrepancies between the ACP document and the resident's GOC, as recorded on their healthcare directive. It was important to nurses that the ACP document accurately reflected the resident’s preferences for care.

In one scenario, a resident’s daughter was insisting that the resident be sent to the hospital to receive a blood transfusion. An RCM was able to honour this resident’s wish to forgo the blood transfusion by bringing a discrepancy in the resident’s ACP and healthcare directive to the daughter’s attention:

> I was trying to prepare the paperwork to send a resident to hospital for blood transfusion, and I opened the ACP – it was ACPM – medical. So she had health-directive there that, specifically stated there that in the case that my blood goes so low, I do not want blood transfusions. So I had to call the daughter back, that we are going against this woman’s wish, because she said she doesn’t want blood transfusions. I said, at this point, this is your mom’s wish that we need to change the ACP to comfort care, and that was when we changed the ACP to comfort care. The healthcare directive was helpful to support the resident’s wish to making her comfortable by downgrading the ACP, when her daughter wanted us to send the resident to hospital for transfusion. So when I'm discussing ACP, I look at the big picture, including the health directive to make sure it matches with the current ACP. (RCM; Interview: 14)

Generating the Content of ACP and Decision Making Conversations with the Resident’s Family

Nurses likened collecting information in order to understand the resident’s big picture to the idea of “doing their research.” The content of what was learned was shared with families to describe the resident’s decline in health. As a result, the nurses could engage in these conversations with a broad understanding of the resident’s status. The nurses were able to incorporate a comparison of the residents' previous health status and functional ability to the current reality. Using this tactic, nurses were better able to convey to families when residents' health condition had deteriorated, paving the way for GOC and ACP discussions:

> You need to do your research. You need to find out their comorbidities, their diagnosis, what their life was like outside of the facility, what they were like in the community and what they like and what they enjoyed, right? So when you give that picture as to what the picture is like within the facility, then that makes them feel like OK yes, definitely it's not the same, there's a difference, there's a big change. This way you prepare for the discussion with families about the gaols of care and ACP. (RCM; Interview: 08)

When formulating conversations to help the family understand that the resident's status was declining , nurses also incorporated the assessments and recommendations of other members of the healthcare team to piece together the resident's big picture. This process was described by one of the RCMs:

> I told the wife, a specialist, from outside the facility will come assess her husband's swallowing, So that gave her a kind of that we are doing everything for him. Then I use the SLP assessment to show that the specialist recommendation was not feeding him and the loss of swallowing was related to his dementia and it was part of the disease process. (Interview: 14)

When curative treatments did not benefit residents who had feeding difficulties, nurses targeted their communication toward the burdens of temporary aggressive interventions, such as a hospital transfer for intravenous rehydration. Nurses tried to educate families, speaking frankly and directly, about the benefits of keeping residents comfortable at the facility by focusing on comfort care and allowing nature to take its course. Nurses believed that verbal reassurance helped families come to terms with the fact that their loved ones were declining. As a result, families were better able to understand that downgrading the ACP level was necessary to optimize their comfort. One of the assistant DOC participants provided an account of this experience:

> We had a resident who is failing, and looked like dehydration and he does have feeding problems. I clarified how we were seeing changes in their loved one. That he wasn't taking food, and I clarified what dehydration meant and what a trip to the hospital meant, and would that really cure it? Technically I incorporated the burdens of hospital transfers and IV fluids as a temporary fix. So, I just talked more about doing our best to feed him here, at the lodge, but if he ate, he ate, if he drank, he drank. We would keep him comfortable and not send him out. So, in the end, the family agreed to downgrade the ACP to comfort care. (Assistant DOC; Interview: 03)

It was evident in this study that, when there was a decline in a resident's status, nurses worked to piece together the resident's big picture through ongoing assessments as well as collaboration with other team members. Once the nurse crafted their own perceptions of the resident's big picture, they sought to obtain an understanding of how the family viewed the resident's situation. They worked to piece together an understanding of the family's big picture. Nurses believed that if a resident's comfort was to be optimized, the nurse's big picture needed to be aligned with the family's big picture of the resident's condition. In order to gauge if the big pictures were aligned or not, nurses assessed the family to get an understanding of their big picture.

Piecing Together the Family's Big Picture

The process identified as 'piecing together an understanding of the family's big picture of the resident's condition' involved nurses initially 'getting an overall feel of the family'. This involved a combination of analyzing the family's characteristics and relying on the nurse's own intuition. Nurses thought that getting an overall feel of the family aided in the development of an individualized approach to communication. Nurses gleaned information from a variety of sources to get an overall feel of the family and understand their big picture. The process of piecing together the family's big picture is described in more detail in the following section.

Sources of Information for Getting an Overall Feel of the Family

Family Characteristics

In order to piece together the family's big picture, nurses collected information on the following family characteristics: (a) knowledge of the resident's health status; (b) ability to understand medical information; (c) readiness to engage in ACP discussions; (d) religious and cultural background; and (e) decision making processes and family dynamics.

Knowledge of the Resident's Health Status

The nurses reported that every family was different and that interactions with each family were unique. They found that knowledge of residents' health conditions and prognosis varied greatly from one family to another. When nurses understood the family's awareness of the resident's health status, they were better equipped to navigate ACP conversations with the family and tailor these discussions to their needs. The following exemplars describe the study participants' experiences regarding the family's understanding of their loved one's health status:

> Families are very, very different. Every single interaction is a completely unique experience. Some families are very engaged with the resident. Some people understand very much about their illnesses and their progression and all of that. And some people understand nothing, – and need lots of guidance and explanation. And each situation I kind of deal with as I gage what the family needs. You have to have a feel of the family to know how to approach the family (Unit nurse; Interview: 01).

> Some families very aware of their loved one's illness and they know where their loved one's life is heading to. Some have no idea about where their loved ones are in the illness trajectories and how they are progressing in their conditions and oftentimes they don't know and they don't see it. And that makes it really hard to talk to them. So you have to have an idea of the families knowledge about their loved ones conditions and then you decide how to go from there with your ACP discussions (Unit nurse; interview: 12).

Ability to Understand Medical Information

Study participants stated that, in general, healthcare professionals did not explain medical terms in an understandable way. They believed that medical terminology was challenging for families and that issues needed to be explained in accessible language to ensure families understood. The following quote from one of the nurses underscores the confusion that medical terminology posed for families, and emphasizes the importance of communication using language that was easy to understand:

> Unfortunately, as healthcare providers, we have our own language, and we don't always explain to people in language they can understand. There is a reason to use appropriate terminology. You know, medicalese is a language all its own. You know, if you speak it, it's relatively easy among the HCPs (healthcare providers), it's a challenge for the patients and families, so in advanced care planning use the language they understand in lay person way. (DOC; Interview: 02)

Nurses in this study indicated that it was beneficial to explain information in the families' mother tongue to enhance their understanding; this was the case even for families who spoke and understood English as an additional language. One of the nurses described the importance of language as follows:

> If they're able to understand English, sometimes words they don't understand like medical terminology can already be heavy. And having a secondary, like English as a second language I think can complicate that because it's interpreted differently. And so, sometimes using language to your advantage in terms of making it the most explained and the most well understood I think is a benefit. So, like I always use this analogy, sorry but like if you have somebody who speaks Tagalog and the whole family speaks Tagalog as their primary language. – even if they're Canadian and they all speak English really well, sometimes that conversation is more comfortable in their primary language because that's the one that they use the most at home. (RCM; Interview: 22)

Readiness to Engage in ACP Discussions

Study participants believed that a family's readiness to engage in ACP conversations was influenced by where the resident had lived prior to moving into LTC as well as by the family's level of acceptance of the resident's health status.

Place of Admission. It was important for nurses to understand where a resident had lived prior to their LTC admission as well as the situations that led to their placement in LTC. Families whose relative had been admitted from another LTC facility, and had already been involved in ACP discussions at another facility, had a higher level of readiness for ACP conversations. Conversely, families of residents admitted from the community or hospital were highly stressed and not immediately ready to engage in ACP conversations. These families required more time and encouragement from nursing staff to engage in such conversations. As captured in the following exemplar, study participants believed that the families of residents admitted from community or hospital were grieving the fact that their loved one was not coming home:

> I think the things that just make it difficult is just where that person is in their process and where they are admitting from. Some families are OK to have that conversation from day one and other ones you might have to wait a little bit before you can start talking about something like that (ACP) because they're not there yet. They're still grieving that their loved one isn't coming home. So it really depends if they're coming from community, if they're coming from hospital, if they're coming from another PCH. Usually the transfers we get from other personal care homes, they're fine. We don't really have to put a lot of work into that one, right, like the more nurturing we have to put into is the ones that are coming from community. There's a lot more loss there and same with hospitals, right. Well she just fell and broke her hip. I didn't think that we'd be here. So it's really just looking at each situation and gauging it from there. And they're not all the same. (DOC; Interview: 19)

Level of Acceptance of Health Status. Study participants believed that a family's readiness to engage in ACP conversations was influenced by their level of acceptance of the resident's health status. Some families were seen as being non-accepting of the resident's decline and unrealistic about the plan of care. These families were characterized by the nurses as being "angry." Other families were characterized as being resigned to the resident's inevitable decline, more willing to "let go," and more realistic about the care plan.

Holding on/Angry Families. Families who were not ready to accept the reality of the resident's decline and who were angry most of the time were characterized by nurses as being the '*complex ones.'* Nurses stated that angry family members often held on to their loved ones and were in denial about the resident's decline. Most were not ready to accept the resident's big picture and had unrealistic treatment goals. These families often only trusted management staff and preferred to direct their communication to the nurse manager and/or DOC, refusing to speak with the unit nurses or social worker. These families were described by one of the participants in the following quote:

> They aren't willing to accept and want to hear nothing about it usually they're just quite angry all the time and they just need a little bit more love. Don't want to hear anything unless it comes from the senior leader. They don't want to talk to the nurse; they don't want to talk to the social worker. They want to come right to me. (DOC; Interview: 19)

Holding on/angry family members were typically the primary caregivers for their loved ones in the community. They had kept their relative at home for as long as they could, and were described by the nurses as not being ready to move their loved ones into LTC. These family members were highly involved in the residents' day-to-day care prior to their LTC admission, and knew their baseline very well. Thus, they took any small changes in the resident's status very seriously and demanded that LTC staff further assess and investigate the reason(s) for these changes. These types of demanding behaviours were intimidating for the unit nurses and made them feel threatened, as described in the following example:

> There are three daughters, they have taken care of the resident since she has been sick. So they were the main caregivers when she was at home. They kept her at home as long as possible and then couldn't do it anymore so now she is with us. The family, again, is super involved in her care and they know their mom very, very well. And I think that some of the nurses are intimidated by that. They feel threatened, right. So it's always like a pissing contest because the family will come in and they'll say, you know, I think my mom has this, or, my mom has a UTI, or my mom is complaining of pain and they

> demanded assessments. But meanwhile for the most part, she's been OK all day. So they're seeing things that we don't see. (DOC; Interview: 19)

The nurses noted that holding on/angry families needed staff to repeat information about the resident's status several times. These families tended to choose hospital transfers and aggressive interventions that were focused on keeping the resident alive, rather than giving priority to their comfort. Nurses believed that families who were angry and holding on made decisions about their loved one's care to avoid experiencing feelings of guilt, which arose from misperceptions that they there were not doing everything possible to help the resident survive. As a result, these families prioritized quantity of life over quality of life. The family members who were characterized as angry and holding on infrequently referred to the resident's wishes or preferences. At times, these family members completely disregarded the resident's written preferences for care, as expressed in their living will. This phenomenon is articulated in the following quotes:

> Some families don't want to let go, they hang on until the last moment. I think it is that the family attachment, and that they don't want to let go, even though they understand what you're saying, but do not to accept it. But just because they can't let go, and the guilt" (RCM; Interview: 14); and
>
> Even when the individual is competent and able to make their own decisions, then the family want to overrule it at the last minute, when the person isn't competent. And very often that's because the family just isn't ready to say goodbye, they haven't faced the reality that that's coming. (DOC; Interview: 02)

Letting Go/Resigned Families. Letting go/resigned families did not exhibit the anger and holding on behaviours previously described. These families were viewed by the nurses as more relaxed and accepting of the resident's decline, and more realistic about the plan of care. These families acknowledged that their loved one was nearing EOL and had accepted that they would remain in the LTC facility until EOL. Letting go/resigned families were ready to discuss ACP and wanted to know more about their loved one's condition. These families were perceived as being grateful for information provided by staff. They were willing to talk to any member of the healthcare team about the resident's status and ACP. They did not require repetition of information about the residents' status and were labelled as '*la-di-dah'*. According to the nurses, family members who were accepting of the resident's big picture were more likely to choose comfort care interventions for their loved ones when compared to those who were in denial. Families who were letting go/resigned could easily understand when the resident's status was declining and did not want to prolong their suffering. Letting go/resigned family members prioritized the resident's best interests when making decisions, and focused on achieving optimal quality of life rather than quantity of life. These types of families wanted to keep their loved ones comfortable at the LTC facility and avoid sending them to the hospital. These families were agreeable to downgrade the ACP level to comfort care without any difficulty or pushback, as noted in the following example:

> When you have somebody is just la-di-dah, relaxed and whatnot, so it doesn't have to give a lot of information, doesn't have to revolve in conversation. So the conversation doesn't have to repeat over and over until they get that point. It's easy for them to understand and then they all just want to make sure that their loved one is comfortable to the very end, right. So if keeping them comfortable means not sending them to hospital, then it's easy for them to say, OK, let them stay or let them be comfortable in your facility and then we'll change the ACP to comfort care. (RCM; Interview: 08)

Religious and Cultural Background

Nurses reported that knowledge of the family’s religious background was important when having ACP conversations. They found that families who were deeply religious, especially those affiliated with Roman Catholicism, had high expectations for medical interventions in the face of declining health status. In contrast, most non-religious families wanted their loved ones to be kept comfortable at the LTC facility, without hospital transfers. The following quote from one of the nurses demonstrates how they prepared to have ACP conversations in the context of families’ religious backgrounds:

> You have to be prepared for when you’re talking to families. Some people are hard-core that their loved one or their mother is already 97 years old, they still want resuscitation and they want all heroics because their religion says that life is sacred and then to the end that they have to fight for it, and if they could make it then they would do whatever. On the other hand, when you have somebody not that religious want to make sure that their loved one is comfortable to the very end, right. (RCM; Interview: 08)

Nurses found that the family’s cultural background also influenced ACP discussions. Families that were characterized as being ‘Canadian’ were believed to have been exposed to the ideas of ACP and LTC for generations and, thus, accepted the notions more readily. Nurses found it easier to discuss ACP with families who had lived in Canada for generations, when compared to those who had recently immigrated. For example, nurses found that Asian families had more difficulty engaging in ACP conversations due to their close family ties and high respect for elders:

> I do know that Filipino and Chinese culture, they have a lot of respect for their elders and that's, I think, a huge part of it. They want to do everything they can for their [tati] or [nani] or whatever, you know. What I mean by that is when they're a comfort care level,

> then they do want them sent into hospital if there's any treatment that can be done. Even sometimes it's a UTI and they want them sent in for that. I think in general the Asian cultures have a hard time to let go. (Unit nurse; Interview: 12)

The following exemplars from two nurses, born and raised in India, describe the cultural differences in ACP acceptance amongst families:

> I want to say that in Canada they're going through it from generations because they're born here, their parents were here, their grandparents were here, their great grandparents were here. They have been going through ACP and long-term care the level of care discussions. I believe they know from the very beginning. And they accept the reality but as I told you in my family my mom doesn't accept the reality or the people in India they do not accept the reality because they get shocked if you will tell them. They don't accept the ACP (Unit nurse; Interview: 13); and
>
> Asian families I think it's very hard to take those kind of ACP decisions, because the people who are Canadian culture, they are – it's very easy to discuss with them all those things, about ACP. But it depends on the culture, in Asian culture I think these are the things to discuss very hard with them, because I can see myself, like as an Indian born. So related to Indian culture, I think it's very hard to discuss those things about my parents. (RCM; Interview: 10).

The nurses noted that the Jewish culture believes life is sacred so Jewish families often feel they have to explore every aggressive intervention to keep the person alive. This belief influences the families' decisions about ACP. For these families, quality of life is not the primary concern; instead, their focus is on survival of their loved one so they will always choose ACP-R. This notion was well stated by an RCM:

> I find the Jewish population are a little bit hard because I think that's their core value: Life is sacred. So when you have that they would really go aggressive and say I want them to survive no matter what, and if they survive and become a vegetable they're OK with that as long as they did survive. So they want to try to make sure that every test is done, everything possible can be done for that person. So, they always chose ACP R. (Interview: 08)

The nurses interviewed in this study noticed generational differences in some cultures, specifically regarding the willingness of family members to engage in ACP conversations, which influenced the way the nurses provided ACP information. Nurses reported that family members who were older, or from the baby boomer generation, were often hesitant to engage in ACP discussions and/or downgrade the ACP level. Moreover, compared to family members who were millennials, information about the ACP had to be repeated over and over. These experiences were captured in the following quotes:

> Especially with the baby boomers, you know, they have a lot of respect with the elders, especially the Filipinos. So that's considered a generation gap that's considered also a culture on their own. In terms of the other generations, like, me, probably this generation, millennials, they're probably different, they're probably more accepting ACP, yeah and the older generation is not accepting it and need information over and over (CRN; Interview: 07); and
>
> The person is still in R, (ACP R) and she in 100 years old and there's a son who is from Portugal, he phones his mom every day, he speaks English. So he said, you know, her goals of care, blah-blah-blah, and he said, oh, I still want to talk to my daughter about it, who is her granddaughter, who lives here. This grand daughter is young and she

> understands well about her grand mother's poor health, but her father has a hard time changing the ACP, I think this is because the attitude toward ACP between them, she is in her 30's and he might be in her late 70's. (RCM; Interview: 04)

Decision Making Processes and Family Dynamics

Nurses believed that it was important to know who the family designated as the decision maker, either formally or informally. The nurses also noted it was crucial to understand the family's decision making processes and dynamics before embarking on ACP conversations. Nurses reported that identifying and communicating with the family spokesperson facilitated ACP discussions and helped circumvent the nurse from getting caught between family members who disagreed about ACP decisions. The following quotes explain the benefits of knowing the process of decision making in families:

> If you have a family that's disjointed and has relationship issues, then that can make it very difficult because one family member wants one thing and one wants another, and then you're stuck in the middle. Knowing your spokesperson for the family is important to have the ACP conversations. And talking to that person could help you to come to a decision on ACP (Unit nurse; Interview: 09); and
>
> I know that sounds but when you go into such detail in terms of advanced care planning, I think it really need to have an insight into how those families function, what their dynamics are, who makes decisions, how they make decisions. So I kind find the family background is beneficial overall for just even care conversations. (RCM; Interview: 22)

Nurse’s Intuition

Nurses stated that they used their intuition in order to get an overall feel for the family, and described this as a skill that took practice. They used intuition to assess the extent to which the family had accepted the resident’s health status and to determine if they were ready to have a conversation about ACP levels. According to one DOC, some families were ready to talk about ACP levels from day one, while others needed more time:

> It's almost like you have to be able to have that insight and that intuition and just kind of feel out where they (family) are. So it's really just like a skill that you have to practice and you learn and some families are OK to have that ACP conversation from day one and other ones you might have to wait a little bit before you can start talking about ACP because they're not there yet. They're still grieving that their loved one isn't coming home. (DOC; Interview: 19)

Nurses reported using what they described as their sixth sense or gut feeling to know when to initiate ACP conversations with families, as well as how each family would respond to the downgrading of ACP levels. These intuitive feelings were based on observations the nurses made on the resident’s first day in the facility, as described by the following two participants:

> Sometimes you can kind of read people, if you had someone come in that’s very anxious and you can see it, then you might be thinking, oh no I am not going to talk about ACP on the first day, but your gut feeling say no I have to do this, by looking that frail resident, thinking anything could happen to them. I always go with my gut feelings (Unit nurse; Interview: 24); and
>
> I don’t have a crystal ball to tell which resident will die soon, but I could tell how each family would react in chancing that ACP down to comfort care even by watching them

> on the admission day. I am right most of the time and others think I have a sixth sense to know this. (RCM; Interview: 04)

Outcomes of Collecting Information

The two outcomes that resulted from nurses collecting information about family members and getting a feel for the families included: (a) individualizing the approach for ACP discussions, and (b) addressing information gaps/misperceptions.

Individualizing the Approach for ACP discussions

Collecting information about the family from the sources previously described enabled the nurses to get a feel for the family. The process of getting to know the family also provided context for the nurses to individualize their approach to ACP discussions. The nurses then engaged in the next pre-condition of 'selling the nurse's big picture to the family':

> I think some families just are more open, and some families aren't, and some families, they just, they don't view their elderly parent as they are old. They're still living back in the time when mom was living at home and she was fine. So you have to take theses differences in consideration and plan how you approach the family with the ACP discussions and telling them where their loved one at *[sic]* in their illness trajectory. (Assistant DOC; Interview: 03)

Addressing Information Gaps/Misperceptions

Assessing family members' understanding of their loved one's big picture was an important component of the nurses' overall assessment of family characteristics and readiness to engage in ACP conversations. When families expressed unrealistic goals or treatment choices, the nurses assessed if the family members: (a) had sufficient information to construct an accurate picture; (b) had interpreted information received accurately; and (c) had accepted and understood the information in the same way as the nurse. Nurses reported that they were responsible for providing information to family members to help them understand an accurate big picture that was congruent with their own:

> We have seen some people truly, what we believe, is suffer. And we have to care for them because families have made decisions that aren't necessarily in the resident's best interest, but the family want to keep them alive, so to speak. Or want to keep them going. And that has caused some distress to staff. "We would never help so-and-so overcome whatever illness." But I think there should be a better understanding about the risk benefit of the decisions in families, that's all. I think it is the nurses, our responsibility to make the family understand the overall big picture. I think nurses should help the family to see how their decisions affecting the resident's overall life. (RCM; Interview: 06)

The nurses needed to have a clear understanding of their own perceptions of the resident's big picture as well as a feeling of the family's understanding and readiness to accept this big picture. Once this was achieved, the nurses tried to implement the next pre-condition for the process of downgrading the ACP level: 'selling the nurse's big picture to the family.'

Selling the Big Picture

"Selling the big picture" was defined as the process by which the nurses made efforts to help family members understand and conceptualize the resident's condition in the same way as the nurse. The driver for selling the nurse's big picture to the family was often triggered by a decline in the resident's health and/or functional status. These conversations were also triggered when the nurse believed that the ACP level on the resident's chart would cause undue pain and suffering. When there was a decline in a resident's health status, the nurse had conversations with family members to help them understand and accept the nurse's conception of the resident's big picture. The ultimate goal of these conversations was to explain the appropriate GOC and ACP level for the resident and seek agreement from the family. In other words, family members need to be sold on and come to acceptance of the nurse's big picture.

Nurses reported that there was no standard script to follow for discussing ACP levels. Furthermore, a standard script would not be practical as each family is unique, with different backgrounds and levels of acceptance of their loved one's condition. Therefore, knowledge of the family's expectations and their understanding of the big picture helped nurses determine the effort needed to sell their own big picture to the family. The following quote from a unit nurse describes how she used an individualized approach to help families see the big picture:

> There's no such thing as you follow. So you have to explain it (ACP) on the level that they'll understand what you're saying. So make sure that you do in such a way that they would understand what you're saying, not just reading what's written in there. You have to explain exactly in a level that they would understand you by knowing the family's background and where they are at. (Unit nurse; Interview: 09)

Situations in which family members were sold on and accepted the nurse's big picture resulted in the resident's GOC being directed toward comfort care. These outcomes were described very positively by the nurses:

> I'll tell you, some of the easiest going, most comfortable families, they've come in with their goals of care that says, comfort. Like, you know, it's just because they've come to this acceptance that this is the way life goes, right. I'm just thinking of this latest fellow that we admitted on comfort care, and the family is just so delightful., we haven't known them for long, but it's like you've known them forever, because they're just so good and accepting the reality. (RCM; Interview: 04)

Based on their assessments of the family members' understanding of the big picture, nurses engaged in a variety of strategies to sell their own conception of the big picture. The ultimate goal of this process was for the resident's family to accept the big picture and choose the appropriate ACP level (C), which the nurses believed would lead to a good death for the resident in LTC. The strategies used to sell the big picture are discussed in the following section.

Strategies Used to Sell the Big Picture

The nurses in this study used a variety of strategies to sell the resident's big picture to their families, including: gentle persuasion; team persuasion; and drawing a line in the sand: enough is enough.

Gentle Persuasion

The strategy of gentle persuasion involved appealing to the families' reasoning and understanding of the situation to help align their perspectives with those of the nurses. Nurses primarily accomplished this by keeping family members in the loop and updating them about the resident's deterioration. This strategy was based on the predication that family and nurse perceptions of decline would be the same, and that families would agree to comfort-oriented GOC.

The following exemplar illustrates how a unit nurse gradually introduced family members to the reality that their loved one was declining. The nurse provided the family with regular status updates to help them see the big picture and understand the discomfort and suffering associated with unnecessary interventions, such as hospital transfers:

> Well we slowly – actually show them that their mom or dad is declining. And if we don't do these things it may not be helping but we'll be doing more harm. Like if it won't happen – it won't happen in a day. Like it's a continuous getting them the information,

> giving them update status and giving them how the changes of their mom or dad is. Like until they could see the big picture that, yeah, you're right, like we are not helping my mom or dad if we keep transferring him or her back and forth from the hospital. Because even transferring them to the hospital back to the home so many times, it's not very comfortable for them. (Unit nurse: Interview: 09)

An RCM reported that, upon noticing changes in a resident's condition, she would tell the family members about interventions that had already been implemented, including physician's orders. She thought this approach would provide context for families to understand the care that was being given and, thus, provide a foundation for ACP conversations:

> When I want to discuss an advanced care plan, I do not go, oh, your mom needs to be changed to ACP C. It's something that, you know, maybe for a week I would have been calling you and saying, your mom's condition is this. So I wouldn't even talk about the ACP at that point, but I will just let you see the big picture of what is happening already with your mom. Your mom has not been eating, your mom has been doing this. So we tried this, we are trying this. The doctor has ordered this. Or sometimes we sent them to the hospital, and they were sent back. You know, like, I just give them the big picture, then we get into the ACP. And then by the time I start discussing the ACP, I would have them understand the big picture. (RCM; Interview: 14)

Nurses undertook a variety of gentle persuasion activities to sell the resident's big picture to the family, including: (a) building relationships with families, (b) educating family members, (c) setting the stage-putting a bug in their ear, (d) fostering perspective taking, and (e) giving families time to process the situation.

Building Relationships with Families

The study participants indicated that building relationships with family members was important to facilitate their acceptance of the nurse’s big picture. Therefore, nurses tried to develop trust with the resident’s family members starting at the time of admission to LTC. They sought to maintain that trust through transparency and regular communication about the resident’s health status. Nurses reported that family members were not willing to engage in difficult conversations unless some level of rapport and trust had already been developed. They believed that strong rapport made it easier to persuade families to embrace an ACP level of comfort care. The following exemplar illustrates the importance of developing trust and rapport to work effectively with residents’ families:

> I do work very hard to develop that rapport and then to maintain it and then to keep people aware of the changes. I believe that that's incredibly important. I try to establish that very, very quickly when I'm admitting somebody to my ward. I'm on a unit, I'm always on the same unit. I have 25 people that I care for. And I always care for the same 25. So you do develop those rapports, which help to have the ACP conversations and make the family change it to comfort care, because they trust me. (Unit nurse; Interview: 01)

According to one of the DOCs interviewed in this study, relationship building was important; if family members did not know a nurse well, they were not willing to talk about ACP:

> You know, it really depends on the family. And it depends on building relationships with families. Some families are open to it from the beginning, but I would say, most families, if they don’t know you, they don’t want to discuss ACP. It’s different in an emergency situation, they're willing to talk about it then, but in long-term care, it’s more about a

> relationship. We want to get to know you, we want to know that you care, before we want to talk about those parts of care. (Interview: 02)

Study participants believed that it was important to keep families aware of the residents' status on an ongoing basis. Nurses initiated conversations as soon as they noticed small changes in a resident's condition. When family members received regular updates on the resident's status, the nurses felt it was easier to initiate discussions about comfort care when the resident's health deteriorated. The nurses believed it was beneficial to consider family members to be part of the care team by keeping them informed about the resident's care. They felt this strategy helped ensure the families' big picture was consistent with that of the nurses.

An assistant DOC reported that she initiated conversations with family members as soon as she noticed small changes in a resident's condition. She stated that regular updates with the family made it easier to initiate conversations about downgrading the ACP level when the resident's condition deteriorated. The following exemplar shows how nurses kept family members in the loop in order to shift their perceptions of the big picture:

> I think the other thing that really makes it easier is keeping families in the loop. So, this shouldn't be a shock that dad's not doing well. Like, when he starts to deteriorate, sort of open up that conversation right there and then, and just say, you know, dad's okay right now, but he isn't really eating, but he picked up. So, we're okay now, but what about next time? Like, make them sort of really see the big picture that, and keeping them fully in the loop. And that's kind of what we do at care conference, is sort of putting, I guess, that bug in their ear before they get there. (Assistant DOC; Interview:03)

Educating Family Members

Nurses believed that educating family members about prognosis and treatment choices played a central role in helping them understand the resident's big picture. Participants reported that family members often had limited knowledge about diagnoses, the physical and functional impacts of illnesses, and the negative outcomes of aggressive interventions, including hospital transfers. Families also lacked information about the different ACP levels. Nurses believed that education about disease progression and ACP levels, especially in the case of dementia, facilitated the development of realistic goals and ACP levels for residents. The study participants described family education as an ongoing process that needed to be initiated early.

One of the unit nurses had set a goal to educate family members about the residents' different diagnoses and ACP options at the time of admission to LTC. She intended to persuade the family to choose a realistic ACP level that would maximize quality of life for the frail resident:

> When they come for admission, my primary goal is to establish that advanced care plan on that date. Because that really dictates how we take care of them. At our personal care home, we don't want anyone with an advanced care plan R because we don't provide CPR on site, so I try my best to educate family about the APC levels and different diagnoses of their loved ones and persuade them to choose level appropriate for the person. I would like them to choose ACP C, this way we can provide quality of life for this frail people. (Unit nurse; Interview: 23)

Due to their lack of understanding about the progression of dementia, family members often opted for medical interventions that would promote life at all costs. In order to improve the care outcomes of residents with dementia, the nurses educated families about the progression of the disease and the traumatic impact of aggressive interventions. They wanted to ensure family members had enough information to understand the big picture so they could make realistic ACP and treatment decisions. The following quote from an RCM showed how this type of education helped family members shift their conception of the big picture to make realistic decisions about GOC and ACP:

> Sometimes we have families who are not of understanding of the progression of dementia. So they always want us to go and keep doing everything we can to fix them like tube feeding or, you know, continue sending them out for investigations into medical concerns, but it's a very, very traumatic experience for the residents themselves. So those are usually the conversations that I get involved with whereas we kind of do a little bit of education with the families, talk about the disease progression and what going out and treatment would look like for the resident if they were to go through these experiences. And then we support the family members in whatever decision they do make for their loved ones but we want to make sure they have a clear understanding. (RCM; Interview: 25)

Nurses reported that families frequently had misconceptions about comfort care; they believed that nothing would be done for residents who were coded as comfort level advance care plan (ACP-C). Nurses were able to provide education that shifted these perspectives and made families less resistant to pursuing comfort care for residents. For example, nurses explained to families that residents who were ACP-C could still be treated for infection with antibiotics in the LTC facility:

> Families also want their loved ones to live long, and also a lot of misconceptions. Like, if they put the resident in comfort care, then nothing will be done. So there’s a lot of resistance prior to education, prior to obtaining knowledge. So if there’s education, then they will be able to understand, like, oh, okay, so if you're comfort care, it doesn’t

> necessarily mean that we just have to leave the resident on her own, you know. It depends. If the patient has a urinary tract infection, we're still going to treat them orally at the home. So then they will understand, like, oh, okay, so you're still going to treat, you know, the ones that make them more comfortable, yeah. So normally, initially they will have a resistance and being difficult, but after the education-they're more convinced, like, okay, so my mom wouldn't really be left alone, something like that. (CRN; Interview: 07)

Nurses also provided education about the progression of disease, illness trajectories, and the impacts of illness on the residents' quality of life. Nurses believed that helping family members understand the clear path and timelines of decline shifted their understanding of the big picture, ultimately persuading them to choose a realistic ACP level:

> The thing that was very successful for me was educate families about the disease progression and to project the trajectory progress or the timeline for them, so if they have this disease what happens to them. So if you educate them the clear path as to how the disease takes part and how the disease will lead to the decline of their loved one, it's easier for them to see that and understand that, oh yeah, I don't want my mom to go through that, or yeah, I don't want them to go out and do that and I don't want her to be in this. So, we promote quality over quantity is what matters, and sometimes they would take that as a positive and change the ACP. (RCM; Interview: 08)

The nurses in this study stated that they educated family members about the causes of dehydration and impacts of hospital transfers for residents with dementia. One of the nurses shared a story about a resident with dementia who was suffering from dehydration and poor oral intake. The education provided to that family helped them understand the big picture, identify realistic treatment goals, and understand the ramifications of their decisions. Through this education, the nurses were able to get the resident's family members on the same page so they could downgrade the resident's ACP level to comfort care:

> We had a resident who is failing and looked like dehydration and he does have feeding problems. He was still on medical, and they were still wanting transfer to hospital. So, we wanted to educate the wife and the daughter and find out what their goal was. We clarified how we were seeing changes in their loved one. That he wasn't taking food, and we clarified what dehydration meant and what a trip to the hospital meant, and wouldn't that really cure it, and no tube feed. So, we just talked more about doing our best to feed him here, at the lodge, but if he ate, he ate, if he drank, he drank. They wanted him to be able to, as they put it, die with dignity. And we would keep him comfortable and not send him out. So, in the end, the family agreed. We both came on the same page and with the same agreement, in the end So, he was changed to an ACP-C and we revised the ACP form. (Assistant DOC; Interview: 03*)*

Setting the Stage: Putting a Bug in their Ear

In this study, nurses used terms such as 'setting the stage' or 'putting a bug in their ear' to help the family understand that the resident may be approaching EOL and open conversations about prognosis and future decisions. Nurses believed that setting the stage was important because it provided a context within which to anchor communication throughout the trajectory of the resident's decline. It also helped family members make realistic decisions when their loved one's condition became terminal.

An RCM reported that she deliberately called family members every week to keep them informed of their loved one's health condition. She stated that these phone calls sometimes took only a minute. She felt this strategy was more effective than only calling families when the residents' condition had changed or deteriorated:

> By making sure that they (family) are updated over everything that is going on. And they are updated with any change in medication, any changes in care, like, in their condition, like, you update them almost daily. And you just make them part of the care team, by making sure that they are part of what is going, we don't wait until something big happens or the condition is deteriorating. I dedicate a day of the week to call families and update them. I'm just calling you, how are you, how are you doing? Calling you to let you know that this is happening about your mom. Mom is off medication and this is what is happening. This happened to her this week, or she got into maybe an altercation with somebody, or she's eating well, or she's not eating well. Like, you just keep updating them, so family is aware of what is happening with resident and when the time comes it is not hard to the downgrade the ACP. (RCM; Interview: 14)

Perspective Taking

Perspective taking involved nurses encouraging family members to think about the interventions the resident would have wanted when he/she was still able to communicate their wishes. Nurses perceived that getting family members to focus on their loved one's own wishes helped them feel less guilty about choosing a realistic ACP level. Exploring residents' prior stated wishes with family members seemed to lessen families' burdens, specifically the feeling that they were holding their loved one's life in their hands. Perspective taking relieved families' fears that their decisions would hasten their loved one's death. In other situations, nurses encouraged family members to consider the resident's quality of life, noting that most people do not want to experience undue suffering and pain at the end of their lives. Nurses believed that provoking families in this way helped them consider choosing less aggressive interventions for their loved ones. Perspective taking strategies also lessened the families' feelings of guilt and eased the burdens of decision making. Nurses were able to successfully implement this approach in most cases.

According to the following quotes, the nurses believed that perspective taking helped family members make realistic decisions:

> I'm more likely to say, did you ever have this conversation with your mom, do you have any idea if she had a note in her pocket to tell you what to do today, what she would say to you, that sort of thing? This way it is easy for families to decide comfort care and they won't feel that guilty (RCM; Interview: 04); and
>
> I will always ask family, what do you think what your mom will say to you if she's still competent to have those decisions. Like will she still want to have those IVs inside her or those further investigations – like what they think. (RCM; Interview: 10)

An RCM successfully facilitated a daughter's acceptance of reality by asking her to imagine herself in the same situation as her mother (the resident):

> A daughter come to me and say, oh, Mom came back from the hospital, she has not opened her eyes. Oh my god, I'm not giving up on Mom, I'm not giving up. Like, she kept repeating that. And then, you know, they were all there, they all knew that she was dying., I said, you know what, - she's not even opening her mouth to take her medication anymore and she's fluid-overloaded. I asked the daughter, just imagine you are going through like her, can't breathe with no quality of life, do you want that? She said no, let her have a peaceful death. Now I'm going to make her to comfort care. It worked and she felt relieved, she hugged me and said thank you. (RCM; Interview:14)

In order to persuade a family to choose comfort care, a unit nurse asked the family to consider the physical and emotional burdens of aggressive interventions on the resident:

> Do you think your loved one can tolerate the trips back-and-forth to the specialist, to the treatments? Can that body tolerate the treatments? Can that body handle all the things that are involved with what's going to happen next? And if you don't think your loved one can mentally or emotionally or physically handle that, then maybe we need to consider going to comfort care and supporting them through what the next journey is. (Unit nurse; Interview: 01)

Giving Time to Process: Downgrading the ACP Level in Stages

The study participants reported that it was important to give family members enough time to process information and avoid forcing them to make ACP decisions right way. Nurses waited until families were ready to accept the big picture, except in cases where the resident was actively dying. If families were not ready to hear about a decline in their loved one's health status, nurses tried to present the information over several conversations. This allowed families to absorb the information slowly and decreased their desire for aggressive interventions. In order to permit families to slowly accept the reality of their loved ones' deterioration, nurses persuaded families to downgrade residents' ACP levels in stages. In cases where the resident was ACP-R, downgrading in stages involved gradually changing the ACP level from R to medical to comfort care. Nurses felt that downgrading in stages gave families more time to process the information and accept the day-to-day decline in their loved ones' health status.

One RCM reported that she and her team helped a family come to terms with their loved one's condition over a six-month period. She and the nurses helped the family understand the consequences of a surgical intervention for their loved one, who already had a poor prognosis and quality of life. The family accepted the big picture and agreed to a realistic ACP level:

> The patient actually was an "R" and was having difficulties, having cardiac difficulties, did have a pacemaker that was actually malfunctioning and has also comorbidity. The family want to send her for surgery and she in a wheelchair and eyes closed all the time. We know she won't do well with the surgery and hospital transfers. So discussions with the daughter was provided spaced out so there was one discussion in November, one in February, and one in April or in March. And then so with that slowly letting them know that this is what's happening, this is where she's going. There were various conversations throughout the six months timeframe just to make sure that they get it. It's not like we're trying to make them change their minds right away, but you have to just ease it in because it's sometimes not an easy conversation to have with families. So it was successful. It did take time. It did take a lot of work. It did take a lot of explanation and conversation with the family. But when they got it, they got it and they were just happy that they did that. At the end we able*[sic]* to downgrade the ACP to comfort care, and like I said, it was in the course of six months so we're easing the conversation. (RCM; Interview: 08)

One of the unit nurses believed that downgrading the ACP level in stages allowed families more time to accept and understand the residents' big picture. This nurse indicated that best practice was never to recommend changing the ACP level directly from resuscitative to comfort care unless the resident was imminently dying.

> Sometimes there's no point of keeping them (residents) on ACP R, if you know that there's no more chance for them to survive. So then we slowly – like if they're

> resuscitation we don’t go straight to comfort. We kind of go in “stages”. What *[sic]*that mean, we ask them (family) to go from ACP R to ACP M, then slowly to ACP C, instead of from ACP R to C. This way they get more time to absorb the information and see the changes in the person. (Unit nurse; Interview: 09)

In summary, the gentle persuasion strategy helped nurses provide information to families about the changes they were seeing in residents over time. This strategy prepared family members for the big picture and the possibility that their loved one was nearing EOL. Nurses were able to educate families and create an environment of trust and transparency that made them more likely to agree to an ACP level of comfort care. Nurses provided family members with regular updates about the resident’s decline and used the strategy of gentle persuasion to help family members understand the discomfort and suffering associated with certain interventions, such as hospital transfer.

Team Persuasion

The strategy of team persuasion was a process whereby the nurses ensured that all members of the healthcare team were communicating the same story about residents’ declining health status to their families. This process aimed to ensure that the team was working toward a common goal of comfort care. Participants described consistency and working together as a team as central to helping families accept the big picture. Consistency required that all members of the team repeatedly paint the same picture for families, in terms of both the content and interpretation of their communication. Successful team persuasion was contingent upon the team’s ability to first see a common picture, then work together to sell it to the family. One of the participants described this strategy as follows:

> Within the disciplinary team, it's easier if everybody knows the health condition, and also if everybody is on the same page, like, that the resident benefitting more *[sic]* from comfort care. So the interdisciplinary team will also give their input, like, okay, you know what, the resident might even be in discomfort if we still continue to give her meals that she can actually aspirate. A lot of times, if it is more of a team that is suggesting, then there is more weight, like, the family member is able to understand more in terms of the different aspects of care, and make the downgrading of the ACP easier. (CRN; Interview: 07)

When nurses were unable to reach consensus with family members on a realistic ACP level for a resident, they interpreted this as an indication that the family members were either in denial of the big picture or needed more information to facilitate their acceptance of the big picture. In such circumstances, nurses utilized the strategy of team persuasion to facilitate family acceptance of a more accurate big picture. The following example demonstrates the use of the team persuasion strategy for this purpose:

> If we've kind of talked about it with the family, and sort of said what we think comfort care is appropriate, and they (family) are still saying, "Oh, we just can't do this. We just can't do this, like let's keep her full R. Like we can't do this". They are in denial so we get input from the interdisciplinary team, it's easier for family if everyone of team knows the health condition, and also the whole team is on the same page, like, this resident is benefitting from comfort care than sending to hospital. (CRN; Interview: 07)

Through the use of team persuasion, nurses ensured that families were presented with a unified picture of their loved one's condition. When nurses had concerns about family members who were not accepting the big picture, they collaborated with the healthcare team through the nursing actions of: (a) working together, (b) using others to run inference, (c) calling family meetings, and (d) leveraging the opinions of hospital staff about an appropriate ACP level, only when residents had been transferred out of the LTC facility.

Working Together

Working together entailed nurses communicating with each other about the resident's declining status during rounds with physicians and shift-to-shift reports. Communication among members of the team aimed to ensure that everyone was communicating a similar interpretation of the resident's big picture. This communication also ensured the team had reached consensus about the appropriate ACP level for the resident, which could then be discussed with the family.

An assistant DOC reported that nurses were responsible for passing on information about residents' declining status from shift-to-shift and discussing this decline with the physician during rounds:

> When someone declines we pass that information to all shifts and we write down on our shift report and it is the nursing job to make sure everyone has the same information about the resident. If they're (family) really, just unable to make the decision, we would then discuss with our doctors during the rounds and ask them to get involved and sometimes we find, just families hearing from a doctor makes a difference and, in my experience if all of us reinforce the comfort care, family will agree with it. (Assistant DOC; Interview: 03)

Nurses reported that their success in ACP was undermined when the team did not work together. Nurses working in a disjointed team found it more challenging to sell the big picture to families and shift families' perspectives to more realistic treatment options and ACP levels. According to a CRN, there was more confusion among families when team members were not on the same page.

Thus, nurses needed to vigilantly work toward ensuring that all members of the team were on the same page. One of the CRNs shared her opinions about working together as a team:

> The importance is that having every team members on the same page then there is really no confusion for the family, right. Like if I call them and then all of a sudden spiritual care calls them and has a conversation, right, and then the nurse manager calls then that’s great. But if all of a sudden somebody comes and says, “Well you know your mom is starving to death”, like you know, that if they just fed her it would better. Do you know what I mean? It undermines and it causes trouble right. So I think that the key piece is having a team that is on the same page. (CRN; Interview: 20)

Although consistency was paramount, it was difficult to achieve unless all members of the team were repeatedly selling the same picture. One of the assistant DOCs reported that hearing the same picture from both the physician and nurses helped families accept reality, as families were more inclined to listen to the physician’s suggestions. The following quote from this participant showed how collaboration with other members of the team was critical to provide consistent information to families:

> I mean we would have sort of myself, we would have the team leader, we would have, the spiritual care, recreational staff, OT and PT, all sort of, us on the same track, saying, "Oh, you know, mom's not doing well, let's not send her, let's keep her comfortable here, and if they're really, really, just unable to make the decision, we would then ask our doctors to get involved and sometimes we find, just families hearing from a doctor makes a difference. And some families, depending on their age too, they still see the doctor as sort of the top of the totem pole, and what he says or suggests, they need to go with, this

> way we make sure all of the discipline give the same information. (Assistant DOC; Interview: 03)

Using Others to Run Interference

The strategy of using others to run interference involved nurses bringing in other members of the healthcare team to engage with family members the nurses found challenging. Nurses also solicited assistance from the healthcare team for families who were reticent to accept the resident's big picture and shift to an ACP level of comfort care.

Involving the Physician. Even though nurses believed they were the best members of the team to discuss ACP levels with families, they sought help from physicians when they were dealing with "difficult" families; that is, families they could not persuade to accept a reasonable ACP level. A "difficult family" was described by the nurses as one where family members have lots of concerns about the resident's declining health and/or lack trust in the nurse. One of the RCMs explained:

> If there is a family with a lot of concerns, a lot of issues. We like to involve the physician as well just to make sure that the collaborative team has been involved in that discussion. Yeah. So I think if it's more of a complex case or the family has a lot of questions then we like to also involve the physician. (RCM; Interview 21)

Another RCM stated:

> I like the way that nurses do the ACP, but sometimes where you have a physician involved when we haven't been able to get what – I don't want to say, get what we want, but where we need help in saying, like, this is not totally reasonable, you know, so we collaborate with the physician to get the to family accept and change the ACP to comfort

> care, because it is not reasonable to send someone all the time to hospital without getting any better. (RCM; Interview: 04)

In another instance, an RCM noticed that a physician's explanation of interventional outcomes made the family more comfortable with the downgrading process:

> I think sometimes families, they want to hear from the doctor, not from us, not from the nurses, so they feel more comfortable when the doctor explains to them about the outcomes and then they're more comfortable to change their advanced care plan. (RCM; Interview: 10)

Involving the Social Worker. Nurses often received support from the social worker with regard to family dynamics, such as family members who did not mutually agree on a realistic treatment plan and/or had issues understanding the role of the decision maker. In these situations, nurses sought mediation support from the social worker to help the family better understand the decision making role:

> It's more like liaising with family in a non-clinical capacity. So they're facilitating, explaining what the differences are between POA and healthcare proxy or designated decision maker. And that I think dispels all the doubt that the families might have. So then once they understand what that legal meanings are then they take their positions, you know. They know that there's a semi-legal context to it so they tend to rally as a group later even though they may not have been seeing eye to eye in the beginning. But that's the approach of the social worker. (Unit nurse; Interview: 24)

Involving the Chaplain. Nurses found that involvement of the chaplain allowed families to express their fears and beliefs about changing to ACP-C. The chaplain's involvement was especially beneficial for families with a religious background. Nurses believed spirituality was connected with death and dying. Therefore, the chaplain played a prominent role in helping family members reach some level of comfort with regard to their loved one's death and dying journey, particularly for family members who were struggling with guilt and grief. Nurses stated that the chaplain's counseling and support helped families work through their emotional challenges and accept the reality that their loved one was receiving comfort care and nearing EOL. Chaplains prayed with families at the resident's bedside and offered the sacrament of anointing of the sick for Catholics who requested it. Nurses believed the chaplain's rituals and prayers instilled families with a sense of peace and mental comfort. The nurses reported that families were more accepting of reality and had an easier time transiting their loved ones to comfort care after completing religious rituals. The role of spiritual care was described by one of the unit nurses:

> I think if the resident and the families are deep into religion and they think that it's important to them, then we facilitate spiritual care before things get worse. After their ceremony they are more inclined to see that as realistic, that death is impending and they do see the need for a change in ACPs. It's almost like the involvement of a church person, a priest, is giving them permission later to be at ease with comfort care measures only. (Unit nurse; Interview: 24)

Involving the Speech Language Pathologist (SLP). Nurses reported that they collaborated with the SLP when residents with dementia suffered from swallowing problems. Nurses used the SLP's assessment and subsequent recommendations to communicate with family members about the big picture, specifically in relation to progressive dementia and associated aspiration pneumonia. The nurses felt that the SLP's report and assessment enabled them to facilitate families' acceptance of the big picture and obtain realistic ACP goals:

> If there's swallowing problems with residents, we facilitate the SLP assessment and use that to get the ACP changed to comfort care, you know most of the residents with dementia develop swallowing problems and they get aspiration pneumonia. It is hard for families to grasp the swallowing issues and related complications, and SLP sometime talk to families. (Unit nurse; Interview: 23)

Involving Management. Nurses sought support from management when family members were not ready to hear the reality of their loved one's condition and kept searching for more optimistic answers, often making inquiries to more than one nurse. Nurses also sought support from management when they felt that family members needed more information in order to make an ACP decision, had unrealistic treatment goals, or had not provided a clear decision about ACP levels.

> When families are combative and argumentative, and twist stories around. So, the family would be calling at different times and talking to different nurses and the nurses would be giving the same story but the families would twist it around. And so, then there is not a clear answer of what they want. They (management) would step in when multiple nurses have attempted to talk with the family and if the family is upset and we have not made it clear and the family has not made an adequate decision on ACP and in that situation when we don't feel like there's a clear answer but the nursing aspect would feel like they should become ACP-C then we collaborate with our management to help us. (Unit nurse; Interview: 20)

Calling Family Meetings

Another facet of team persuasion involved calling family meetings. Nurses in this study identified that family meetings were an effective way to bring physicians, nurses, and other members of the healthcare team together with family members. At these meetings, members of the healthcare team could reinforce the big picture, clarify treatment goals, and support the family. Family meetings were effective avenues for facilitating communication between the family and the care team, creating space for interactions, and providing anticipatory teaching. These meetings were intended to help family members accept the big picture and reinforce the healthcare teams' perspectives about a reasonable ACP level, along with realistic treatment options for the resident. An RCM spoke about the purpose of family meetings:

> We call family meeting, when the family is not really getting it from us, the physician will be there with other team members. And sometimes there's a little more education provided around dementia and prognosis and risks and benefits with interventions such as sending to hospital, and what to expect for the future by the physician and this meeting give family an opportunity to ask questions. (RCM; Interview: 06)

A unit nurse described how calling a family meeting, and the ensuing discussions, helped a resident's wife downgrade his ACP level to comfort care. The unit nurse also facilitated the involvement of the spiritual care person and supported the wife. The nurse provided the following account of this experience:

> We called a family meeting with the physician, the nurse, and the other healthcare team and we explained our assessments and the reasons why he needed to be on comfort care. The doctor explained about his conditions and said the hospital can't do anything for him. So, it was hard because it wasn't an easy decision for her (wife) as well, but when the physician already said the progression is worse. Finally, the wife agreed to downgrade the ACP from medical to comfort care and the resident passed away peacefully and the wife was there with him. We were supporting the wife and I called the spiritual care

> person and he came and prayed with the wife. At the end she was happy that he died comfortably and she thanked all of us. It was so great that we *[sic]*able to keep him at the facility. (Unit nurse; Interview: 11)

A CRN reported that family meetings were effective in downgrading residents' ACP levels because members of the interdisciplinary team could provide their perspectives about residents' declining status and make suggestions to enhance their comfort:

> If the family had a question about the resident's decline, we call family meeting, so OT or a PT can also explain the role of the positioning as a comfort measure. So that's part of the – that's why we also get the input of the other disciplines. and these *[sic]*information helps family to see the reality and family meetings are very effective in downgrading the ACP levels. (CRN; Interview: 07)

Leveraging the Opinions of Hospital Staff

Despite the nurses' best efforts to convince family members that hospital transfers for aggressive interventions were not in the best interest of residents, such transfers did occur. Even though participants thought these transfers were unnecessary and caused the residents pain and suffering, the transfers often resulted in residents returning to LTC with an ACP-C designation, instituted by hospital staff. In these cases, the transfer was deemed to have a positive outcome. Nurses believed that families were more willing and comfortable to accept a change in ACP status from personnel in an acute care facility than from those in LTC settings. An RCM explained:

> I think the problem is to let go, to accept the reality of her husband's condition. It's something that is we often see, they (family) have a hard time accepting the reality. It's so difficult most times to accept the reality of things. They (family) have their own wish

> on what they want for the person, and it’s a kind of attachment to that, oh, I'm just giving up them. So they want to do everything up until the end. It is difficult for us to follow the family’s wishes and we try everything to change the ACP to comfort care but at the end we send them to the hospital and the hospital change to comfort care and the family feels better once they hear from the hospital staff. (RCM; Interview: 14)

A unit nurse confirmed that hospital transfers were often instrumental in persuading family members to agree to an ACP-C designation. She noted the importance of documenting on the transfer form if LTC staff had made prior attempts to convince families to pursue the goal of comfort care. This ensured that hospital personnel had some context about prior discussions with family members. The unit nurse made the following statements about hospital transfers:

> If a family member is adamant about somebody going to the hospital that I believe should not, that I believe will be not productive for the resident, or the experience, or anything – – or the outcome. I’ve had those situations. Lots of education of the family, but also respecting their wishes, I mean, if they are adamant, you send them. If you’ve given them all the information you can, reassure them that you believe that the hospital can’t do anymore for them than you can. This will be a taxing on the person to go – to be in an environment where they’re not familiar to be met by strangers and then treated with an outcome that likely won’t change the final outcome. We’ve tried to – you know, but a lot of people still think that the hospital is going to be the answer, right. So they go to the hospital and at the hospital, the ACP usually changed to comfort care and they send the person back, this is the way we get what we want at the end- the ACP C. (Unit nurse; Interview: 01)

A unit nurse reported that family members were more willing to change the resident's ACP levels after speaking with a doctor at the hospital. She thought that families might have been more willing to accept the reality of the situation when it was explained by a doctor, rather than a nurse:

> They (family) want – they would like everything to do be done but until they're faced with that situation, So, I would say -when they hear it from the hospital then that is a doctor at a hospital like there is a distinction between being a doctor and being a nurse. The fact at the end of the games – at the end of the day, I have to choose what the Power of Attorney wants so I send them out to get the ACP changed to comfort care and they hear from the hospital doctor that the hospital can't do anything and the ACP is downgraded to comfort care there. I like that so now we can keep the resident comfortable. (Unit nurse; Interview: 23)

An RCM stated that some family members wanted all possible investigations done at the hospital to ensure that no stone had been left unturned. When families heard directly from hospital personnel that the appropriate approach was to focus on comfort care, it usually persuaded them to change the resident to ACP-C:

> When family is in denial and they are not ready to accept it, we send them (residents) to hospital and then the hospitals talk to the families and changed their ACP level and they've come back as comfort. I think because they've now had a trip to acute care, we've done everything we can and they're realising, if they go to the hospital and they can't do anything. And I think also they see how hard it is on the resident to be shipped back and forth like that. (Unit nurse; Interview: 17)

Nurses reported that once hospital staff had confirmed that the resident’s prognosis was poor, family members were more accepting of the resident’s big picture. Family members were more willing to downgrade the resident to ACP-C after hearing the hospital staff’s rationale for not implementing medically inappropriate/futile care and after witnessing the pain and suffering caused by the hospital transfer. Nurses believed that when they failed to sell the big picture to families, sending residents to the hospital was a win-win situation; family members were satisfied with a second opinion from outside medical experts and nurses got what they were trying to achieve for the residents, specifically downgrading the ACP level to promote comfort.

Drawing a Line in the Sand: Enough is Enough

The strategy of “drawing a line in the sand: enough is enough” referred to nurses assertively advocating for comfort care when gentle and team persuasion approaches had been ineffective. The activities nurses used in this strategy included: (a) forcing family, and (b) questioning physicians on futile interventions.

Forcing Family

Family members who continued to hold what nurses believed were unrealistic and unreasonable goals were always problematic for nurses. Unrealistic goals resulted in poor quality of life for the resident and made it difficult if not impossible for them to achieve a good death. Nurses in this study were willing to tolerate unrealistic goals and choices in some situations, but felt they were forced to tolerate them in others. As the need to act on an unrealistic goal became more urgent (e.g., when futile care caused harm for residents), nurses promptly intensified their approach, which was described as drawing the line in the sand: enough is enough. This approach was aimed at getting family members to shift their understandings and, subsequently, their goals.

It was evident that this approach helped with the downgrading process to ACP-C most of the time:

> Once in a while we are okay to go along with the family, but at times we are forced to follow their wishes. But, we think someone is imminently dying and they still want them on resuscitation and they don't want to change the ACP, then yeah, we can't tolerate that. It is enough and we try our best to change their mind to help the person die peacefully. (RCM; Interview 22)

Two conditions under which the nurses were forced to follow the family's unrealistic goals were prognostic uncertainty and respecting the family's religious beliefs. Nurses stated that low levels of prognostic certainty made for a cloudy big picture. In these cases, nurses were forced to go along with the family's unrealistic GOC. As prognostic certainty increased (i.e., as a resident's condition worsened), the nurses were able to assertively advocate for a realistic goal of comfort care.

Nurses felt that futile treatments were inappropriate because they did not improve quality of life and often induced pain and suffering for the residents. In those situations, nurses assertively advocated for quality of life. They arranged family meetings and tried to help the family understand the impacts of aggressive interventions on their loved one's quality of life.

A unit nurse reported that she saw a male resident being "tortured" by interventions aimed at attaining unrealistic treatment goals. She assertively advocated for this resident by making a case with the family to restrict any further futile interventions. She arranged an urgent family meeting and advocated for cessation of the futile interventions, which would have allowed the resident to remain at the facility for comfort care. Her enough is enough approach helped the family shift the resident to ACP-C. The following is an account of her experience with this resident and family:

> There would be, like so for instance, there was a person, there was a gentleman who had an abdominal aortic aneurysm and he was on ACP R and family want to do everything to keep him alive and they were not getting the big picture. Then the aneurysm had been operated and then he ended up with a small bowel obstruction. So, at that point we were like, he’s been through enough, let’s just keep him comfortable. He went to hospital and obstruction was non-operative, we supported the family all along, but we felt like it is torture so then we said, that’s enough. So, he was medical and then in a couple of weeks his condition deteriorated and we talked to the family we said, and that’s enough, let’s just let him be here at the facility and change his ACP to comfort care because aggressive interventions are not providing any quality of life in him. We called a family meeting and communicated the reality to the family and they downgraded the ACP to C. (Unit nurse; Interview: 17)

Questioning Physicians on Futile Interventions

Not only did nurses assertively advocate with family members, but they also questioned physicians about the rationale for providing futile interventions. Nurses drew a line in the sand when physicians’ life-prolonging interventions were not providing comfort, and when ACP-C was a more realistic approach. They questioned physicians about ongoing, futile antibiotic treatment for re-occurring aspiration pneumonia in residents with dementia. Nurses helped physicians understand the residents’ big picture and strongly suggested that treatment plans and GOC be re-evaluated. The study participants noted that nurses played a key role in the discontinuation of futile therapeutic measures. The nurses were able to significantly impact residents' level of comfort by negotiating futility with families and physicians, using the strategy of drawing a line in the sand: enough is enough. The use of this approach is well illustrated in the following example:

> You know, I told the doctor that we think – and I went in to the man (doctor), I said, within the past two months, this person (resident) has been on about five different types of antibiotics to treat the same symptoms. What are we trying to do here, as the person's not getting any better? And we kept putting this food in this person's mouth and everything is coming out. So we can change the ACP from medical to comfort care and change the goal of care here. If we are feeding the person, it's not comfort anymore, if they could refuse the food, they wouldn't even open their mouth. And then I asked the doctor, why are you prolonging this person's life? He's been given antibiotics almost every week, he's not turning around, he's not getting any better, it is enough, we should make him (resident) comfort care. (RCM; Interview: 14)

Outcomes of Selling the Big Picture

The following outcomes were realized when nurses were successful in selling their big picture to family members: reaching consensus; promoting a peaceful, dignified death; decreasing family stress; and increasing family satisfaction with care.

Reaching Consensus

The main outcome of selling the big picture was reaching consensus between nurses and family members about the resident's big picture. This consensus facilitated the shifting of GOC from aggressive, curative interventions to comfort care in LTC, without hospital transfers.

An assistant DOC described how consensus between the nurses and family enhanced a resident's comfort by revising their ACP status and keeping them in the LTC facility:

> In the end, the wife and daughter understood what is happening with him. They wanted him to die with dignity at the facility. We (nurses) really wanted to keep him comfortable and not send him out. So both we and the family came on the same page and with the same agreement, in the end. So, he was changed to an ACP-C and we revised the ACP form. (Assistant DOC; Interview: 03)

Acceptance of the nurse’s big picture and agreement on GOC by all parties culminated in the revision of a resident’s ACP form. Revising the ACP form reflected a downgrade from the existing ACP level to ACP-C:

> She (wife) decided to downgrade the ACP to comfort and then I made a new ACP form for comfort care. So, she didn't want to send him to the hospital anymore, she said let's keep him in the facility and provide just comfort measures. Then after a week, he is on end-of-life. We had the end-of-life orders in place, all the measures in place, and that it was the best decision that she made to keep him the facility and just provide comfort measures until the end and he died peacefully with wife at his side. (Unit nurse; Interview: 11)

Promoting a Peaceful Dignified Death

When the ACP form was revised to ACP-C, the GOC shifted to keeping the resident at the facility and providing interventions that promoted comfort and a peaceful death. Nurses believed comfort-oriented care was essential in providing a dignified and peaceful death in LTC: “I think we have to try and make them comfortable as possible we can, and change their ACP to comfort care to let them die with dignity” (RCM; Interview: 06).

The nurses reported that selling their big picture helped ensure a smooth transition to EOL and contributed to a peaceful death for residents. The study participants felt that ACP-C supported the trajectory of the EOL care plan and the residents' final journey in life. Downgrading the ACP level helped residents stay at the facility and encouraged a peaceful death, with family at the bedside. When the residents were designated as ACP-C, the nurses were able to focus on optimizing their comfort and easing the dying process:

> The resident population that we're admitting now are coming here to die. This is their last stop. This is their last journey. So the ACP-C supports that. It supports that transition. It supports that trajectory. It supports the care plan. Comfort care support the smooth transition to end-of-life and helps with the final journey in everyone, it helps resident, family and staff. (DOC; Interview: 19)

Decreasing Family Stress and Increasing Family Satisfaction with Care

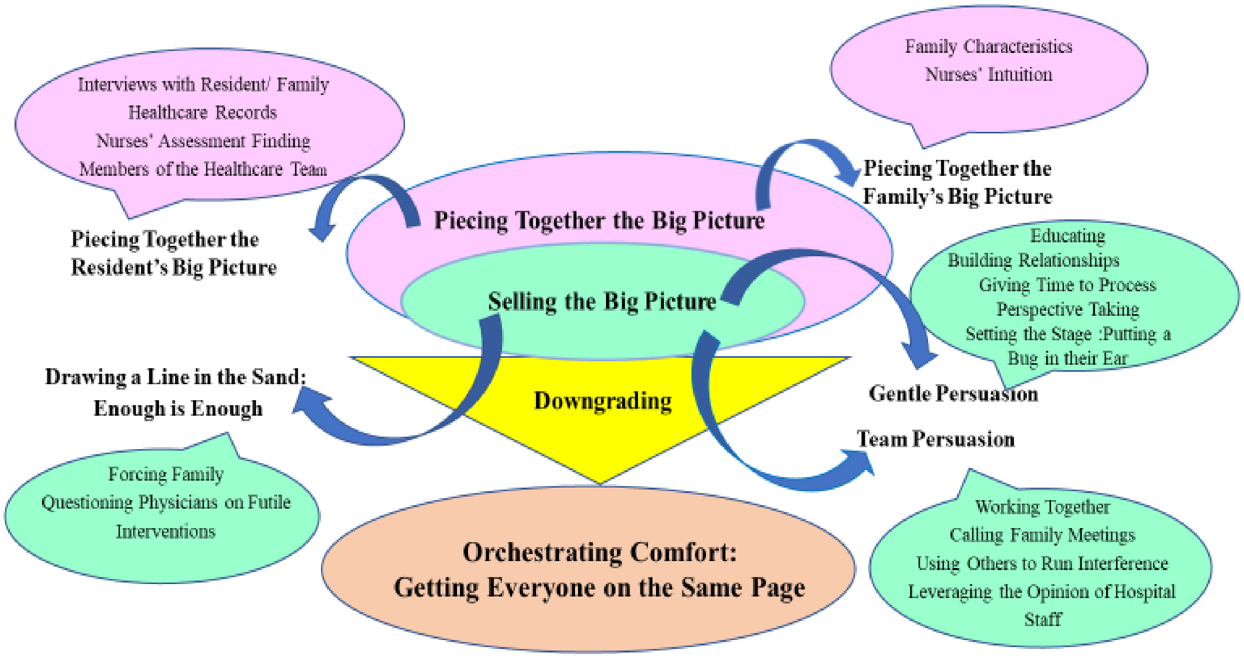
The nurses noted that family members seemed to experience lower levels of stress and higher levels of satisfaction when residents were coded as ACP-C. When residents were downgraded to comfort care, family members perceived that their loved one was safe at the facility and did not have to worry about visiting them at the hospital. As explained by one of the participants, families felt they could spend more time with the resident at the facility:

> They (family) will not think about visiting the hospitals anymore. They're just going to be thinking about spending more time in the facility with their loved one, and the residents are not exposed to other infections, they feel like they're safer when they're in the facility and the family look less stressed. (Unit nurse; interview: 11)

The schematic representation of the pre-conditions as well as the strategies and nursing activities associated with the downgrading process are presented in Figure 2. The next section describes the barriers and facilitators of the downgrading process.

Figure 2

The Process of Downgrading



Barriers to the Process of Downgrading

Several barriers were identified that inhibited nurses' ability to downgrade the resident's ACP level. Those barriers were analyzed from a socio-ecological perspective and are described in the following section as well as in Figure 3.

Resident Level

Resident Characteristics

Age of the Resident. The nurses in this study reported that residents' age was often a barrier to downgrading the ACP level to comfort care. If the resident was younger, the power of attorney (POA) (i.e., family or PGT) usually chose ACP-R because they wanted everything done in order to keep them alive. Nurses had the impression that when the resident was younger, family members tended to focus on their loved one's age and ignore their disease(s), as they were not ready to let go. These notions were evident in the following account from a unit nurse:

> I think it's harder for people that somebody relatively young and it would be so much harder for them to choose something besides R because they're viewing the person like still like maybe not seeing all the diseases or whatnot that the person has. Of course, they're looking at the person and they're only like say 52 or something. Sometimes if you have somebody really on the younger side or even in their sixties because to me that's young. So and that's really hard because you don't want to let go of somebody that's that young. (Unit nurse; Interview: 12)

Nurses reported that the PGT was always reluctant to downgrade ACP levels in younger residents. According to an RCM, the PGT wanted to keep a resident as ACP-R, even though the individual had a significant brain injury, because he was only in his fifties:

> Usually the ones that they (PGT) don't agree with downgrading would be because the person is of quite a young age. So we do have some people here who were in their 50s when they were brought in and they either have like usually MS but we have had someone who has quite a significant brain injury, but he was quite young, like in his fifties. So the PGT, wanted that person to remain at resuscitation. (RCM; Interview: 25)

Resident being under Public Guardian and Trustee (PGT). Most of the study participants reported that it was extremely difficult to downgrade an ACP level in residents who were under the supervision of the PGT. Nurses reported that PGTs usually choose ACP-R for residents and would only downgrade to comfort care when the resident was actively dying. Nurses believed the delay in downgrading to ACP-C caused suffering and often contributed to unnecessary hospital transfers for the residents. These sentiments are evident in the following exemplar: "I found PGT's clients go to hospital more often than others and they (PGT) are comfortable choosing ACP R and tend to go to ACP comfort care only when someone is at end of their life, literally dying" (RCM; interview: 10). Similarly, another participant stated:

> I find the PGT are more comfortable with R and then they'll only really change to C when someone's close to dying. This means more unnecessary hospital transfers and suffering in residents, PGT delays the downgrading of ACP to comfort care and when the downgrading happens most of them are dying. (Unit nurse; Interview: 20)

Delaying the Completion of Advance Care Planning for Residents under PGT. Nurses reported that there were delays in completing ACP forms for the residents under the PGT. These delays resulted in unnecessary hospital transfers and increased suffering. When a resident was under PGT, the form could only be completed by a physician. However, most LTC facilities do not have a physician on-site to complete the ACP document at the time of admission. Once the appropriate paperwork was completed by the physician, the social worker faxed the papers to the PGT and waited for the PGT's decision on the resident's ACP level. The resident remained ACP-R until the PGT made a final decision regarding ACP level. The nurses in this study reported that delays in choosing an ACP level occasionally resulted in inappropriate hospital transfers for the residents. In general, nurses did not have direct contact with the PGT regarding ACP discussions. One of the participants articulated the challenges associated with ACP and PGT in the following quote:

> Anybody who is under public trustee, when they come in, we treat them as an ACP R, they are, on resuscitation. We treat them as an ACP R until their ACP is decided, because physicians are not available on site right away, when they (residents) come in. So the physician has to do some paperwork for the public trustee resident, because they have to do the assessment and send those assessments to the public trustee. (RCM; Interview: 10)

One of the DOCs expressed frustration with the delays in obtaining ACP levels for the residents. She wanted the nurses to have a say on the residents' ACP levels to avoid the dilemma of dealing exclusively with the PGT on this matter:

> Usually the public trustee won't really do anything without the doctor helping us. And so then sometimes you're in limbo right, because if you're waiting for the doctor to come in, then you're literally sitting here with this resident who has no ACP. That's the hard part. That's the frustrating part. It would be nice if as the nurse we could say, OK they're going to be this ACP level. Because then it makes it hard because you don't know what could happen. Anything could happen in two days or one day. The resident status could change and then you're scrambling. (DOC; Interview: 19)

A CRN reported that the delay in getting the paperwork done by the physician caused unnecessary hospital transfers of residents. While waiting for the PGT's decision regarding ACP, residents were sent to the hospital for any changes in their condition, even when nurses felt that a transfer was unwarranted. One of the nurses explained the reality of this process:

> They (PGT) won't change the ACP unless they have all the documentation done and all the writing done and the forms filled out. Which means if physician isn't in house right away, those don't get done for a day or two. So there's always a delay in getting an ACP. Which could result in unnecessary transfers to hospital. Because if we don't have that ACP; we have to err on the side of treating – over-treating, right. But if something were to go wrong with that resident before we got the documentation we would send them out to hospital right away. (CRN; Interview: 15)

Prognostic Uncertainty. Nurses stated that it was hard to predict prognosis when there were low levels of certainty and the big picture was cloudy. In these cases, nurses were not comfortable with facilitating the downgrading of residents' ACP level. Nurses described the "*roller coaster ride*" of prognostic uncertainty, particularly when residents survived an illness but declined one or two steps from their previous baseline. Some families did not want to accept the decline and wished to continue sending their loved ones to the hospital for aggressive interventions. In these situations, some nurses felt intimidated to initiate and facilitate the downgrading process, as they doubted their own predictions of the resident's decline. One of the participants explained these feelings using a specific example:

> Sometime it is hard to predict, especially if they have nine lives. One lady that I could think of, had end-stage CHF and each time she goes to the hospital we thought she never come back, but she is back each time, but needing more care. It is like a roller coaster

> ride, almost died and back again, in bed doing nothing, next day up and talking and eating. So some nurses don't want to talk about ACP with her family because they are not comfortable with being wrong, I can't blame them. But I like to be wrong, so I tried to persuade the daughter and she wanted to keep her mother on ACP M. So we just kept the ACP level medical and send her out each time. (CRN; Interview: 15)

Family Level

Family Characteristics

Family Dynamics. Family dynamics were found to be a barrier to effectively crafting an advance care plan that promoted comfort in residents. The family dynamics that inhibited the downgrading of ACP level included: disagreement amongst family members about the appropriate ACP level; guilt over downgrading the ACP level; denial of the resident's diagnosis; holding on family members; avoidance of ACP discussions; putting the family members' interests first; and involvement of out-of-town family members.

Disagreement Amongst Family Members About the Appropriate ACP Level. The participants reported that in some cases family members did not agree with each other about the choice of ACP level. This occurred more frequently when more than one family member was designated as POA and when family members did not agree with the POA's decision. Nurses found that ACP discussions were more challenging when family members disagreed with each other. Nurses felt stuck in the middle of the disagreements and noted that the resident suffered until the family reached a mutual agreement. The following exemplar describes the above-mentioned experiences: "If you have a family that's disjointed and has relationship issues, then that can make it very difficult because one family member wants one thing and one wants another, and then you're stuck in the middle" (CRN; interview: 15). Another participant stated:

> What makes it hard is when families don't agree with each other – one family member is in agreement but the other one isn't, and maybe they share a POA, so they have to go home and hash this out and somehow come to a conclusion and meanwhile the resident is here is, suffering, while their family deals with their dilemmas. That makes it difficult. It makes it (ACP) very difficult when you don't have all the family on board. (Assistant DOC; Interview: 03)

A unit nurse described a situation where a family member who was highly involved in the resident’s day-to-day activities had no legal decision making power. In this type of scenario, the nurses avoided discussing the ACP level unless there was a crisis with the resident:

> Their own family dynamics play a role with, you know, some of the members not agreeing, some of the members having decision making powers versus somebody who is very involved in their (residents) daily living but not have that legal power to change ACP level. So it becomes quite blurred, that line, and that’s when – we usually try to skip that or avoid that (ACP) discussions, when there’s no crises around. As opposed to deal with that (ACP) when something untoward is happening to the resident. (Unit nurse; Interview: 24)

Guilt in Family Members about Downgrading ACP Level. Feelings of guilt prevented family members from engaging in effective ACP discussions. In their minds, choosing ACP-C meant giving up hope and/or sentencing their loved one to death. Nurses believed that, in some cases, the feelings of guilt may have been related to past relationship issues with the resident. Some family members felt guilty for placing their loved one in LTC, and compensated for these feelings by trying to prolong the resident’s life. The following quotes from RCMs showed how family members’ feelings of guilt affected the downgrading process:

> I think it's just the guilt of, am I sentencing this person to death? Because I heard somebody say, yeah, I'm not going to sentence my mom to death. If she dies. I have to decide on this (ACP C), I'm sentencing her to death, I'm giving up on her. I don't want to give up on her; I still want everything to be done. So you keep explaining to them. And there are some people, they will get it, but they will still remain adamant, because of their guilt (RCM; Interview: 14); and

> More likely guilt, that's what I see here more. Most of the family members probably have guilt that they have not come to terms with and thinking that if their loved one stay or linger longer that they could actually repay or actually make a difference out of it, right. Probably something likes that or maybe something in their past, relationships that did not work well in the past and now they've sent them to LTC. (RCM; Interview: 08)

Denial of Resident's Diagnosis. Nurses thought that some family members were in denial about their loved one's declining status. It appeared to be difficult for some families to accept that their loved one had dementia, needed to use a wheelchair, and could no longer speak. Nurses felt that families wanted to believe their loved one had not deteriorated from their healthy, community-dwelling baseline, and were unable to accept the significant health changes that had occurred in LTC. Since these families often wanted to do everything possible to prolong life, they tended to choose a higher level ACP (M or R). These challenges were described by one of the participants:

> I think they (families) are like in denial that their significant other is in that state of their life, you know, because they used to be so active and now they see them in wheelchairs, they don't remember anything, some of them can't even talk they just make sounds; so I guess they're in denial and they want to feel like they want to help, you know. It's like

> they couldn't help before so they feel like they could like help them now by making sure that their life is safe, like that, so I think that is why they are choosing a high-level ACP to keep them alive and keep them going. (Unit nurse; Interview: 18)

Holding on Family Members. Nurses stated that family members who were holding on tended to choose more aggressive interventions, which focused on keeping the resident alive rather than giving priority to their comfort. Holding on family members were often in denial of the resident's decline, were not ready to accept the resident's big picture, and had unrealistic treatment goals. Holding on family members were primarily motivated by their own feelings of guilt when making decisions for the residents' care; they needed to believe they had done everything they could. When making decisions, holding on family members paid little attention to the resident's big picture and/or the resident's best interests. These families gave priority to quantity of life rather than quality of life. Holding on family members infrequently referred to the resident's wishes or preferences and sometimes completely disregarded the resident's written preferences, as stated in their living will. According to one of the participants:

> Some families don't want to let go, they hang on until the last moment. I think it is that the family attachment, and that they don't want to let go, even though they understand what you're saying, but do not to accept it. But just because they can't let go, and the guilt that, okay, if I (family member) sign this, I'm giving up on this person, makes it very difficult. I'm sentencing her to death, I'm giving up on her. I don't want to give up on her, I still want everything to be done for her. (RCM; Interview: 14)

Study participants reported that the level of attachment between family members and their loved one could be a barrier to initiating ACP discussions. Some family members wanted their loved one to live as long as possible, despite their poor quality of life. The nurses felt these family members were not ready to accept the reality of the resident’s situation and wanted to hang on to their loved one, doing everything possible to prolong their life. This notion was evident in the following quote from an RCM:

> Some of them are definitely not ready to let their loved ones go, right, so they would rather have Mom stay for the longest whether they’re debilitated or bedridden as long as Mom is around and fine. So, some definitely not, they haven’t probably said everything, or they still want them hanging around. (RCM; Interview: 08)

A unit nurse described a situation where a family member who was extensively involved in their mother’s care had difficulty letting go. The nurse thought that the family member’s desire to hold on could have been due to personality, mentality, or the bond they had with the loved one. The unit nurse described this scenario in more detail:

> Really, it's often people that are really involved in their loved one's lives. I know it's very hard to let go of somebody but I feel like there's some people with the personalities that they really want you just to keep doing everything you can to prolong that person's life and they don't want to ever think about them passing away. Whether it's the bond or attachment they have with their loved one. It's the mentality. (Unit nurse; Interview: 12)

Putting off ACP Conversations. Participants reported that some family members were reluctant to engage in ACP conversations until they were forced to do so by a crisis event. Nurses stated that some family members refused to engage in ACP conversations during the residents’ admission to the facility or at annual care conferences. Family members who postponed ACP conversations were usually having a hard time accepting the residents’ decline or had close relationships with their loved ones. Nurses reported that families’ refusal to engage in ACP conversations caused suffering for residents, as a result of unnecessary hospital transfers and painful interventions. One of the nurses described this phenomenon as follows:

> Sometimes it's difficult to approach some families because they really don't want to discuss it. They have a really hard time. They want to put it off and they don't want to sit down and discuss it. They don't want to, like be it over the phone or just even in a meeting at the facility, and when we do our annual case conferences too, they just don't want to discuss it and they'll say, well we're going to think about it, we'll think about it. And they put it off and put it off until it comes to kind of a critical point where you really have to really engage them very strongly in that conversation, while the residents were suffering from unnecessary care. (Unit nurse: Interview: 12)

Arrival of a Long-Lost Family Member. Participants indicated that consensus about a resident's ACP was sometimes disrupted when a long-lost family member, with demands for aggressive and unreasonable treatment, arrived in the final days. Nurses reported that the involvement of out-of-town family members could complicate the downgrading of residents' ACP. These family members frequently had limited or no contact with their loved one and did not have the authority to make decisions on their behalf; they re-entered the residents' lives near the end, then dictated aggressive medical inventions for them. Nurses re-directed these family members to the residents' POA and continued to follow the ACP level chosen by the POA. A unit nurse recounted one such experience:

> I did have one situation where the family member in charge said comfort care. Keep them here. End-of-life is fine – all of that – and another family member called, that I had never met, never heard from through all the years that person had been there, and now wanted

> sent to hospital. This family member was from out of town. In this situation we went with what the family member in charge decided. (Interview: 01)

Similarly, an RCM reported she had situations where long-lost family members made requests that would compromise residents' EOL care. In one case, a daughter who resided in the US wanted her mother to receive aggressive interventions, even though she was in the process of dying:

> We had a situation where I remember that a daughter who has not seen her mom for many years called us, and she asked us to send the resident to hospital for IV or tube feeding. I think the daughter lived in the U.S. She was quite pushy and angry with us for not sending her mom to the hospital. We asked her to contact her brother who was the POA for the resident and we told her, her mom was on comfort care, and it was decided by her brother. We had this kind of situation where they had not seen or had no contact with the residents, come into the picture when the residents were dying and make things worse. (RCM; Interview: 25)

Acting in the Best Interests of the Family: Putting Family's Interests First. Nurses in this study found that family members did not always choose a realistic ACP level according to the resident's best interests; instead, they made ACP decisions that suited their own best interests. Nurses reported that family members often tended to err on the side of caution, choosing more aggressive interventions for their loved ones. Nurses found it challenging to balance unrealistic ACP decisions with doing what was best for the resident's quality of life. Nurses stated that it was difficult to promote quality of life in these situations. As a result, these situations caused distress among residents and staff. This notion was described by two unit nurses:

> We just have to look at what's the best for the resident that we have. Because we're the ones looking after the resident, so. In the same token though we cannot just displace what the family is wanting, so. This is where the plan gets very hard, so that's it (Unit nurse; Interview: 09); and
>
> Usually the families will be like based on their interest, because you know how it's supposed to be like based on the interests of the residents, right, but usually it ends up being based on what the family wants, right, like does the resident really want that, you know. (Unit nurse; Interview: 18)

Overruling Resident's Wishes by Family. Participants reported that family members sometimes overruled the resident's own wishes. In some cases, family members would wait to make decisions until the resident was unable to decide for themselves. In rare instances, they completely ignored the stated wishes in the resident's living will; nurses assumed that the residents may not have shared their living will with their family. Nurses reported that these families wanted their loved ones to live longer and were not ready to accept reality. As a result, they often requested aggressive medical interventions. Family members' failure to acknowledge the resident's stated wishes had a significant impact on nurses' efforts to provide comfort care:

> Some of the conflicts have been around what the individual wants, versus what their family want. Even when the individual is competent and able to make their own decisions, then the family want to overrule it at the last minute, when the person isn't competent. And very often that's because the family just isn't ready to say goodbye, they haven't faced the reality that that's coming. (DOC; Interview: 02)

In one example, an RCM reported that family members chose ACP-R for a resident, against the stated wishes in her living will. In their minds, the living will had been invalidated by the deterioration in her cognition since the time it had been drafted:

> We have a resident who came in here, she's quite impaired cognitively, and the family wanted her as resuscitation, this person came in with a living will which states very clearly, like I have never seen one so detailed. She doesn't even want antibiotic treatment for anything and that's in a living will. And the family is completely against it. We've had many conversations; they will not change it because to them, now that she's cognitively impaired it's not in place anymore. (RCM; Interview: 25)

Family Member Knowledge

Family Member with Healthcare Provider Background. The nurses in this study reported that family members who had healthcare experience were a barrier for downgrading the ACP level. The nurses found it harder to achieve an ACP level that focused on the resident's best interests when family members were also healthcare providers. These family members tended to want their loved one to live longer and lacked an understanding of the concept of quality of life or the ethical ramifications of futile interventions. Family members who were healthcare providers themselves seemed to think they already knew everything about ACP and clung to their own beliefs and attitudes, putting their own interests over those of their loved one.

An RCM reported that one resident had a son who worked as a physician and was also his POA. The son chose ACP-R against the advice of the healthcare team and refused to downgrade his father to ACP-C:

> When we tried to discuss with the family the son who was the power of attorney was a doctor. So sometimes when they are medical professionals it is really hard because they

> want their loved one to live as long as they can. Then they don't understand about ethics, and they don't understand about quality of life. And he said he doesn't want to change the ACP. He wants to keep it as resuscitation at our facility. We kept at R because he was not in agreement with us for comfort care. (RCM; Interview: 05)

According to one of the DOCs, family members who worked as healthcare providers were a nightmare for the care team. The DOC thoughtfully diffused these situations by reinforcing and reiterating information about the residents' best interests with the family:

> I think, based on my experience those ones that are healthcare providers are usually more of a nightmare. It's insane. Because you would really expect that it would be easy, right, like they get it, they know it. I think with the ones that are healthcare providers, they just think they know everything. And they know it and that's it. It doesn't matter how you explain it, how much love you give them, how gentle you are, they are right. There's no changing it, there's no winning. So all you can do is just bringing it back to the residents, you're constantly just trying to diffuse the situation because any little thing can tip them off. And it's not about them. They're part of it but this is about what's best for their loved one. So it's just trying to reinforce, reiterate the same information. (DOC; Interview: 19)

Family Member Knowledge Deficits

Nurses reported that selling of the big picture to families was complicated by a variety of factors, including families' lack of knowledge about dementia, lack of awareness about the different levels of ACP, misunderstandings of comfort care, and limited acknowledgement that LTC would be their loved ones' last place of residence.

Lack of Knowledge About Dementia. Nurses reported that there was a lack of knowledge about dementia as a terminal illness, including its effects on swallowing and its association with re-occurring aspiration pneumonia. In addition, families were not aware of the negative impacts of aggressive interventions, such as hospital transfers, on residents with dementia. This knowledge gap left family members wanting to fix everything by sending their loved ones to the hospital for aggressive interventions. These notions were captured by one of the nurses:

> In dementia, we get a lot of aspiration pneumonias. And no one told the family that whole process about the brain and how it works, and how the swallowing works, and how it's expected and this is a natural progression and kind of side effect of this disease as it deteriorates. And so, no one shares that and is honest with their family. I think there needs to be more education with the family members about dementia and it being a terminal disease. I'm not sure if some people realize that it is terminal and there is no cure, and you know, it eventually – there is side effects from it that will kill them. (CRN; Interview: 15)

Lack of Knowledge About the Different ACP Levels. Participants in the study echoed the sentiment that family members had limited overall understanding of the different levels of ACP. This was particularly evident with regard to the differences between comfort care and EOL care. Due to this limited understanding, family members kept their loved ones at ACP- R to ensure they would receive all possible life-prolonging care. The nurses reported that family members required education about the differences between ACP-C and the medical level advance care plan (ACP-M). The following quote from a unit nurse demonstrated families' knowledge deficits about different ACP levels:

> I think, they (families) just don't know. I just don't think they understand the difference between R, M and C because they think if they put them at C that we're not going to do

> anything if residents get sick, you know. ‘Oh, comfort we are not going to do anything’, you know, so they always want like R and like you have to treat everything possible. (Unit nurse; Interview: 18)

Misunderstandings of Comfort care. Nurses reported that families’ reluctance to downgrade residents to ACP-C was the result of a lack of understanding about the concept of comfort care. Some family members believed that when their loved one was ACP-C, nothing would be done; others thought that comfort care and EOL care were synonymous. Due to this knowledge deficit, some family members wanted to upgrade their loved one’s ACP from C to M, or even R, especially when residents were admitted to LTC from the hospital. The following quote from an RCM captured family members’ misconceptions of comfort care:

> When the family gets to the long term care from hospital, the one thing turned around, because of misconceptions that if they are comfort care, nothing will be done for them at long term care. And they want to upgrade them to medical, and some will even go up to the level of resuscitation. The question I always ask them (family) is that, why do you want to change it from comfort care to medical, when they came in here. And most times they say, oh, I just want to change them to medical, because I feel if I leave them at comfort care, nothing will be done for them (resident) and they will die. (RCM; Interview: 14)

Some family members thought that changing their loved one to ACP-C was akin to sentencing them to death. One of the nurses reported on this, stating:

> When we advocate for comfort care they (family) will say, like, I'm not going to be the one who is going to put my mom to death. I'm not God, I'm not going to play God. Because a

> lot of misconception is that when the resident is on comfort care, you know, that's the end of your life. (CRN; Interview: 07)

Lack of Acknowledgement of LTC as the Last Place of Residence. Nurses found that families often lacked an awareness that the LTC facility would be their loved ones' last place of residence. This made it difficult for family members to engage in ACP conversations. Many families clung to the hope that their loved ones would get better and move back to the community:

> When they come to a LTC facility, they think that their loved one even though, you know, they're going to live forever, and people cannot sort of wrap their head around the fact that this is the final place. I think the family is just in general, a lot of them have a hard time knowing that the nursing home or by the time they get to the nursing home, you know, it's the last place they're going to be. (RCM; Interview: 21)

According to an RCM, family members sometimes held onto unrealistic beliefs that their loved ones would return to the community:

> One of the barriers is that families often don't have, a realistic idea I would say of what people are when they're in long-term care. Often families are very hopeful that their loved ones are going to get better and move back home, and so an advanced care plan is a challenging conversation to have when someone doesn't believe that their family is going to be staying there permanently and they are somewhat at end of their journey or life. (RCM; Interview: 22)

Healthcare Provider Level

Nurse Characteristics

Lack of Knowledge About the Resident/Family. Some nurses felt they lacked the required knowledge about residents' diagnoses and family dynamics to participate in ACP conversations. Other nurses questioned their ability to accurately predict residents' prognosis and tried to avoid ACP conversations:

> I see some (nurses) that are very reluctant. Some feel they (nurses) don't know enough about the medical conditions. Some feel that they're just – I'm just on this ward for a day, why should I have to have that discussion? The families don't know me, the resident doesn't know me. Some feel like, well, maybe the condition's changing but maybe I'm not sure. You know, I might be wrong. (Unit nurse; Interview: 01)

Playing God. Study participants reported that some of their nurse coworkers questioned if they had the authority to select ACP-C for a resident. These coworkers felt they were playing God if they advocated for comfort care, and tended to allow someone else to engage in ACP with families. The nurses thought that adequate education could enable their coworkers to build confidence in having ACP conversations:

> There is always a notion in nurses that when you're trying to set the ACP level, that you are actually like, almost playing God, right. There's always a feeling, like, do I have that authority to make this person to comfort care. Do I have this authority over this person? So, some nurses don't want to take a chance and they leave it for someone to do it. (CRN; Interview: 07)

Discomfort with Death and Dying. The study participants reported that nurses' own comfort levels with death and dying influenced their ACP conversations. They believed that many nurses were not comfortable having ACP conversations or dealing with a dying resident. They noticed that some nurses even questioned why residents who were at EOL had not been sent to the hospital. The study participants believed that nurses had to be comfortable having candid conversations about death and dying to engage in ACP discussions with residents' families.

According to a CRN, many nurses were not comfortable with telling family members that their loved one was dying, and felt they might be able to keep the resident alive by sending them to the hospital:

> I know I've seen nurses who are very uncomfortable with death and dying to the point where sometimes you know we have someone palliative and they're questioning why aren't we sending them to hospital. And like – because they feel like they need to do more and they're just not comfortable saying you know this person is dying and that's what's going to happen for them. And so, if they're not comfortable with it themselves then yeah, they're very uncomfortable discussing it (ACP). (CRN; Interview: 15)

A DOC felt that some nurses' own unresolved issues with death and dying inhibited them from initiating difficult conversations with families. She believed that nurses needed to feel comfortable with death and dying in order to have these potentially emotionally charged conversations:

> I think the biggest difficulty is the nurses' comfort level, and for me, that's not an issue, but for many of our nurses that's a huge issue. It's not a conversation they feel equipped to have. Because if you've got a whole bunch of unrelieved issues around death and dying, you're not the right person to have an ACP conversation with somebody. Because you're getting into very deep – it can be very deep and difficult conversations, so you need to be grounded in yourself. (DOC; Interview: 02)

An RCM reported that new nurses often lacked experience with death and dying and had to work for some time to gain lived experiences of EOL:

> I think so much of it, when it comes to this, is about the experience people have had with death and dying. Many nurses graduating today have never seen someone die. They don't know, until they've worked for a while, they don't know what those last few hours, days, weeks are. They know it from a textbook, but that is different from having lived it. (RCM; Interview: 10)

Being a "New" or Casual Nurse. Participants in this study found that new or casual nurses had difficulty engaging in ACP discussions with family members. They believed that new nurses were uncomfortable and fearful of talking about death and dying. They also noted that new nurses lacked the knowledge and experience to have difficult conversations, especially about EOL and/or when meeting family members for the first time. The participants also felt that casual nurses were not equipped to have ACP discussions with families because they were not familiar with changes in the resident's condition over time. These notions were captured in the following exemplars:

> It's such a legal document so they (new nurses) feel like they don't have the confidence to discuss it, or they feel like they don't know enough and when they do talk about it. And it was just the nervousness of being a new nurse I guess. Or even like families, like you know when you meet someone for the first time you can tell if they're very resistant to discussion, I guess that too plays a part. Well when I was a new nurse, I was nervous, you know (Unit nurse; Interview: 18); and
>
> A casual won't be able to discuss it (ACP) with the family like what changed over the few months. Because if you're casual then you don't know, you see what's there today or

> what's there the other time that you were there. Like you don't have a good picture of the decline, so it has to be the regular nurse who knows the resident very well. (Unit nurse; Interview: 09)

Advance Care Planning Knowledge

Study participants almost unanimously reported that they had not received any formal ACP education. The WRHA's first education session about ACP took place approximately 18 years ago, when ACP was first introduced into the healthcare system in this region. Newly hired nurses reported that they received a brief description of ACP, including how to use the ACP form, during their job orientation. Some nurses reported that they had become self-educated about ACP during their course of employment. Self-educated nurses were only familiar with the basics of ACP and expressed the desire to learn about the different levels of ACP in more detail. They felt that further education would make them comfortable discussing ACP levels with residents/families. These nurses also wanted more training so they could advocate for an appropriate ACP level.

Nurses that participated in the study wanted to see more detailed ACP education, specifically with regard to residents' comorbidities and ACP status as well as the relationships between ACP levels and prognosis/outcomes. Nurses reported that their ACP education had focused almost exclusively on use of the ACP form, rather than the actual process of ACP or how the different levels impacted LTC residents with end-stage illnesses. In general, nurses felt that ACP education was absent from nursing curriculums. A newly graduated unit nurse confirmed that education about ACP was severely lacking in her nursing program. She reported that the three levels of ACP were only discussed for the purposes of teaching the students when to call a "code blue":

> Well in nursing school, you know, they didn't go through. I think they briefly discussed it because they were supposed to help us with our clinical so they were like "OK this is ACP duh-duh-duh the three levels and this is like what each one is about" and then so when you go to clinic, they're like "OK this is the ACP so you know when to call a Code Blue" you know, just like that stuff. So yeah we did learn in nurses' school in order to figure out if we needed to call a code. (Unit nurse; Interview 18)

An RCM was frustrated with the fact that ACP education was almost entirely focused on the ACP form. She believed that ACP was taught in black and white terms, without any effort to explain the consequences of each ACP level for residents at EOL. She wanted ACP education to focus on the effects of different ACP levels on quality of life, while also considering the implications of prognosis and comorbidities:

> I think that a lot of these things are taught in very black and white, like these are your choices, this or that without a lot of what is the consequence of those choices? – I mean, it's not formal around that, it's just learning a new form, right, "Here's another form, the form's committee blah, blah, blah." So this is what you do, but I don't know that it's specific or sort of geared to particular areas, just black and white, here's the form, it's on the chart no matter where you show up. I think there might be a role for more thorough education around what does that (ACP) entail when you're having those conversations, especially in the PCH setting where people are close to death and dying – So what does that mean in terms of prognosis?" (RCM; Interview: 06)

A unit nurse reported that she received a brief yearly reminder about ACP rather than any formal or proper education. She received her last ACP in-service 18 years ago, when it was originally introduced into the WRHA:

> It (ACP) probably falls into the yearly reminder of how we need to do our admissions, and they would say, but that would only be a comment as in it falls into the – you have to do it (ACP) in 24-hour thing. So it would be a comment rather than education on ACP. So I think you'd probably get education on it on orientation only. I would bet, which happened to me, like. 18 years ago. So that I haven't had any education about the ACP itself, except there was a change form which was about 12-15 years ago. And I'm sure when form changed, we got a little bit of something of it (ACP) in-service then, because I would say that was probably it. That was probably all. (Unit nurse; Interview: 01)

Reluctant to Initiate ACP Discussions with Family

Study participants unequivocally agreed that nurses were the best providers to discuss ACP levels with family members. Regardless, many nurses experienced some degree of hesitancy to engage in ACP conversations. Nurses cited several reasons for their reluctance to participate in ACP. The main barrier appeared to be their general discomfort with having ACP conversations. Many nurses did not feel confident answering family members' questions and delegated that responsibility to their colleagues:

> This is going to sound horrible, but I think some of our nurses don't want to do the conversation because they just want to pass that job off to others. Yeah, I think a lot of that is why the nurses don't want to. Again, some of them are just probably not comfortable with it or, you know, wouldn't know – or are afraid what questions will be asked and wouldn't know how to answer them. Yeah, so some self-confidence I think. (RCM; Interview: 25)

An RCM stated that ACP discussions were a significant liability for nurses and felt that many nurses were fearful their credentials would be compromised if they did not carry them out properly:

> I think, a lot of nurses would say this is a lot of responsibility and it's difficult, you know, ones that are uncomfortable and they would say "Well, this is my nursing licence and if I don't explain it properly, you know, I'm in trouble." (RCM; Interview: 21)

Cultural Factors

Culture of the Nurse. Study participants reported that ACP conversations were influenced by the nurses' cultural orientation. Nurses not educated in Canada tended to have more difficulty with ACP conversations and often worried about making mistakes at the end of residents' lives. Asian-born nurses who participated in the study described that their cultural influences made it difficult to have ACP conversations with family members. Since elders were highly respected in their culture, deciding on an ACP level without input of an elder compromised their cultural values. The following quote explained an Asian-born nurse's struggle with downgrading ACP levels:

> It's really a big factor with the culture, especially me, I'm an Asian, and we have a very close-knit family. So family is dear and we have a lot of respect toward our elders. Now, if you're deciding to change the level of care to your elder, that would clash with my culture, saying that I'm not respectful, right, because I'm now deciding what the elder should do in her life. Instead of the elder telling me what to do, I'm now making decisions for that elder, and then it clashes with my culture. For example, I know that you have deteriorated, I know that the comfort care level would be appropriate for this person, but really myself, I see that, oh, this elder, I shouldn't be getting involved with it. And so

> when the time comes that the family will be there to discuss ACP, I will have a really hard time explaining to them, because I'm not convinced myself. Yeah, I believe that culture is part of the factor that makes one not comfortable discussing the ACP. (CRN; Interview: 07)

Being an Internationally Educated Nurse (IEN). All the internationally educated nurses who participated in this study reported that ACP and/or LTC facilities did not exist in their country of origin. Therefore, they had a hard time with ACP conversations. These nurses required time and education to become familiar with ACP because it was a new concept. Some nurses stated that the first time they ever saw a DNR order was in Canada. In their country of origin, the concept of DNR did not exist; healthcare providers defaulted to providing everyone with life-prolonging measures. The following quotes from internationally educated nurses demonstrate the above-mentioned notions:

> Sometimes, because in my culture we don’t have advance care planning. We don’t have long term facilities, so sometimes we don’t deal with those advanced care planning. As I said, we're not familiar with advanced care planning. We don't call it like comfort, medical, and resuscitate. So, I think the nurses like me who are educated in other countries are also having a hard time doing that advanced care planning. So, I think we need more like educational information about, how to deliver ACP (Unit nurse; Interview: 11); and
>
> In my country, we tried to keep everybody alive. We tried to give them every treatment we do have. There’s the resuscitation for everyone. And here in Canada this was the first time I saw DNR note, do not resuscitation. (Unit nurse; Interview: 13)

A DOC reiterated that internationally educated nurses struggle with ACP conversations due to their limited exposure to EOL care and ACP prior to working in Canada:

> I think many of our nurses originally trained in other countries, and their orientation to Canadian nursing did not include end-of-life care. And so if culturally you're from a different culture and you have no exposure to it" (DOC; Interview: 02)

Having English as an Additional Language. The study participants felt that nurses who had a first language other than English often struggled to find the right words to explain ACP levels to family members, as these words did not come naturally for them. Study participants thought that these nurses may benefit from education about the appropriate terminology for ACP discussions, which may improve their overall confidence with these discussions.

An Asian-born unit nurse described her struggles to formulate the right words for ACP conversations. She believed that families were more comfortable and made ACP decisions more easily when they spoke with nurses who were born and raised in Canada. She thought these nurses could conduct ACP discussions more naturally given that English was their primary language:

> I'm Asian, so when I explain it (ACP) to them (family), it might be different when somebody else explaining. Like maybe they're more comfortable when people of their kind will explain it, you know, with their own language and all, and that it's more simple words from them compared to like me. I think, the choice of language or choices of words. So, I am formulating the right choice of words, it doesn't come naturally. When that's your first language then it comes naturally, you can explain it more, right. But when it comes from me, and I'm still formulating all the right words so that I can give the best explanation to them. So, I think it also has an effect, like, for example, they will

> decide easier when they talk to somebody who they're comfortable more in their language, you know. I think language can be a problem for nurses whose first language is not English, we struggle to find the right words, you know. I think the only struggle for Canadian born & raised nurse, they would have is emotional, but delivering it to the resident in their own language, in their own primary language is not difficult for example. It comes naturally from them. (Unit nurse; Interview: 11)

Similarly, a unit nurse reported that some of the nurses who spoke English as a second language struggled to find the right words for ACP discussions:

> I say for nurses with English as their second language really struggle to put forth it (ACP). I think, what they're trying to explain to the families just because they don't know how to word it. It is very difficult to find the proper words to explain the levels for them. The words don't come naturally. With education and teaching them the right words can improve the implementation of ACP. (Unit nurse; Interview: 12)

Physician Characteristics

Nurses reported that physicians' interactions with families were not helpful in promoting realistic ACP levels for residents. Physicians' ability to facilitate the downgrading of ACP levels was hindered by their lack of interest in ACP discussions, lack of availability to have such discussions, and lack of relationship/rapport with family members, lack of on-call physicians' knowledge of resident and physician's communication style along with physician taking a path of least resistance.

Lack of Interest in ACP Discussions

It was evident from the participants' reports that physicians were not actively involved in the downgrading of ACP levels. In general, it appeared that physicians tried to avoid participating in the ACP process. This notion was evident in the following descriptions: “The flip answer is as little as he (physician) can get away with it (ACP). He doesn’t like to get involved at the other end of – end-of-life. He doesn’t ... He will if I make him” (Unit nurse; Interview: 01); and “I’ve worked with many physicians, most of them are not so great in ACP, and not even interested in addressing the issue” (RCM; Interview: 04).

Lack of Availability

Nurses reported that physicians were often difficult to contact. Therefore, they felt that it was not realistic or possible to rely on physicians to facilitate ACP conversations: “The physician is always saying, you know, yeah, I'm available, if you want me to help you have those conversations just call me. But then you can't get a hold of him. So that's really not helpful” (DOC; Interview: 19).

Lack of Relationship/Rapport with Family

The nurses reported that physicians did not put much effort into developing relationships or rapport with family members, and only called them when absolutely necessary. Family members lacked confidence in physicians because of their limited rapport with them and did not want to follow their suggestions about ACP. These claims were evident in the following description: “The physician tends to call only when absolutely needed. So he doesn’t always have that relationship. The families don’t know him as well” (CRN: Interview: 15). Another participant indicated:

> The physician doesn't put as much of that caring into the relationship at the beginning or throughout the course of admission So the families don't have confidence in the physician, they're not going to listen to something that you have to say, especially when it comes down to advanced care planning. (DOC; Interview: 19)

Lack of On-Call Physicians' Knowledge about Resident

The participants reported that on-call physicians did not work at the facility and, therefore, lacked knowledge about the residents. Nurses usually contacted on-call physicians via telephone when there was a change in a resident's status. The on-call physician generally defaulted to sending the resident to hospital and was not involved in ACP conversations with family members. On-call physicians had limited knowledge about the residents and limited involvement in ACP discussions, making it difficult for them to facilitate downgrading of residents' ACP levels. These notions were well captured by the nurses in this study:

> On weekends, we more likely call the on-call physician, but they (on call physicians) don't know the residents. So it's just an on-call group and they don't really hold a practice here, they don't have residents here and they don't know the residents and most of them send residents to hospital when their condition declines, because they don't know the residents (RCM; Interview: 08); and

> On-call physicians, they don't really know the residents. So then that's really kind of difficult because you have to phone this doctor and he doesn't really know this person and you have to give them what your knowledge of this person is and what you have made your findings to be. I've never had an on-call doctor talk to the family about ACP or anything about the resident and they send everyone to the hospital, when the residents status change. (Unit nurse: Interview: 12)

Taking the Path of Least Resistance

When family members demanded interventions, nurses reported that physicians often chose the easy path of sending the resident to hospital. In such situations, physicians were not comfortable challenging the family members' expectations and chose not to discuss the residents' best interests with the family:

> I find sometimes, the doctors don't want to challenge families' expectations with – and have that conversation with the families to try and help them understand what would be best. Instead, they'll just default to sending them to acute care instead because it's just more comfortable. It's easier to do. And I think, maybe that's because again, they don't have that relationship built up with that family. And if the family, being very demanding and saying they want this, this, this and this, the doctor will just say well just send them out then. (CRN; Interview: 15)

In other instances, communication became problematic when physicians felt challenged by family members. This breakdown in communication hampered the ACP downgrading process. As a result, residents' ACP levels remained resuscitative and they were transferred to the hospital every time their health status changed:

> When they (doctors) get defensive. When they (doctors) feel challenged. So then it's like the doctors stop listening to the family, the family's not listening to the doctor and you're just talking over each other and it's not productive and it's not helpful for resident care at all. So the resident will be send to the hospital for everything and the resident will stay as ACP R, because they don't want to listen each other. (DOC; Interview: 19)

Communication Style

The nurses in this study perceived that physicians' communication styles were not effective in helping family members choose realistic ACP goals. They stated that physicians did not speak about residents' prognoses in a straightforward manner. The nurses also felt that the physicians' communication lacked empathy and compassion.

Protecting Self. During ACP conversations, study participants reported that some physicians were more concerned with protecting themselves than helping the family understand the reality of the resident's condition:

> I think when the doctors talk to the family, most of the time they have a careful conversation, what I mean is that it's more about protecting their butt, right, than actually having like a frank conversation about what the resident actually needs. Because lots of times the family's in turmoil when you're having those ACP conversations, so having a careful conversation isn't going to help them. (DOC; Interview: 19)

Do not Beat Around the Bush. Participants reported that physician-driven ACP conversations with family members were more intense, direct, and less empathetic when compared to nurse-led discussions. Nurses described physician-driven conversations as '*blunt,' 'rigid,' and 'cold.'* The nurses described the physicians' conversations as clinically focused and impersonal, and wished they would be more sensitive and caring in their interactions with families. Nurses found that physicians' direct and factual conversations were not helpful in downgrading residents' ACP levels:

> I don't want to say that a physician is heartless, but I think they're a little more clinical. I would say the terms are a little more geared toward diagnoses, prognosis. I've seen physicians, where I sit there and I think to myself, no, no, don't say that, don't use the word vegetative state, you know, because you've developed this relationship with the family, right. I hope they put some caring and sensitivity in their conversations, especially it come down to ACP. (RCM; Interview: 02)

An RCM reported that physicians were strict and formal in their communications with family members. This participant felt that the physicians' communication style, referred to as "do not beat round the bush," did not help family members make realistic decisions about ACP:

> The physician-driven ACP discussions are more formal and intense. Based on the doctors that we have here they are very strict, very formal. When they do have a discussion with families they don't beat around the bush, so they are straight and direct and to the point. No empathy or feeling forwards the family and they didn't help the family in deciding a realistic ACP level. (RCM; Interview: 08)

Institutional/Organizational Level

Care Milieu: Practices, Processes and Environments

Insufficient Physician Presence

The nurses reported that physicians' presence in LTC was limited since they only visited the facilities once a week for couple of hours and never attended care conferences. The nurses felt that the physicians' absence from the facility as well as their limited contact with family members meant they played a lesser role in ACP conversations:

> Physicians in long-term care are not basically ready to have a long, drawn-out conversation. They come once a week for an hour or two for their rounds and just leave. Here, where virtually none of our residents or families, had ever met the physicians, and they might see them once, then they become less of a key player in ACP discussions. (DOC; Interview: 02)

A CRN reported that care conferences provided opportunities to discuss ACP levels with family members but that he had never seen a physician in attendance: "I seldom see a physician coming to a care conference. In fact, I don't see them. I don't see them in a care conference. And care conferences are very effective in terms of reviewing the ACPs" (CRN; interview: 07).

Team Not on the Same Page

Participants reported that it was difficult to downgrade the ACP level if all team members were not in agreement, or "on the same page." The nurses stated that inconsistent information or careless comments from even just one member of the healthcare team could undermine the families' ability to accept the big picture:

> You know, it makes it harder if the whole team is not agreeing on the same thing. We have had situations where, you know, most of the staff feel that comfort care would be best but one of them doesn't because residents are good in their shift all the time or something. One of the biggest barriers I think is not having every on the same page. It is hard when team members that disagree on the same ACP level and it doesn't help family to accept it. (RCM; Interview: 25)

Inadequate Time

Nurses felt there was not enough time for them to have delicate ACP conversations due to heavy workloads. One of the nurses voiced the following:

> It is really busy in long term care. Some people don't understand how busy it is and how draining it can be. So now to have this conversation (ACP), you've got 20 other things to do. Sometimes I don't think nurses are given the amount of time they need to have those delicate conversations. (DOC; Interview: 19)

A unit nurse stated that ACP discussions were rushed at annual care conferences because the nurses had limited time to spare:

> Sometimes it's very rush so you don't have a lot of time and then when it's done at the care conferences, they really don't have a lot of time to sit and discuss it. To be honest, those care conferences are only supposed to be about 15-20 minutes long and ACP is very small part of it. (Unit nurse; Interview: 12)

Impoverished Therapeutic Space

The nurses reported a lack of access to private and quiet spaces in their facilities where ACP conversations could be held. They wanted a place with less distractions and a more home-like atmosphere in which to hold heavily clinical ACP conversations, instead of at the busy nursing desk:

> I wish if we have a quiet area where there's no distractions, is a good idea, and something comfortable that's not clinical, instead of in an office, in something that's more home like with sofas or couches; something that's a little bit more home like so that there's not so much clinical aspect to it, because it's a heavy clinical conversation. We don't have anything like that. (RCM; Interview: 22)

According to one of the unit nurses, the facility she worked at did not have a comfortable place to hold ACP discussions. She was forced to hold ACP discussions in the empty dining room or at the busy nursing desk:

> Our facility does not have any nice area for ACP conversations. There's a possibility that the small dining room, if it's not being used for a meal, may have space that I can go in there and shut a door, but most often it's the residents' room. And sometimes it happens at the desk. A busy hub and that's not good, but there's really no place. (Unit nurse; Interview: 01)

Faith-Based Facilities

Nurses reported that they had to put a lot of effort into downgrading the ACP level while working at faith-based facilities when compared to non-faith-based facilities. Nurses noticed that family members at faith-based facilities were more easily swayed to extend life at any cost because of their religious beliefs. Nurses found the ACP downgrading process to be much easier in non-faith-based facilities, since it seemed that family members at these facilities were more focused on quality rather than quantity of life. Faith-based facilities frequently sent residents to the hospital for aggressive interventions to keep them alive, as reported by the nurses:

> I find that being in a faith-based facility they (family) are very strong with their beliefs and so they're not easy to be swayed so you have to really put all of your effort in and discuss every single detail about their condition and diseases. So it takes more out of you as a professional to describe and actually explain in layman's terms what goes on. So when you work in a non-faith-based facility for them it's more likely quality of life, not quantity of life. And then they also are easy to say that OK if their loved one is dying then it's OK and they would just want them to be as comfortable as possible. So not as much of work in terms of getting them to be OK to have their loved one go, or to have their loved ones ACP as C. (RCM; Interview: 08)

Family members at faith-based facilities dictated care levels for their loved ones and wanted them sent to the hospital even if they were ACP-C:

> As in faith-based facilities family dictates what happens, so there are times when they've already said their wishes for their family as a "C", but if they're not comfortable with it, some families would still want their loved one sent and so we do as they ordered. So yeah, it's what it is. (RCM; Interview: 08)

A CRN reported that faith-based facilities discouraged the downgrading of ACP levels. In face, these facilities actively encouraged residents to be ACP-R in order to keep them alive at all costs:

> Faith-based facilities send resident often to hospital, because they are very into life, right, they would do anything just to save, or they would do anything to lengthen the life of their loved one, because I think that is what they grew up with. some of the homes, especially the faith-based homes, they still encourage people to have R, or resuscitation. (CRN; Interview: 07)

Insufficient and Unclear Advance Care Planning Form

Nurses found that the ACP form being used during the study period had several pitfalls, which prevented from successfully facilitating the downgrading process. Nurses noted that the lack of specific information about different interventions caused difficulties in customizing care plans according to residents' wishes. Nurses felt uneasy about the fact that the form did not require a family member's signature and were therefore reluctant to engage in ACP discussions.

Wishy-Washy ACP Form. Study participants described the current ACP form as vague and "wishy-washy." They stated there was not enough space on the form to specify the details of the treatments that residents/families desired. This notion was supported by an RCM, who felt that the ACP form had limited space to record the residents'/families' specific wishes. She stated that having more room on the form would make it easier to document specific information for each resident:

> I don't think it (ACP form) leaves enough room for those intricate conversations if they're done properly, where they're like, you know, "Well I don't want them to have a tube feed but I would like them to have XYZ". So you can have a little bit more room to make that conversation more specific to that person. (RCM; Interview: 22)

The nurses felt that ACP levels were unclear and open to different interpretations. They suggested that the form include a list of possible medical interventions that family members could choose from in order to help them better understand ACP levels. Nurses thought that customizing the ACP form or detailing more specific options/instructions on the form could help with downgrading ACP levels while also honouring the residents' wishes. Some nurses thought that family members would be more easily persuaded to downgrade their loved one to ACP-C if there was a menu of interventions/treatments on the ACP form. The following exemplars captured the above-mentioned notions:

> It's (ACP form) very wishy-washy that way, that document. I would like a form with the ability to pick and choose what interventions should or should not be carried out, you know. Like it would be nice to have an ACP document that would say "a list of treatments" which makes the ACP discussions understandable, especially for families and they can be swayed much easier to downgrade the ACP to comfort care (Unit nurse; Interview: 24); and
>
> The customisation of the ACP form is the one big part there, because a lot of times it's very vague. The goals of care form there, the description is very vague. It is open to a lot of interpretation, if they can customise it, as I said, on ACP M, if the resident or the family would not want any further investigation, and then they will say, do not send anymore to the hospital. Make her more comfortable with this and this at home. I think, the ACP can be better if we are more detailed in terms of different treatments, and it need to be more specific. This way we can keep the residents at home and make them comfortable. (CRN; Interview: 07)

Nurses from this study also believed that having CPR as an intervention on the ACP form was false advertising, as CPR was not offered in-house at many facilities. In fact, CPR was actively discouraged by the management and physicians at certain facilities due to limited resources and poor outcomes. To purposefully avoid CPR, physicians would speak with family members when changes occurred in a resident's condition and persuade them to downgrade the resident from ACP-R. These notions were well captured in the following exemplars:

> It's (CPR) a big contradiction and false advertising, when the service is not provided in-house. And by the time they're (EMS) coming, the time difference from the time they will start doing resuscitation on them (residents), and the time it's supposed to be, like, within five minutes, and they won't get here within that five minutes. The big delay of EMS coming and start doing CPR, to bring people back from death. (Unit nurse; Interview: 24); and
>
> I think the condition changes, right, the doctor wants to inform the family right away so we don't have to get to perform the CPR, so they want to like convince the family to go from R to M or something. (Unit nurse; Interview: 18)

One facility refused to admit residents who were ACP-R. These residents were forced to choose a different facility, as indicated by the following participant:

> When we get the admission package, if they're ACP R then I send it back to the LTC access centre and either the hospital care coordinator or the community case coordinator has that conversation with them and says, if you want to be an ACP R then you need to choose a different personal care home. (DOC; Interview: 19)

Missing Family's Signature on the ACP Form. Nurses felt uncomfortable that the ACP form did not require a family member's signature. The nurses viewed the ACP form as similar to a consent or waiver form, both of which required the signature of the person agreeing to the conditions on the form. Therefore, nurses found it strange that the ACP form did not require such a signature, especially since these forms pertained to discussions of life and death. Nurses wanted the decision maker for the family to sign the form to make it legally binding. The following exemplars from the nurses effectively captured these claims:

> I also found that nurses are less comfortable with the ACPs now, because families don't have to sign it. And I found that's where less nurses became comfortable with it, is when the person or the family member actually weren't signing it anymore. I personally would like to have the family sign it (Unit nurse; Interview: 12); and
>
> I really wish the family signs it. When they agree with the levels they understand the risks and benefits of those levels. If we take an exercise class, we have waiver for it. If we have this. Why shouldn't we have them to get sign it for discussing life and death, right. Makes sense and make it more legal. (RCM; Interview: 22)

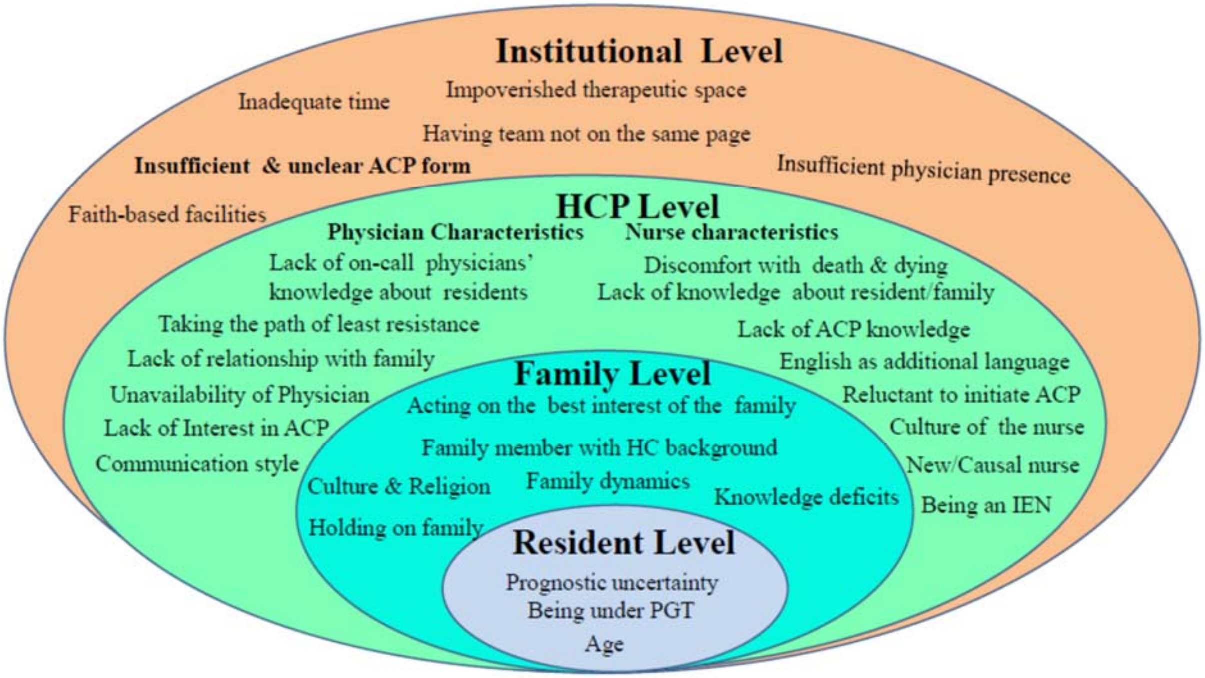
A unit nurse reported that the absence of a family member's signature on the ACP form was misleading, making it appear as if the healthcare provider had decided on the ACP level instead of the POA. In reality, the form was completed by the healthcare provider after having a discussion with the POA in which the POA had chosen the desired ACP level:

> A place for the family to sign. It's that's what missing on the form. Make clear that it's not the healthcare provider that's deciding. If they have a POA that it is the POA who is deciding on their ACP and like that is after it's been explained to them. Because it seems like the form itself, it says that it was the healthcare provider deciding what the ACP of this resident was on that form itself. We picked it up and so if you look at it, it would be

> the healthcare provider who is deciding this resident is an ACP R or ACPC without the family’s signature on any of it, so maybe that should change. (Unit nurse; Interview: 09)

Figure 3

Barriers to the Process of Downgrading



Facilitators to the Process of Downgrading

Several facilitators were identified that enabled nurses to downgrade residents' ACP levels. These facilitators were analyzed from a socio-ecological perspective and are described below, as well as in Figure 4 (at the end of this section).

Resident Level

Resident Characteristics

Change in Resident's Status. Participants reported that a gradual decline in the resident's health status or sudden change in their condition, especially when prognosis was poor, facilitated the downgrading process of the ACP level. In these situations, the nurses geared their efforts toward engaging in conversations with family members about comfort care and making the residents comfortable:

> If the person has really declined in their health status would be one for downgrading. For example, if they had suffered a stroke or if they'd had an MI or decline in their health status due to their other illness and they are still an R for resuscitation, then at that point we want to downgrade to comfort care, so we can keep the residents comfortable at the facility. (Unit nurse; Interview: 12)

Involvement of Resident in ACP Discussions. Nurses believed that ACP conversations were easier when residents were invited to participate. Unfortunately, many residents in LTC settings lack the capacity to make their own ACP decisions. In spite of this, nurses maintained that ACP discussions would have been easier if the residents could express their own wishes, as family members were not always aware of their desires:

> If the resident can be involved, it is easier. Well, at least you're hearing from them what they want. I think it would be, because they're making their decision. You're not trying to

> ask family to make this important decision for somebody who may not know what their goals of care. (Assistant DOC; Interview: 03)

Presence of a Healthcare Directive. The nurses reported that it was easier for family members to choose an ACP level for their loved one when there was an existing healthcare directive or living will. If there was a living will, nurses would follow the directions written in that document. As well, nurses reported that families usually chose less aggressive interventions in the presence of a living will.

The following exemplar from a CRN showed how a healthcare directive helped downgrade a resident's ACP level. In this situation, the resident's daughter was unaware of the existence of a healthcare directive and wanted medical interventions for her mother. By following the resident's living will, the nurse was able to honour the resident's wishes. The resident's ACP level was downgraded to comfort care according to the directions in the resident's pre-existing living will:

> I was trying to prepare the paperwork to send her to hospital, and I opened the ACP – it was ACPM – medical. So she had health-directive there that, you know, when she was competent. The daughter doesn't have that copy. Not even do we have it in her documents, and it's specifically stated there that in the case that my blood goes so low, I do not want blood transfusions. So I had to call the daughter back, that we are going against this woman's wish, because she said she doesn't want blood transfusions. I said, at this point, this is your mom's wish that we need to change the ACP to comfort care, and that was when we changed the ACP to comfort care. The healthcare directive was helpful to support the resident's wish to making her comfortable by downgrading the

> ACP, when, her daughter wanted us to send the resident to hospital for transfusion. (RCM; Interview: 14)

Family Level

Family Member Characteristics

Knowledge of ACP. Nurses reported that discussions about ACP levels were easier and more efficient when family members were familiar with the different levels of ACP. If family members lacked knowledge, nurses had to spend a significant amount of time and effort providing education:

> It's very good when you feel like the family, the resident, everybody involved understand what ACP is. They understand all the ramifications, all the options, and they've chosen according to what they believe is going to support the resident in question. Having a good understanding of the ACP levels makes a big difference. (Unit nurse; Interview: 01)

Letting Go Family Members. As mentioned previously, family members who were letting go tended to choose comfort care interventions for their loved ones. They acknowledged the residents' declining condition and did not want to prolong their suffering. These families were more open to having ACP conversations. In these cases, the ACP level was downgraded to comfort care without any difficulties:

> When you have somebody is just la-di-dah, relaxed and whatnot, so it doesn't have to give a lot of information, doesn't have to revolve in conversation. So, the conversation doesn't have to repeat over and over until they get that point. It's easy for them to understand and then they all just want to make sure that their loved one is comfortable to the very end, right. So, if keeping them comfortable means not sending them to hospital,

> then it's easy for them to say, "OK, let them stay" or Let them be comfortable in your facility and then we'll change the ACP to comfort care. (RCM; Interview: 08)

Active Visitation of the Family. The nurses stated that downgrading the ACP level to comfort care was easier when family members visited the resident frequently. Regular visits allowed them to see the resident's declining status for themselves. In addition, they were more familiar and open to having conversations with the staff. These families tended to have a good understanding of the resident's health status and treatment plan, and were more willing to downgrade residents to ACP-C when compared to families who visited less frequently. The following exemplar from a unit nurse demonstrated how ACP discussions were influenced by families' active visitations:

> Like when families that visit quite often have no problem downgrading the ACP level. It is not difficult for them to understand and change in loved one and need for comfort care, because they see their loved one quite often and they pretty much know the decline. We frequently communicating with the families during their visits as well. (Unit nurse; Interview: 09)

Healthcare Provider Level

Nurse Characteristics

Nurse Knowledge. It was evident from the participants' comments that having good assessment skills, along with a passion for palliative care increased the nurses' confidence in EOL care. As well, knowledge of the residents helped them provide information to family members in an honest and secure way. This ultimately helped the nurses persuade families to choose a realistic ACP level for their loved ones:

Knowing the Resident. Nurses noticed that their own level of knowledge of the resident's diseases and prognosis was directly correlated with the ease of engaging in ACP discussions with families. For example, nurses' awareness of the resident's poor intake and decreasing functional status helped them present the big picture to family members. Nurses reported that their own knowledge of the resident allowed them to present the honest reality to families in a sensible and caring way:

> I think it is nurse's knowledge about the person. Knowing the resident will make the things easier to discuss the ACP. You have to tell them (family) the reality in an honest way to help them (family)understand the big picture. (Unit nurse; Interview: 13)

Having Good Clinical Knowledge. Good clinical knowledge helped nurses provide information to family members and facilitate ACP decisions. Nurses felt that if they gave information to family members in a confident way, without questioning themselves, they more readily downgraded the resident's ACP level:

> Being sure of your clinical knowledge, strong in your clinical knowledge and being able to present the information in a really secure way. So that they (family) feel like you know what you're talking about. Because if they feel like you're questioning yourself and you don't really know what you're talking about, it's going to be difficult for them to decide based on what you're giving them, and not giving them really good information. If you give families good information, it is easy for them to change the ACP. (CRN; Interview: 15)

Having Knowledge and Passion for Palliative Care. Nurses reported that their knowledge and passion for palliative care made them comfortable talking about death and dying and having difficult ACP conversations. This notion is evident in the following exemplar: "I am very passionate about palliative care. I'm very comfortable about talking about death and dying. I think my palliative care knowledge helps me to have these difficult ACP discussions" (CRN; Interview: 20). This notion was affirmed by another participant who stated:

> I think I'm comfortable because right from being a student I loved palliative care. So I think that there is that heart connection with that side of life. That I don't shy away from. So I think that's part of what adds to the comfort. But I think that the whole idea of me always having loved palliative care helps a lot. It doesn't bother me to talk about that death and dying. (Unit nurse; Interview: 01)

Seasoned Nurse. A seasoned nurse was described as an experienced nurse who was comfortable engaging in ACP conversations with families. The most influential condition, and perhaps the one over which nurses had the most control, was their comfort and experience. In this study, experience referred to the length of time a nurse had worked in LTC. Comfort was a much more difficult concept for the study participants to describe. However, most of the nurses were able to give examples of comfortable and uncomfortable nurses. Comfort was most often defined as a nursing characteristic that encompassed such things as the nurses' willingness to engage in conversations about dying, the ease with which they could use the words death and/or dying in a conversation, and their ability to speak with families about a terminal prognosis:

> I think you have to be comfortable and in a good place with death and dying yourself. I've seen nurses who are very uncomfortable with death and dying They're (nurses) just not comfortable saying you know this person is dying and that's what's going to happen for them. And so, if they're not comfortable with it themselves then yeah, they're very uncomfortable having a discussion about it (ACP). (CRN; Interview: 15)

Participants reported that prior experience made them more comfortable with ACP conversations. Seasoned nurses had the confidence to help family members make realistic ACP decisions. Participants found that well-experienced nurses, who had been involved in many ACP conversations, effortlessly facilitated the downgrading process:

> I think experience makes it easier. I mean, having someone experienced there to talk to families who really understand the different levels makes it easier. I think experience makes it easier. So if you have an experienced nurse who's done a lot of it (ACP) can easily downgrade the ACP to comfort care. (RCM; Interview: 21)

A DOC reported that seasoned nurses were experts due to their long years of experience. These nurses knew the residents well and had developed strong rapport with family members, which helped with the downgrading process:

> It really depends on the nurse. So if I have like a seasoned nurse, then they are very confident, they'll have those conversations and help the family make that (ACP) decision. Just like, you know, you have your novice and your expert. It's really just that expert level. There are probably quite a few nurses here for 11 years. So that means they know those residents just as well as the families do and the families take comfort and take pride in that. And they have that relationship, and trust with the family, so it is easy to change the ACP. (DOC; Interview: 19)

A unit nurse agreed with the above DOC's description and stated that her 18 years of experience, along with her work in other areas of nursing, increased her confidence with engaging in ACP discussions:

> Well, I guess I have the comfort level of doing it (ACP) and being 18 years of doing it, did it in Transitional care unit (TCU), respite and now long-term care, I guess I've just

> developed a confidence in discussing it with people, but definitely an experience, like new grads won't even want to attempt to do that. (Unit nurse; Interview: 17)

Personal Comfort with Death and Dying. The nurse's comfort level was an important factor that helped family members understand the reality of the resident's status while advocating for comfort care. Nurses believed that they themselves needed to be comfortable with death and dying in order to share the reality of the resident's status with family members. Nurses who had more experience with death, and held more ACP conversations, felt more comfortable with death and dying: "I'm comfortable talking about death and I'm comfortable being honest with the families about what the reality is, I think you have to be comfortable and in a good place with death and dying yourself" (CRN; Interview: 15*)*. This statement was corroborated by another participant: "For me I would say it's the comfort with death and dying. Some nurses have had more deaths, or have experienced more deaths, and have experienced more conversation with family" (RCM; Interview:08).

Making ACP a Priority. Study participants reported that they made ACP discussions a priority, even though these conversations were time consuming. They preferred to have these discussions before a crisis occurred in order to keep the resident as comfortable as possible. They believed that taking the time to have these conversations helped facilitate the downgrading of ACP levels:

> I think we make it (ACP) a priority, it's very hard because it's time consuming and we don't get enough time and we make time to do it because it is important have those discussions before a crisis. I think it is important have those conversations to make the resident comfortable before things get worse. (RCM; Interview: 22)

Building Relationships with Families. The participants reported that building trusted relationships with family members was an important foundation for having difficult ACP discussions. Family members were not willing to talk about ACP levels unless they had developed some level of rapport and trust with the nurses. Family members who had trusting relationships with the nurses usually agreed to the nurses' recommendations regarding comfort care:

> I think just building that relationship – like being able to build a relationship with a new family a new resident quickly helps. Because they have to have some sort of trust in you to be able to have a discussion about end-of-life. You can't lead an ACP discussion without some sort of rapport with them first. If you aren't able to build a rapport with them at all it can be tough. They (family) might not even want to talk about it. Like, you don't know my mom why are we talking about this we just met. So, I think making it (ACP) easier is being able to very quickly build a rapport with them. Get them to trust you. And then being sure of yourself. (CRN; Interview: 15)

Effective Communication. Nurses in this study felt that effective and ongoing communication between nurses and family members made ACP conversations easier. The participants also believed that routine status updates helped keep family members informed about their loved one's health status. Nurses reported that ongoing communication with family members helped avoid future surprises and prepare them for the resident's EOL, while also highlighting the need to downgrade ACP levels to comfort care:

> I think an effective communication makes it easy to change the ACP level. An effective communication and timely update of the residents' situation not only giving the family an update when there's changes, but also keeping them updated every time, even if there's no worse situation that's happening. Means that the two parties are in – agreeable, and can

> understand clearly what's being said, and what's being explained. If they're getting more and more updates also they know what’s going on. And I think they are involved in the care conference, but more than that, the timely updates with them helps a lot in downgrading. (Unit nurse; Interview: 09)

Nurse Practitioner Characteristics

The nurses in this study reported that NPs in the LTC facility were more efficient in facilitating families’ acceptance of the residents’ big picture when compared to physicians. Nurse practitioners facilitated the downgrading process by building relationships with family members and providing information in a caring way. Family members readily listened to NPs and, as a result, were more willing to change their loved one’s ACP to comfort care.

Making Connections with Family. Participants reported that NPs put more effort into building relationships with family members from the beginning, maintaining regular telephone contact that enhanced trust. Nurse practitioners spent more time explaining interventions and the plan of care to family members. They also had more expertise and comfort with ACP discussions, when compared to physicians. Family members listened to NPs and were more willing to change ACP levels to comfort care:

> Nurse practitioner conversations, I think because there's a lot more put into the relationship at the beginning that it's easier to have ACP conversations. The nurse practitioner is kind of here more, does answer families, does call families back, does give them regular updates as needed or communicates the plan of care if there's going to be changes or they're going to order blood work. She involves in the ACP discussions and families trust her more and they are more willing to accept her recommendations of comfort care. (DOC; Interview: 19)

A CRN described the NP as “one of the nurses on the team” because of her familiarity with family members and their level of comfort with her:

> I think the nurse practitioner has more connection with the families, she comes to the facility more often, she phones the families more often. She actually develops a relationship with the families. I find our nurse practitioner is more like one of the nurses on the team where she knows the families and they’re more comfortable with her. (CRN; Interview: 15)

Laying Everything Out in a Caring Manner. Nurses found that NP-driven ACP conversations were less formal when compared to physician-led discussions. Nurse practitioners were characterized as approachable and took the time to present information to family members in an honest, clear, and direct manner. Nurses felt that the manner in which NPs shared information facilitated the downgrading of ACP levels.

An RCM reported that, compared to conversations with physicians, NP-driven ACP conversations were less tense and families felt more comfortable asking questions:

> The nurse practitioner take more time and to say and like, she would say, we’ve tried this and we’ve tried and there’s really nothing more that can be done and. I think the nurse practitioner is clear and straightforward in a caring way. I guess maybe they take a little more time with the family, where the physicians sometimes are, you know, more rigid, so families are more open the nurse practitioner’s discussions and family listen to her and change ACP to comfort care. (RCM: Interview: 08)

Institutional/Organizational Level

Care Milieu: Practices, Processes and Environments

Building Clinically Strong Nurses

Nurses believed that they needed to have strong clinical and critical thinking skills in order to piece together the big picture. Nurses who had strong physical assessments skills along with good pathophysiological and diagnostic knowledge reported feeling more comfortable with assessing the progression of residents' diseases. Nurses stated that it was important to have access to education that focused on building nurses' assessment skills and increasing their knowledge of chronic illnesses. They thought annual refresher courses would increase nurses' confidence in their assessments and help them piece together the big picture:

> We really need to look at the education and making sure that their (nurses') assessment skills and that their critical thinking skills are stronger. Because then they'll feel more comfortable having these (ACP) conversations. I think a physical assessment is a big one and then also just refreshers on chronic conditions and the elderly, and understanding you know the progression of a disease. And then comorbidities and how like that anatomy and physiology part. And understanding – like looking at a lab work, getting a physical assessment, and then being able to put those pieces together and say, you know, I see where this is going. (CRN; Interview: 15)

Presence of House Medical Officer

Nurses reported that having access to an on-site house medical officer (HMO) aided in ACP discussions. Consistent access to an on-site physician was helpful to ensure residents were assessed in a timely manner. If a resident's condition declined, the HMO spoke with family members after completing an assessment and had them consent to downgrading the resident to ACP-C:

> Well, there’s always an HMO on-site. She is here for 24/7, even in the night if something happened. We do have access to the physician and they talk to families and try to change ACP to comfort care if the residents’ condition changes. (RCM; Interview: 06)

Availability of On-Site Nurse Practitioner

Nurses in this study stated that the accessibility and availability of an on-site NP helped family members better understand their loved ones’ conditions and facilitated their decisions regarding comfort care. Nurses reported that the NP was on-site more frequently than the physician; the physician visited once a week, whereas the NP was at the facility five days a week. The NP had more involvement and face-to-face interactions with family members, which resulted in a higher level of trust. The NP was always present at care conferences, where ACP levels were reviewed; physicians were seldom present at these conferences. One of the participants spoke about the value of having the NP on-site:

> I would say, because the nurse practitioner will be there, you know, more often than the physician – I believe the physician comes by once a week – the nurse practitioner would be there, like, Monday to Friday. So the involvement of the nurse practitioner is more frequent than the physicians. And I believe with the frequency would come also the expertise. Like, if you're doing it (ACP) all the time, then you're more comfortable, you're more effective. Not saying that the doctors or physicians are not effective, but then they (physicians) are only there once per week. It’s different if it’s a phone call, because you don’t have the face-to-face interactions, and it’s very formal with a phone. I seldom see a

> physician coming to a care conference. The nurse practitioner is always present at the care conference. (CRN; Interview: 07)

Some of the DOCs struggled with the lack of access to physician support. One of the DOCs voiced the importance of having more NPs in LTC facilities: "I think the LTC should have more nurse practitioners it would be way better than having physicians" (DOC; Interview*: 19).* Similarly, another DOC stated: "If we had a nurse practitioner, the nurse practitioner would be part of our team, because they're available more often than the physicians are. We really struggle with physician availability" (DOC; Interview: 02).

Supportive Management

It was evident from the study participants that the support of management was essential in downgrading ACP levels. Nurses found it helpful to seek support from management when needed. Managers stepped in if family members required further clarification or if the nurses were having difficulty downgrading the resident's ACP level. According to the nurses, managers were able to successfully downgrade the ACP level most of the time.

An RCM reported that the DOC at her facility was very supportive of staff and talked to families whenever needed in order to help with ACP conversations:

> I think management is good, our director of care is very supportive. She does answer our queries or questions. And if we think director of care can help us with getting comfort care, we ask her to help and then she's pretty much good with talking to the families about ACP. So, I think management has a full support to the staff if they need any support or any assistance, so management is there to help us with the ACP conversations. (RCM; Interview: 10)

One of the unit nurses indicated that managers were supportive of the nurses' requests for assistance. This nurse also postulated that the managers' position and perceived power played a role in their higher success rates of downgrading ACP levels:

> If the family is upset and we have not made it (ACP) clear and if nursing feels like if the family has not made an adequate decision. So, in that situation when we don't feel like there's a clear answer but the nursing aspect would feel like they should become an advanced care plan C then – we ask our management to help us. Being higher up so, maybe their power behind it. So, I would say it's maybe sometimes it would be the tone of voice or just being in the position they have, so we use them to get the ACP changed to comfort care and they are very supportive. (Unit nurse; Interview: 20)

Provision of Education

For Families. The participants believed that education about ACP levels and recognition of dementia as a terminal illness would help family members make realistic ACP decisions. Nurses believed that annual ACP education, targeted at families/residents and facilitated by a physician or NP, would help keep everyone on the same page. They thought this event could be held at the resident council meeting, which was coordinated by the recreational staff or spiritual personnel.

An RCM believed that family members were not aware of the concept of ACP, since it had not been discussed until their loved ones were admitted to LTC:

> Definitely is very important to have education for the family especially in the long-term care facility. Family should have kind of information or some kind of education for the better understanding of ACP. Because nobody has discussed with them about the ACP, until their loved one comes to the facility. So maybe the facility to have some kind of

> education for the family, so they will understand more about ACP. And if family has that education, so then I think it will be easy for the facility to discuss about ACP with the family. Because they will know better and it helps with changing the ACP when the resident declines. (RCM; Interview: 10)

An RCM wanted families to have access to more education about the different levels of ACP. She thought this type of education could keep everyone on the same page by promoting a uniform understanding of ACP levels:

> I'd like to have more education for the families of the resident in the long-term care facility. So they should have a better understanding what is ACP, what are those three levels of goals of care and this way when we discuss about it everyone know what we are talking about it and this way all are on the same page. (RCM; Interview: 22)

A CRN wanted families to be educated about the meaning of a poor prognosis as well as the expected clinical complications of dementia:

> I think there needs to be more education with the family members about dementia and it being a terminal disease. I'm not sure if some people realize that it is terminal and there is no cure, and you know, it eventually – there is side effects from it that will kill them. (CRN: Interview: 15)

For Nurses. All of the nurses stated that they wanted more education in order to increase their comfort level during ACP discussions. They recommended compulsory ACP education for all nurses to ensure that nurses' were acting from the same body of knowledge. Some suggested yearly ACP education with a discussion forum, where nurses could learn from each other and share experiences. Some nurses recommended ACP drills and role playing for ACP conversations, as they felt this might increase nurses' confidence levels. Others viewed ACP as a skill and believed that nurses' competencies should be assessed before they completed ACP discussions independently. Some nurses wanted professional licensing bodies, like the College of Licensed Practical Nurses of Manitoba and the College of Registered Nurses of Manitoba, to offer special ACP training through their continuing education programs.

A DOC thought that wound care education should be replaced with education about ACP conversations, as most LTC nurses would have experiences with death and dying in the course of their work. This DOC provided justification for her opinions and stated that ACP was not something that could be taught in a single session:

> I honestly think that there may be more value in providing education for nurses about advanced care planning, than there is in wound care, for all nurses. And here's my rationale: Every person we care for will have – will die. Not every person will develop a wound, and so there is – I mean, there's reason why everybody needs to know how to prevent wounds. But I'm not sure everybody needs to know how to treat wounds, because you can get an expert to help you with that. Everybody should have advanced care planning. I think the other thing is, it's not something that is teach once and leave alone. (DOC; Interview: 02)

The participants believed that having ACP champions, similar to wound care champions, could increase ACP uptake at the facility. They believed that experienced nurses could act as ACP champions and that other nurses could consult with these champions when facing any ACP-related challenges:

A CRN envisioned that nurses with more experience could be mentors to new nurses, and assess their ACP competency during real-life ACP conversations with family members:

> I honestly think the best way to provide training to these new nurses is to have them – almost like when you have a skill you have to get signed off on it. So you have to watch one or two with a more experienced nurse. And then you do one or two with that person watching you and they kind of sign you off and it's more of a mentoring program. I think that would be the best way to do it. Because real life situations and conversations I think are the best way to learn. I definitely think they shouldn't be left to do them on their own, when they're brand new; it's a learned skill. It's not something you just know how to do. (CRN; Interview: 15)

A unit nurse believed that ACP drills could be implemented to help nurses practice ACP discussions: "I would like to have ACP drills like fire drills where you go through it, here's your resident, this is what they're presenting with, now have the discussion on ACP" (Unit nurse; Interview: 17). Another unit nurse wanted ACP education to be introduced through the WRHA's learning management system (LMS) as a self-learning package, which could be completed on an annual basis along with other mandatory education modules. She believed the LMS educational platform was convenient and allowed nurses to complete modules according to their own availability:

> It would be nice if there was like a formal education, like a self-learning package, in LMS. I think that would be more convenient. It would be easier just to do it through LMS. with an audio, so it's like on your own time but you're still obliged to finish it by a certain, you know, due date. I haven't done one on ACP but that would be nice. You know because we have to do yearly education on different topics anyways right and you have to like renew it yearly. (Unit nurse; Interview: 18)

Having a Team on the Same Page

Nurses felt that it was easier to downgrade ACP levels when there was agreement from the key players and everyone had the same understanding. Nurses thought that the key to downgrading ACP levels was making sure the team was on the same page: “When there's an agreement in all healthcare team members and the family. And when there’s an effective understanding from all. And when the family can easily decide on comfort care when everyone is on the same page” (Unit nurse; Interview: 09).

Integrating ACP Conversations in Routine Practice

Participants reported that talking about ACP regularly and making ACP conversations an everyday practice helped family members and nurses become more comfortable with the topic. They believed that increasing familiarity with ACP helped family members downgrade ACP levels to comfort care at the appropriate time.

In the following exemplar, a DOC believed that nurses needed to be as comfortable talking about ACP levels as they were about urinary tract infections:

> We need to talk about advanced care planning as much as we do urinary tract infections. That's kind of how I compare it. And they're like, oh. At the same time, you're comfortable talking about UTIs (urinary tract infections), you should be comfortable talking about ACP. This way when the time comes the families know what it is and there is no problem with changing their ACP to comfort care. I think the familiarity and use of it in everyday practice. (DOC; Interview: 19)

Introducing ACP Prior to LTC Admission

Nurses expressed disappointment in the fact that family members were often not told about ACP prior to their loved one’s admission to LTC. Nurses stated that earlier introduction of families to the ACP process would make ACP decisions more efficient during LTC admission. Nurses believed that primary care physicians and homecare coordinators were well positioned to introduce the concept of ACP, as they were typically involved in the resident's transition process from community to LTC. Nurses also believed that inclusion of the GOC package, along with the other documents for the paneling process, would introduce the ACP process to families prior to their loved one's admission to LTC.

The nurses recognized that the process of transitioning a loved one to LTC was stressful for families. They also acknowledged that approaching family members about ACP levels on the first day of admission was too much for them to process, especially when they had limited background knowledge about ACP. The nurses felt that, if families were introduced to the ACP levels prior to the resident's admission, they would be better prepared and more willing to engage in ACP conversations. The nurses believed that the healthcare team member involved in the LTC paneling process would be best suited to introduce families to the ACP process, because they already had a relationship with the family members. The above opinions are reflected in the following quote from a DOC:

> It always makes me sad when someone comes into long-term care and this is the first time anybody's talked to them about ACP. Like, I honestly believe it should be part of the decision making process prior to placement in LTC. The people who are helping with the panelling should have these conversations. It can be done by a home care case coordinator or the family doctor. And so these people are much better positioned in terms of the relationship with the family/resident. (DOC; Interview: 02)

Designating ACP Responsibility to the Nursing Profession

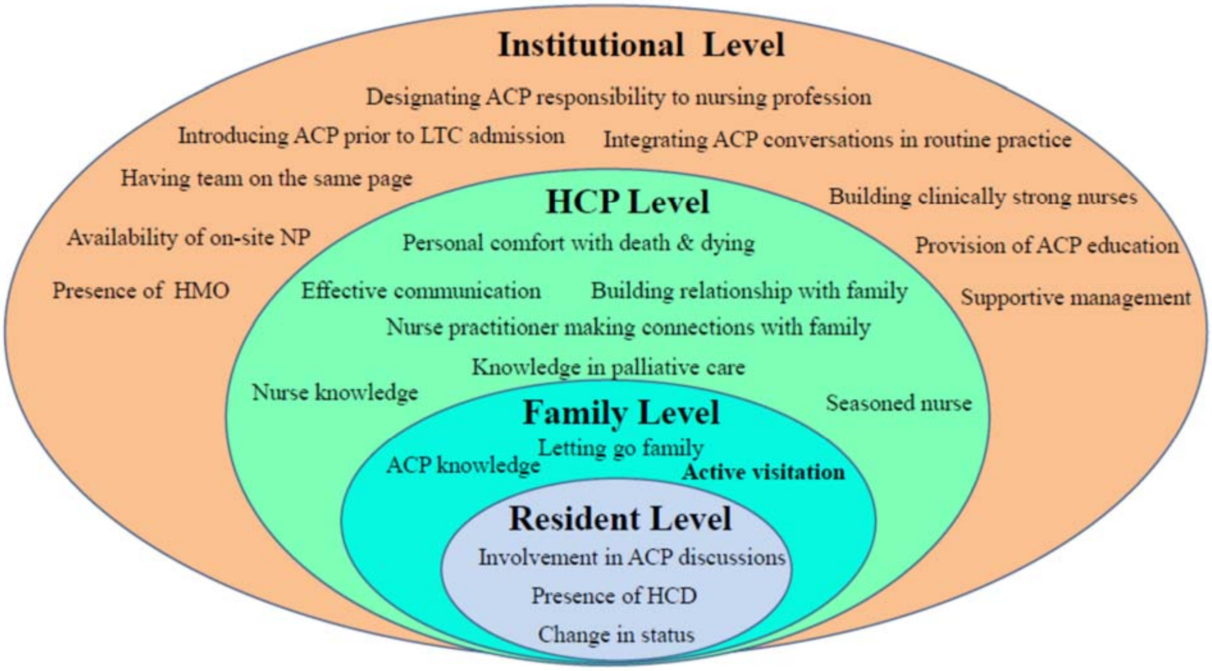
Participants in this study strongly believed that the responsibility for ACP should be designated to one profession. They argued that ACP discussions should be delegated to the nursing profession because every individual who entered the healthcare system would inevitably come into contact with nurses. Participants felt that nurses already function as leaders in the ACP process and, as a result, should be provided with ongoing education, support, and guidance around appropriate language for ACP conversations.

A DOC wanted the responsibility for ACP conversations designated to the nursing profession in LTC facilities. She believed that nurses should receive ongoing education and support in order to have these difficult conversations with families:

> I think the biggest change is more recognition, that I think it needs to get defined to a discipline. Because as long as it is everyone’s job, it’s no one’s job. I do not believe physicians are the right person, or the right profession. I think it’s nurses, because virtually every person that comes in contact with our healthcare system, has contact with a nurse. So I think it’s nursing, and certainly in long-term care it’s nursing. And I think we need to encourage nurses, provide them with training, provide them with the language, the mentoring, the support, to be able to have those conversations. I want the ACP responsibility to define, to the nursing discipline. (DOC; Interview: 02)

Figure 4

Facilitators to the Process of Downgrading



Consequences of Downgrading

The positive and negative consequences associated with the downgrading of ACP levels occurred at the resident, family, and healthcare provider levels. These consequences are described below and depicted in Figure 5 (at the end of this section).

Positive Consequences

Resident Level

Smooth Transition to End-of-Life and Dignified Death

Nurses reported that downgrading ACP levels to comfort care helped residents smoothly transition to EOL and ultimately contributed to a peaceful death. According to the study participants, the comfort care ACP level supported both the trajectory of the EOL care plan and the final life journey of the residents. Downgrading the ACP level helped residents remain at the facility where they could die peacefully, with family at their bedside. When residents were ACP-C, nurses were better able to manage their comfort and ease the dying process:

> The resident population that we're admitting here are coming to die. Changing ACP to comfort care supports the care that you're going to be providing to the family and to the resident. Comfort care support the smooth transition to end-of-life and helps with the final journey in everyone, it helps resident, family and staff. (DOC; Interview: 19)

Family Level

More Satisfaction with Care and Less Stress

According to nurses, family members were less stressed and more satisfied when residents were designated as ACP-C, rather than ACP-M or -R. After the downgrading process, family members felt relieved that their loved ones were safe in the LTC facility and did not have to worry about visiting them at the hospital. One of the nurses expressed this sentiment in the following statement:

> I think that is (ACP-C) the best. Because family will not think about visiting the hospitals anymore. They're just going to be thinking about spending more time in the facility with their loved one, and then the residents are not exposed to other infections, they feel like they're safer when they're in the facility and not to be sent into hospital. (Unit nurse; Interview: 11)

Healthcare Provider Level

Rewarding Part of the Job

Nurses who participated in this study identified downgrading the ACP level to comfort care as the most rewarding part of their job. They felt it was worth taking the time to talk to families to get the ACP level changed to comfort care. One of the CRNs felt that it was a beautiful experience when a resident died at her facility. She stated that when a family member expressed gratitude to her, and felt their experience had been like that in a movie, it made her feel like her job was rewarding:

> Personally, it's the most rewarding part of my job. When someone passes at the facility and it's beautiful then it's totally worth it; or like you know to hear a phone call from this man, you know. Yesterday he called and he has a funeral home and he's saying thank you, like that's wow, you know, and so – or someone leaving and saying, "Boy this was like a movie", you know, it's worth it having the time to talk to families and the get the ACP to comfort care. (CRN; Interview: 20)

Negative Consequences

Resident Level

Suffering due to Lack of Agreement on a Realistic ACP

Participants in the study stated that it was very difficult to provide the appropriate care to residents when the decision maker was not supportive of the downgrading process. Decision makers sometimes ignored the resident's wishes, and chose what they or other family members wanted instead of what was in the resident's best interests. As well, the PGT's strict adherence to designating residents as ACP-R led to unnecessary suffering and increased hospital transfers.

A unit nurse found that families' unrealistic treatment goals tended to cause unnecessary suffering and pain, especially when they wanted medical interventions to keep their loved ones' alive regardless of advanced age or advanced disease:

> Well, it's always hard when you know that the person, say you have an 80 pound woman, we have a frail lady or who's 94 years old with end stage CHF and the family wants resuscitation and you're knowing that, there's nothing more that can be done. Even if they're medical we'll send them to hospital, they'll send them back, and chances are if I have to do CPR I'm just going to break ribs. So, how do you help the resident when the family is not supportive and they wanted everything done for their loved one. (Unit nurse; Interview: 17)

Failure to Honour Resident's Living Will

Participants reported that family members sometimes completely ignored the resident's legally binding living will. Resident's often specified in their living will that they only wanted to receive comfort measures, but family members chose to proceed with aggressive interventions anyway. Family members assumed that the resident's current cognitive impairment invalidated their previously established living will.

An RCM gave an example where family members chose ACP-R against the resident's stated wishes in her living will. The family members were not in agreement with downgrading the ACP level, even after several conversations with the nursing team:

> We have a resident who came in here, she's quite impaired cognitively, and the family wanted her as resuscitation, this person came in with a living will which states very clearly, like I have never seen one so detailed. And they would want none of this. They don't even want antibiotic treatment for anything and that's in a living will. And the family is completely against it. We've had many conversations; we've had all the kids on the telephone at once all to have this conversation. And they oh, they will not change it because to them, now that she's cognitively impaired it's not in place anymore.it is very difficult when family go against the resident wishes and not supportive to what she wanted. (RCM; Interview: 25)

Healthcare Provider Level

Emotional Toll

Some study participants reported that ACP conversations were the most emotionally exhausting part of their job. They reported that these emotionally draining conversations took a personal toll. As described in the following quote, the nurses felt their relationships with the residents and their families made these discussions harder, but they pushed their feelings down and kept doing their jobs:

> I think for me it takes an emotional toll on me every time I have the ACP conversations. It's the most emotionally exhausting part of my job because I have to give a bit of myself

> every time. And I do that willingly because that's just, I need to. But there is a personal cost to that at times, you know, I just feel emotionally because of the, you know just the different feelings. I think the downside for me as a professional it's draining. (CRN; Interview: 20)

Even though this DOC was comfortable with ACP discussions, she felt the conversations had a negative effect on her:

> I'm comfortable with it but it still hurts me. You're a human being and you're a nurse. And you've built relationships with these people. There's lots of times where you have those hard ones and you just keep pushing it down and then you might go into the broom closet, just let it out, cry, you come back out, you're fine. (DOC; Interview: 19)

Conflict Between Personal and Professional Values

Some nurses from Asian cultural backgrounds had difficulty recommending comfort care for residents, due their own cultural values and beliefs. These nurses' cultural values emphasized a high level of respect for elders and believed that elders should be involved in decision making. It was hard for nurses from certain cultural backgrounds to suggest ACP-C for an elder even when comfort care was appropriate. The nurses knew they had a professional responsibility to maximize residents' comfort, but felt that the elder should make their own healthcare decisions. They perceived that making decisions on the elder's behalf, without their input, was a direct violation of their cultural values.

In this study, an Asian-born nurse stated that his own suggestions to downgrade residents' ACP levels were incongruent with his values and beliefs. He voiced feeling uncomfortable having ACP discussions with the elder's family members:

> I'm an Asian, and we have a very close-knit family. So family is dear and we have a lot of respect toward our elders. Now, if you're deciding to change the level of care to your elder, that would clash with my culture, saying that I'm not respectful, right, because I'm now deciding what the elder should do in her life. Instead of the elder telling me what to do, I'm now making decisions for that elder, and then it clashes with my culture. (CRN; Interview: 07)

At times, nurses’ own religious beliefs created moral distress. Nurses felt as if they were acting against their own beliefs and moral values in order to carry out their professional responsibilities. These nurses reported that their religious beliefs were to prolong life, and felt that not offering interventions to keep the person alive infringed upon their beliefs. As a result, these nurses felt uncomfortable engaging in the process of downgrading ACP levels.

In one example, a unit nurse recommended comfort care measures and advocated for family members to keep their loved ones at the facility, against her own religious beliefs. Deep down, she wanted to send residents to the hospital for life-sustaining treatments. This nurse described how she had to prioritize her professional responsibilities over her religious beliefs:

> It's always hard, because in my religion it is to prolong life, so I always want to extend life and everything. So, I'm not used to the comfort care, I'm not used to this comfort care option. So, it’s really hard for me to like tell families to keep them (residents) here and provide comfort measures because deep inside me I want them to be sent to the hospital and do more – you know, more medical treatments for them to survive, right. But because I’m here and I have to do it because that’s the nursing responsibility and intervention that I have to give. So, I think the nurses like me who are in the same country are also having a hard time doing that ACP. (Unit nurse; Interview: 11)

Witnessing Suffering and Feeling a Moral Obligation to Reduce that Suffering

Some participants reported that they felt helpless when family members refused to downgrade residents to ACP-C and did not understand the futility of aggressive interventions, even after witnessing their loved ones suffering from these interventions. These family members wanted to keep the resident alive at all costs by offering aggressive interventions, which were not in the residents' best interests. Nurses reported that they could not do anything to alleviate the residents' suffering in these situations and were obligated to honour the family's decisions. At times, nurses reported feeling as if the residents were being tortured by the interventions and that they were forced to watch in silence. When it was not possible to downgrade ACP levels through discussions with family members, nurses had to send the residents to the hospital whenever they were asked to do so.

In one example, an RCM reported that the unrealistic decisions of a family put the resident through tortuous interventions and resulted in emotional distress for staff, who had to witness the resident's distress. The RCM stated that in this difficult situation, staff could only support each other emotionally and listen to each other's feelings:

> Well, we talked about it a lot in every shift; we just had the opportunity for people to express their feelings. "This is very difficult" but again, we just had to provide the care. I think people tried to support each other, that even though we see it as torture, the family don't. And even the psychiatrist was agreeing that it's just torturing this lady by putting the feeding tube etc. but we don't have any choice. So that's the situation we're in. So we had to provide the care. And we have to care for them because families have made decisions that aren't necessarily in the resident's best interest, but the family want to keep

> them alive, so to speak. Or want to keep them going. And that has caused some distress to staff. (RCM; Interview: 06)

In another situation, a unit nurse stated that efforts to downgrade a resident's ACP level were unsuccessful, so the nurses were obligated to follow the son's wishes and transfer the resident to the hospital whenever he demanded:

> The hospital has been telling him (son) as well to keep her (resident) in comfort, but he refused as well. And he refused with us as well, even after the physician talk to him. So, we just follow what he's wished for. We're just taking it day-by-day with him. Like for example he wants his mom to be sent to the hospital, we just do it because that's his wish. But it is hard for us to see she is suffering by going back and forth, we are really sad to see this, but what can be do, it is the POA's decision, we tried and the hospital tried to change the ACP to comfort care, but we all failed. (Unit nurse; Interview:11)

Similarly, an assistant DOC stated they had no choice but to watch residents suffering in silence. The DOC described a situation where family members wanted the resident to be ACP-R and opted for numerous futile interventions, despite the resident's extensive cancer:

> When someone comes in ACP R, and you know that they're maybe full of cancer and they're (family) still wanting to transfer to do ultrasounds and MRI's and everything. Emotional, it is hard, you're putting the resident through all this for – anything at end. We want them to be on comfort care you just have to kind of talk it out with colleagues and ultimately you have to follow what the POA want. We can't do anything, we can only advocate. (Assistant DOC; Interview: 03)

Feeling of Being Resented by Physicians

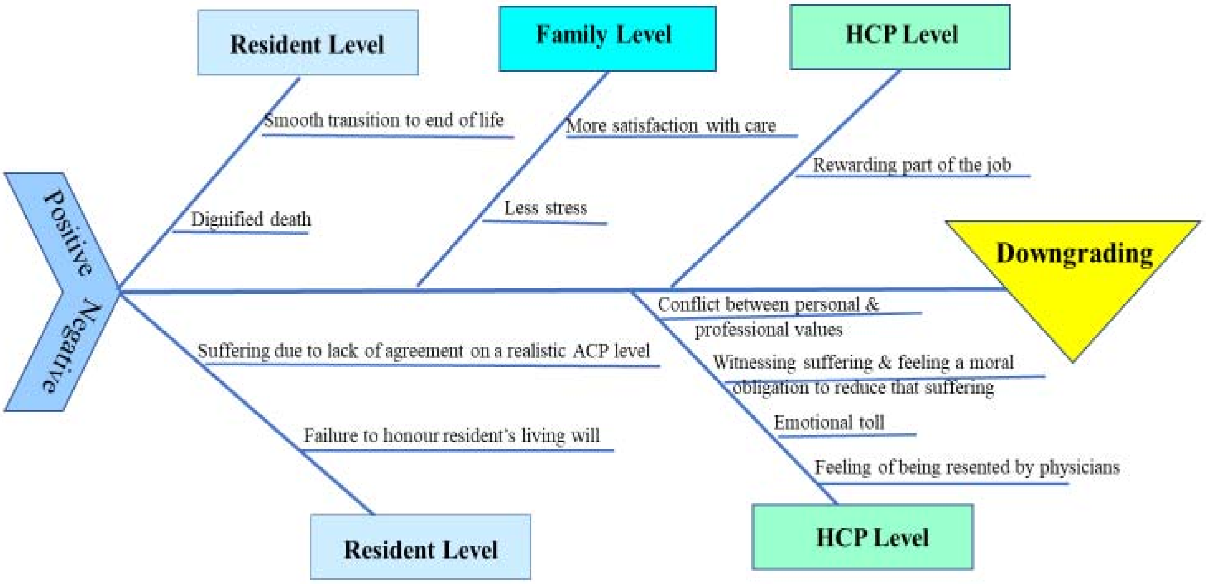
Nurses sometimes felt that the physicians had wronged them. They described scenarios where the physicians said one thing to the resident's family and then did something completely different with the resident, which had not been explained to the family. The nurses felt responsible for the physician's actions and felt obligated to defend them to the family.

A unit nurse reported her feeling of being *left to dry* when a physician told family members that ACP-C meant no change in care; the following week, this same physician stopped the medications that were managing the resident's chronic conditions. The unit nurse provided the following account of this situation:

> If a family comes in and he's talking to family, he'll say going to comfort care means nothing will change in the care, your loved one will receive here. It doesn't change anything in the care, and all it does is it means that we will support them and help them to live best as they can till the end of their days. The following week, he will say okay, we have ACP C. We're going to stop this medication and that medication because those are all, like, treatments of medical conditions. But you didn't describe that to the family, and now you're leaving me to explain why you're changing these to the family. But I feel left out to dry when he does stuff like that. I feel like when he's describing it to the family and I'm sitting there, I cringe because I think next week I have to do this. You know, if they change it to APC C, next week I'm going to be explaining all the med changes that he's done. (Interview: 01)

Figure 5

Consequences of Downgrading



Summary

Nurses who participated in this study believed that LTC facilities were the residents' final homes, due to their advanced age and/or progressive chronic conditions. Nurses believed that life-prolonging aggressive interventions neither provided comfort nor improved quality of life for LTC residents. Therefore, nurses directed their strategies and actions toward shifting family's unrealistic treatment and care goals to an ACP level that they considered more realistic for actively promoting the residents' comfort. Two pre-conditions needed to be met in order to be able to downgrade residents to ACP-C: (a) piecing together the big picture, and (b) selling the big picture. In order to piece together the big picture, nurses assessed the resident's overall condition as well as their family member's understanding of the big picture. The nurses in this study believed that families' requests for unrealistic treatments and unreasonable care goals stemmed from their lack of acceptance or general misunderstanding of the big picture. Nurses tried to facilitate families' acceptance of the big picture through a process called 'selling the big picture.' Strategies nurses used in selling the big picture included: (a) gentle persuasion; (b) team persuasion; and (c) drawing a line in the sand: enough is enough. When nurses were able to successfully sell the big picture to family members, the resident could be downgraded to ACP-C.

Table 4 summarizes the pre-conditions, nursing strategies, barriers, facilitators, and consequences of the process of downgrading the ACP level. The next chapter provides details of the upgrading process of the model.

Table 4

Summary of the Downgrading Process

Process of Downgrading				
Pre-conditions	**Strategies**	**Barriers**	**Facilitators**	**Consequences**
Piecing Together the Big Picture	Piecing together the resident's big picture Piecing together the family's big picture	**Resident/Family Level**	**Resident/Family Level**	**Positive**
		Age of the resident Resident being under PGT Prognostic uncertainty Family dynamics Acting in the best interest of the family Family member with healthcare background Family member knowledge deficits Culture and religion	Change in resident's status Involvement of resident in ACP discussions Presence of HCD Family's knowledge of ACP Letting go family members Active visitation of the family	**Resident/Family Level**
				Smooth transition to EOL and dignified death More satisfaction and less stress for families
		Healthcare Provider Level	**Healthcare Provider Level**	**Healthcare Provider Level**
Selling the Big Picture	Gentle persuasion Team persuasion	Lack of knowledge about resident/family Discomfort with death and dying New/causal nurse ACP knowledge Lack of education about ACP Reluctance to initiate ACP discussions with family	Nurse knowledge Seasoned nurse Personal comfort with death and dying Making ACP a priority Building relationship family Effective communication NP making connections with family	Rewarding part of the job
				Negative
				Resident Level
				Suffering due to lack of agreement on a realistic ACP level Failure to honour resident's living will

	Drawing a line in the sand: enough is enough	Being an internationally educated nurse Having English as an additional language Culture of the nurse Physicians’ lack of interest in ACP discussions Physicians’ lack of relationships with family Unavailability of physicians Physician taking a path of least resistance Physician’s communication style Lack of on-call physician’s knowledge about resident	**Institutional/Organizational Level**	**Healthcare Provider Level**
		Institutional/Organizational Level	Building clinically strong nurses Presence of on-site HMO Availability of on-site NP Supportive management Provision of education Having team on the same page Integrating ACP discussions in routine practice Introducing ACP prior to LTC admission Designating ACP responsibility to nursing profession	Emotional toll Conflict between personal and professional values Witnessing suffering and feeling a moral obligation to reduce suffering Feeling of being resented by physicians
		Insufficient physician presence Having team not on the same page Inadequate time Inefficient and unclear ACP form Impoverished therapeutic space Faith-based facilities		

Chapter 7: The Process of Upgrading

Introduction

The nurses who participated in this study reported that they were unable to maximize comfort for LTC residents who suffered from painful acute events when there was an ACP-C designation in place. The nurses believed this was due to the fact that LTC physicians, paramedics, and acute care staff in EDs/hospitals had differing attitudes and perspectives about the meaning of ACP-C. According to the nurses in this study, LTC physicians, paramedics, and acute care staff tended to perceive comfort care as being synonymous with EOL care. Therefore, these healthcare providers believed that ACP-C meant the resident was actively dying. The prevailing perspective among care providers was that residents' acute symptoms, related to conditions such as fractures and bladder infections, and EOL symptoms should all be managed at the LTC facility, without the need for aggressive hospital interventions.

In contrast, study participants strongly believed that LTC residents required aggressive interventions to maximize comfort in the face of acute events. The participants implemented the strategy of "upgrading" residents' ACP levels during periods of acute illness, to shift the goals of treatment to those they believed were more appropriate at that time. Nurses believed that comfort could only be optimized when the resident's family and healthcare team both recognized and acknowledged that treatment could either be managed through a hospital transfer or at the LTC facility, without transfer (e.g., with oral antibiotics for infection). According to the nurses, upgrading residents' ACP levels helped orchestrate comfort care by bringing the residents' big picture to the attention of key decision makers, including family members, LTC physicians, paramedics, and hospital staff.

The following sections discuss the nurses' perceptions of the upgrading process and provide a detailed description of each of the pre-conditions, strategies, barriers, facilitators, and consequences associated with this process. The schematic representation of the upgrading process; the barriers and facilitators to this process, as analyzed from a socio-ecological perspective; and the consequences of the process are presented in Figures 6, 7, 8, and 9. The upgrading process is summarized in Table 5, on page 322. The nurses accomplished the process of upgrading by meeting two pre-conditions: (a) piecing together the big picture, and (b) selling the big picture.

Piecing Together the Big Picture

The pre-condition, 'piecing together the big picture,' referred to the process that nurses used to gain a clear and fulsome understanding of the impact of acute illness on residents with ACP-C. This pre-condition also encompassed the knowledge and attitudes of LTC physicians, paramedics, and acute care hospital staff regarding ACP-C. In order to piece together the big picture, nurses conducted assessments of acutely ill residents. The nurses subsequently elicited the perceptions and attitudes of LTC physicians/paramedics/acute care staff regarding treatment of acute illnesses for residents who were ACP-C. Nurses were then able to piece together the resident's big picture, which was a critical first step in achieving the outcome of 'getting everyone on the same page.' The focus of care could then be shifted to curative/aggressive interventions in order to maximize the residents' comfort.

The nursing strategies used to piece together the big picture included: (a) assessing the resident, (b) learning the family's wishes for managing acute illness, and (c) understanding the attitudes of LTC physicians/paramedics/acute care staff toward caring for a LTC resident who was ACP-C.

Strategies Used to Piece Together the Big Picture

Assessing the Resident

Assessing the resident was a critical first step in identifying the associated signs and symptoms of discomfort from an acute event. Data from the assessments were used to guide decisions about treatments and/or interventions in order to maximize the residents' comfort, thereby honouring their ACP-C status. The occurrence of an uncomfortable acute event signalled to nurses that there was a need to shift the focus of care to curative/aggressive interventions/treatments that actively maximized comfort. Nurses' assessments of acute illness are discussed in the following section.

Nursing Assessments

Pain Related to Falls and Fractures. Nurses assessed residents who had experienced a fall for the presence of excruciating pain and possible fractures. Since LTC facilities had limited access to timely x-rays, nurses needed to transfer the residents to a hospital for confirmation of any fractures, and to determine appropriate interventions that would maximize the residents' comfort. In most instances, the nurses believed that surgical interventions would improve pain and quality of life for residents who had sustained a hip fracture:

> We don't have the access for x-ray or confirmation of a fracture right away, it takes, sometime 3-5 days to get x-ray done at LTC, that even the resident is on ACP C– we want to send the resident to hospital, because, we want to know where the fracture is and if they (residents) have a fracture they are in excruciating pain and discomfort we want to know what comfort measures we're going to give to the resident. (CRN; Interview: 07)

Pain Related to Infections. Nurses assessed residents for wound infections and ongoing pain or drainage at surgical sites, particularly after hip surgery. According to the nurses, some residents remained uncomfortable despite the initiation of analgesics and oral antibiotics at the facility. In some cases, an infection did not respond to treatment with oral antibiotics in the LTC facility. The nurses wanted to maximize residents' comfort by transferring them to the hospital for intravenous antibiotic infusions, as these interventions were not available in LTC. One of the nurses described her observations as follows:

> We were treating pain, and we were doing lab works, and we were trying to figure out where the pain was coming from – a month later, a small hole and drainage. Bingo. We now know she got an infection on her hip from her hip surgery. She is on ACP C. She is on pain control, and she is on antibiotic already because we had the prophylactic antibiotic, but the prophylactic obviously didn't work, and the pain medication wasn't working, so this lady definitely needs IV antibiotic infusion at the hospital to make her comfortable. (Unit nurse; Interview: 01)

Nurses also assessed residents for bladder infections that caused pain and distress. They monitored for signs and symptoms of urinary tract infection, including urinary frequency, urgency, pain during urination, malodourous urine, hematuria, and sudden onset of incontinence. Nurses noted that signs of bladder infection in residents with dementia tended to present as increased agitation, restlessness, sleepiness, or hallucinations:

> Sometimes people in their life if they've had a urinary tract infection; you know that it's painful. You can just tell the way they act; they are in and out of the washroom all the time, some become agitated or wanders more. The health care aids are very good at telling us about the leaky urine, bloody urine or strong urine. (CRN; Interview: 20)

Uncontrolled Bleeding Wounds from Falls. Nurses assessed uncontrolled bleeding from lacerations and/or wounds that resulted from falls. In order to control bleeding and enhance comfort, residents were sent to the hospital to have the wounds sutured. This was another intervention that could not be performed in LTC: "We couldn't get the bleeding under control we would have needed to send him (resident) out, to get him sutured to control his bleeding, it is comfort right?" (RCM; Interview: 05)

Pain and Discomfort Related to Unsuccessful Foley Catheter Insertion. Nurses stated that they assessed residents with chronic urinary retention for pain and discomfort when Foley catheter re-insertion was unsuccessful. In these cases, ultrasound-guided Foley catheter insertion at the hospital was required to make the resident comfortable:

> Well I had a male resident, with ACP-C and had a Foley catheter and the nurses were unable to change it due to a prostate issue and he was in extreme pain and discomfort and screaming, So they did send him in for that so that they could use the ultrasound to guide the Foley insertion and make him comfortable. (Unit nurse; Interview:12)

Subjective Opinions of Nurses Toward Acute Illness in Residents with ACP-C

Nurses interviewed for this study believed that they should intervene when residents experienced acute events because alleviating their pain and suffering was the humane thing to do. The nurses unequivocally agreed that relief of suffering caused by acute events was critical to ensuring dignity at EOL for residents who were ACP-C. Nurses reported that it was sometimes possible to provide dignified comfort care without transferring residents to the hospital. For example, study participants stated that treating painful bladder infections with oral antibiotics at the LTC facility helped facilitate resident comfort and avoid the unnecessary pain and suffering of hospital transfers:

> You know, sometimes people in their life if they've had a urinary tract infection, they know that it's painful, if you could give them antibiotics, for their suffering to make them

> comfortable that's what I want. This help them to stay at the facility without sending them to the hospital. (CRN; Interview: 20)

In other cases, a transfer to the hospital was necessary. Nurses appreciated the difference between intervening to ensure comfort and intervening to eradicate/cure pre-existing conditions or engage in resuscitative measures:

> Like you cannot have someone with a broken hip in pain because that's not technically comfort. Yeah, we have encountered some problems – like if someone had broken a hip – and they (hospital)'re sending this person back to me not doing anything because they're comfort care –-- personally, I would have a big problem with that. The hospital is still bound to treat like a resident while they're in discomfort, like because we're – don't forget, like we're sending them (residents) because they're not comfortable. It's not because we're sending them so that they could be completely resuscitated to their normal self, like it's for their comfort. (Unit nurse; Interview: 09)

Nurses identified that residents with hip fractures and advanced dementia were the exception to the rule that all fractures required a hospital transfer for treatment/investigation. Study participants were adamant that surgical interventions for non-ambulatory residents with advanced dementia would not improve their quality of life. Rather, they felt that managing the residents' pain in the LTC facility was the better option: "Sometime, fixing the hip not good, especially the person is in a wheelchair and has no quality of life, sleeping all the time. It is better to manage their pain from the fracture at the facility" (DOC; Interview: 19*)*. Another nurse corroborated this statement: "I agree hip fracture surgery is not worth it if the person has dementia and they need total care and are non-ambulatory" (Unit nurse; Interview: 12).

The following section describes how nurses obtained an understanding of the family’s wishes and assessed the LTC physicians, paramedics, and hospital staff’s perceptions about ACP-C.

Learning the Family’s Wishes for Managing Acute Illness in Residents on ACP-C

The nurses reported they always communicated with the residents’ family when their assessments identified an acute illness. They wanted to ensure that families were informed of the potential or actual discomfort experienced in relation to the acute event. The nurses also took this opportunity to explore family members’ feelings about sending the resident to hospital. Nurses reported that most families wanted their loved ones to be comfortable during an acute illness and agreed to a transfer:

> If they (residents) fell, if they were like ACP C. We would call the family and we would say, "You know what, mom has fallen now. She is on ACP C, but she is in pain here, she's clearly got a fracture. Do you want us to send to hospital and have this treated? Most of the family want treatment to make the resident comfortable. (Assistant DOC; Interview: 03)

Nurses respected family members’ perspectives when they were not in agreement with transferring residents who had a hip fracture and were ACP-C. These families believed that hospital transfers and admissions would worsen the residents’ health status. Nurses described that these families preferred to have the residents’ pain managed at the facility, with analgesics:

> It was what the daughter said. My mom is on comfort care I don’t want her to go to the hospital. The daughter said her mom become worse when she goes to the hospital and she wanted us to manage her pain from the fracture here (LTC), we respected that, and we get that. (Unit nurse; Interview: 01)

Understanding the Attitudes of LTC Physicians/Paramedics/Acute Care Staff Toward ACP-C

Attitudes of Long Term Care Physicians

According to the nurses, LTC physicians' had varying opinions about the treatment of infection in residents designated as ACP-C. Some physicians equated ACP-C with EOL care and would not send residents to the hospital for treatment of acute events. Instead, they opted to sign the facility's standing EOL care orders for symptom management. They believed that antibiotics only served to prolong life, not promote comfort, and increase residents' suffering. Other physicians believed antibiotics were an important part of comfort care. One of the unit nurses made the following observations: "There are certain doctors who will treat residents with comfort care at the facility, not to send to hospital. But even the decision varies with the doctors. We do have a doctor who will send the resident" (Unit nurse; Interview: 13).

The nurses reported there was a frustrating level of variability among physicians in terms of their willingness to prescribe antibiotics to residents with ACP-C. The older attending physicians at LTC facilities seemed to believe that ACP-C meant antibiotics should not be prescribed. The nurses wanted physicians to have a standardized approach to prescribing antibiotics for residents who were designated as ACP-C. One of the CRNs shared her experiences with physicians in regard to antibiotics:

> In our facility some of [the] doctors view comfort care as no antibiotics and a lot of people find that that's a real struggle. And the one other thing I have to say is that the one physician that's a little bit older here was the one that said, 'Well comfort care is no antibiotics at end-of-life. (CRN; Interview: 20)

Attitudes of Acute Care Staff

According to the nurses, acute care staff at hospitals viewed comfort care as synonymous with EOL care. They believed that residents with an ACP-C were dying and, thus, only required palliative care measures to provide comfort at the LTC facility:

> My biggest concern often is when residents are admitted and they want comfort care as their goals of care. They fall and break a hip, or I have somebody with sepsis and I want to send them to hospital for treatment for that and they (hospital) see comfort care there and send them back immediately thinking they are end-of-life. And this resident has been on comfort care for four years already and this is not end-of-life. I believe they (hospital) see ACP-C as within about six weeks to live. (Unit nurse; Interview: 01)

Nurses stated that acute care staff often became angry with LTC staff and questioned their decision to send residents with ACP-C to the hospital. Acute care staff told nurses that residents with ACP-C should not be sent to the hospital for any reason. The acute care staff indicated that these residents would be immediately returned to their LTC facility, without the provision of treatments/interventions. One RCM recounted the following observations:

> If they (residents) are on ACP C, hospital would not look at them, they would send them back. When they go to hospital and they continue to be a “C” they get sent back right away and they don’t get the treatment that is necessary for them, or what the family or we believe that they should get. (RCM; Interview: 08)

Attitudes of Paramedics

During acute events, paramedics were often called to transport residents to the hospital and/or respond to the situation. Nurses reported that paramedics did not understand why residents with ACP-C levels would be transferred to the hospital, and questioned the nurses about these decisions. Nurses indicated that the paramedics believed residents with ACP-C would not benefit from uncomfortable interventions; as a result, they felt that a hospital transfer was a waste of resources. The nurses who participated in the study voiced their opinions that paramedics were hard to deal with:

> They (paramedics) think if ACP is C then nobody should go to the hospital from LTC. Their (paramedics) attitude is either of wasted resources or what will be the benefit of putting the resident through a series uncomfortable intervention. They come, they see somebody very frail, or advanced age. And then they question "OK, why are we sending this lady?" (Unit nurse; Interview: 23)

An RCM described her experiences with paramedics who were opposed to hospital transfers for residents with ACP-C:

> You get a lot of pushback from EMS. I think that they (EMS) don't see the importance of the care of the older adults. And they questioned you about why are you sending a C? Long-term care does not get the respect that it deserves, and it's always been that way. (RCM; Interview: 10)

Outcomes of Piecing Together the Big Picture

Piecing together the resident's big picture required a nursing assessment of the resident's acute illness, knowledge of the family's wishes for promoting comfort during acute illness, and knowledge of the attitudes of LTC physicians/paramedics/hospital staff toward ACP-C. The outcomes of collecting this information included: detecting discomfort in residents related to acute illness; gauging alignment between the family's wishes to maximize residents' comfort and nurses' beliefs about the residents' best interests; identifying differing attitudes among LTC physicians/paramedics/acute care staff with regard to the meaning of ACP-C; and generating content to shape nurses' communication with families about optimal ACP levels.

Nurses needed to be armed with a thorough understanding of the resident's discomfort in order to implement the next pre-condition for upgrading ACP levels: selling the big picture. To sell the big picture to families, nurses tried to gain consensus on the treatment goals and ACP levels they believed would optimize residents' comfort. The nurses also needed to be aware of families' wishes for managing acute care events as well as LTC physicians/acute care staff's views of ACP-C, and their readiness to treat acute illnesses. The pre-condition 'selling the big picture' is described in the next section.

Selling the Big Picture

The pre-condition 'selling the big picture' was defined as the process by which nurses tried to help families and LTC physicians/paramedics/acute care staff understand and conceptualize the resident's condition and optimal plan of care in the same way as the nurses. Triggers for selling the big picture were acute illness in residents who were ACP-C as well as LTC physicians/paramedics/acute care staff's indifferent and/or uninformed attitudes toward comfort care. Effectively selling the big picture to families helped nurses enlist residents' family members as allies in advocating for comfort-focused care plans. The strategies used by nurses to sell the residents' big picture to their families as well as to LTC physicians/paramedics/acute care staff are discussed in the following section.

Strategies Used to Sell the Big Picture

The strategies nurses used to sell the big picture included: (a) building consensus through education, and (b) working the system.

Building Consensus Through Education

Nurses educated families, paramedics, and LTC/acute care physicians to shift their perspectives to align with those of the nurse.

Educating Families. Nurses in this study stated that, at every care conference, they reviewed the circumstances/acute events under which residents with an ACP-C might be sent to the hospital to ensure comfort. When acute events occurred, nurses were responsible for educating families about the importance of transferring residents to the hospital. In this exemplar, a DOC reported that she educated families on the importance of sending residents with ACP-C to the hospital: “We gave families a little education on different scenarios such as fractures and uncontrolled bleeding for sending residents to hospital, when we review the ACP levels at care conferences, I think it helps them for the future” (DOC; Interview: 02).

Nurses also educated families about how ACP-C served as a barrier for residents to receive interventions at the hospital in the event of acute illness. In order to successfully upgrade residents’ ACP levels for hospital transfers, the nurses believed it was critical to increase families’ awareness of the negative implications of ACP-C during acute illness. In addition, they saw great value in informing families of acute care staff’s indifferent attitudes toward residents with ACP-C.

In this exemplar, an RCM informed a family about the pain and suffering experienced by their loved one after sustaining a fracture, along with the acute care staff’s attitude toward the resident’s ACP-C status:

> I had a lady who was on comfort care and she fell and we suspected she fractured her hip, I called the daughter and said, “your mom is in extreme pain and she needs to get surgery

> at the hospital to make her comfortable". I also said, if she is on comfort care, the hospital won't take her and they will send her back. (CRN; Interview: 20)

Being able to shift family members' perspectives through education was seen as helping to forge an alliance between nurses and families. Families could then became allies with the nurses to advocate for the residents' comfort.

Educating Paramedics. Participants in this study thought that it would be advantageous to educate paramedics about the reasons residents might be transferred to the hospital. They also believed that paramedics should be informed of families' requests for treatment. The nurses felt that this type of education would reduce tension between nurses and paramedics. Nurses in this study also took the time to educate paramedics about the limitations of the LTC facility, specifically their lack of resources with which to restore residents' comfort during acute events. This concept was well articulated by one of the participants:

> They (paramedics) questioned us, why are we sending this lady?" But that's when we educate them as to what the family and we want for the resident and what the circumstances are and what resources we have at LTC. I do some education with them (paramedics) about what we can do at the LTC and why they (residents) have to go to the hospital. (Unit nurse; Interview: 23)

Nurses reported that they stood firmly behind their decisions regarding hospital transfer, even when they were questioned and judged by paramedics. Nurses continued to advocate for the residents' best interests despite the attitudes of paramedics/acute care staff. Nurses justified the need for a hospital transfer by confidently presenting their assessments of the resident's condition and stating that the transfer was endorsed by the LTC physician and resident's family.

The nurses' strong advocacy skills as well as their comprehensive knowledge of the residents' condition and families' wishes helped sell the big picture to paramedics:

> The paramedics were upset and then they say but this and this and this and this and I'm like no, they(residents) need to go. And so, you just have to be kind and firm and firmer and directive to them (paramedics)" (Unit nurse; interview: 23).
>
> When paramedics questions the judgement of the facility or the judgement of the nurse or the doctor that's actually sending the patient out. Then we just let them know that that's it is our decision, that's what the family wishes, and so that's why she's going, or he's going, we strongly advocated for the residents and give the information to the paramedics in a more confident way, showing them, we know what we are doing, you just listen to us. (RCM; Interview: 08)

Educating Physicians. The nurses reported that physicians had different attitudes toward the care of residents with an ACP-C, when compared to those who were ACP-R or -M. These attitudes were evident in physicians' unwillingness to treat infection in residents with an ACP-C or to send these residents to the hospital for any acute events. The physicians seemed to believe that residents with an ACP-C were at EOL and did not need any treatments other than for EOL symptoms. Nurses had to educate the physicians that comfort care does not always equate to EOL care in LTC settings. Nurses also informed them that residents with ACP- C could still live for many years. As a result, these residents could still benefit from antibiotic treatment and hospital transfers for the purpose of maximizing their comfort. As stated by one of the participants, "This person has been on comfort care for four years already and this is not end-of-life" (Unit nurse; Interview: 01).

Physician education also required that the nurses inform them of the families' wishes. This information often persuaded physicians to adopt the nurses' desired ACP levels for specific residents. Family and physician endorsement of the ACP level had the added benefit of dismantling paramedics and acute care staff's criticisms of the nurses who sent frail residents to the hospital.

Nurses also tried to educate acute care physicians about resident transfers during telephone conversations. This education included making physicians aware of the fact that LTC facilities are home to older as well as younger residents, the latter of whom tend to have more complex illnesses that require hospital-based treatment for acute events and comfort care. One of the RCMs described this process as follows:

> Well, sometimes there are 60-year-old people in nursing homes who just might have lupus. They might have multiple sclerosis, but they're 60, and they get pneumonia from their chronic illness, and they need the hospital. I think there needs to be education for them (acute staff) as well, because a lot of these people are not 99. A lot of nursing home residents are young now and they just have chronic illnesses and more complex illnesses, and we need to still take care of them. (RCM; Interview: 21)

Working the System

Working the system referred to nurses' ability to manipulate the system to achieve the goal of comfort care for residents experiencing acute illness, either at the hospital or in LTC. Nurses in this study described that they worked the system in two ways: (a) changing the ACP-C to medical, and (b) creating a sub-category of ACP-M by adding the phrase 'no hospital transfers.'

Changing ACP-C to ACP-M. Nurses in this study understood that, according to the rules of the current system, residents with ACP-C in their chart would not be transferred to hospital to receive comfort-focused interventions without first upgrading their ACP level. Nurses were able to upgrade residents' ACP levels (from C to M) prior to initiating a hospital transfer by providing education to residents, families, and LTC physicians and persuading them about the need for the transfer. As a result, nurses were able to work the system to achieve their desired care goals for the residents. One of the nurses described such an interaction with a resident's son:

> I said, with your permission, I will change the ACP back to M from comfort care so that we can get better accommodation at the hospital. He said. 'absolutely'. That's what I did. So, I had to change the ACP in order to get comfort for my resident because of the pain. To me, that shouldn't have to happen. I shouldn't have to manipulate the system to get the care for my resident. I believe they (hospital) see ACPC as within about six weeks to live. (Unit nurse; Interview: 01)

The previous exemplar directly contrasts the experiences of nurses who did not successfully work the system prior to sending a resident to the hospital. In these situations, nurses were not able to alter ACP levels, which compromised the residents' comfort. One of the nurses explained:

> She (resident) was on comfort care, I was the nurse taking care of her that day. I did everything to make her comfortable and she has problem breathing, then I called the doctor. I received the order to send her to hospital and I sent her, and she was back in two hours. They didn't do anything. Then that evening another nurse called the family and asked them to upgrade the ACP to M to send to her to the hospital and she went to hospital that evening and they admitted her and treated for CHF, which made her breathing comfortable. (Unit nurse; Interview: 13)

Creating a Sub-Category of ACP-M. The second way that nurses worked the system was through the creation of a sub-category of ACP-M. Nurses were obligated to follow the orders of LTC physicians who decided not to treat acute infection in residents with ACP-C. In these cases, the nurses strategically and independently created a new category of ACP-M. This new category was created by including adding the phrase ‘without hospital transfer’ to the ACP-M level. According to the nurses, ACP-M ‘without hospital transfer’ was an interim step above ACP-C. Nurses suggested this subcategory of ACP-M to families who wanted their loved ones to receive treatment for infections at the facility. In this way, the nurses were able to promote comfort for frail residents, while satisfying both the physicians and the residents’ families:

> We’ve somewhat created another category of goals of care, which is medical, no hospital transfers. Because that then clarifies that we want the physician to treat, but the family would prefer not to send the resident to hospital. So that’s kind of a sub-category of medical that we instituted as a shorthand way of saying, you know, okay –In my mind that could be comfort care, but for our physician, comfort care really means that his role as a physician is only providing end-of-life/palliative orders. (DOC; Interview: 02)

In a similar statement, a CRN confided: “Sometimes people in their life if they’ve had a urinary tract infection we know that it’s painful. And my work around that was saying ACP [with] medical no transfer because medical no transfer the physician should prescribe antibiotics” (CRN; Interview*:* 20).

Outcomes of Selling Big the Picture

Improving Comfort for Residents

Successfully selling the resident’s big picture resulted in an upgrade of the ACP level to maximize comfort; GOC shifted to aggressive and/or curative interventions and treatments for residents experiencing acute events, either at the facility or in hospital. Upgrading residents' ACP levels prevented them from experiencing the pain and suffering that was common during hospital transfers. The upgrading process also maximized residents' comfort during painful infections because physicians felt comfortable prescribing oral antibiotics at the LTC facility. Nurses described this outcome as a win-win:

> We can't keep them (resident) on ACP-C and say treat them for infections, because our physician does not treat residents for infections when they are on comfort care ACP. So, we have to make sure that the ACP form matches what the family wants, so making the ACP form to medical with no hospital transfers to reflect the family's wishes and allow the physician to treat the residents for painful infections. (RCM; Interview: 05)

Nurses reported that families appreciated the suggestion to upgrade residents' ACP levels, especially when the upgrade resulted in positive outcomes. For example, the daughter of a resident reported that she and her brother were happy that their mother could once again enjoy wandering after undergoing hip surgery:

> The family was happy, she (resident) got the surgery for her hip fracture and she able to walk again. The daughter called and said to me, [name], I am so happy that your nurses asked me to change my mom ACP from comfort care to medical to send her to the hospital, me and my brother are happy and I think my mom is also happy that she can walk again, and that the only thing she enjoys is wandering around and she can walk to the roof garden again with us. (DOC; Interview: 19)

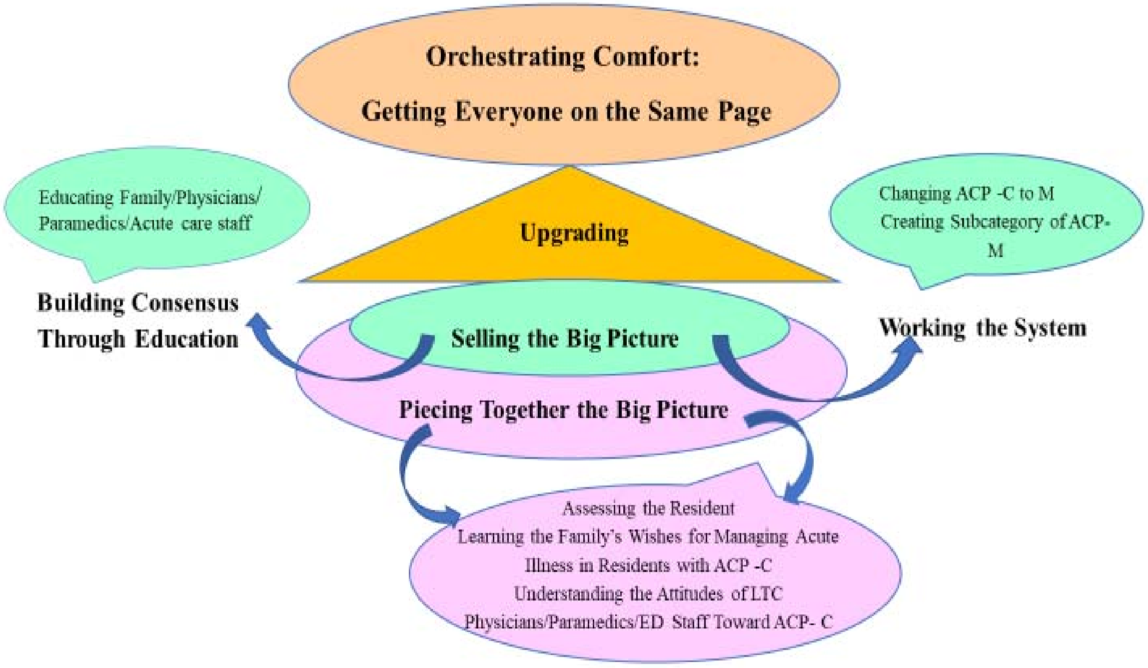
Nurses reported that their knowledge of acute care staff's attitudes toward residents with ACP-C levels was helpful to proactively upgrade residents' ACP levels. Nurses used their skills of persuasion to achieve consensus between families and physicians regarding ACP levels:

> We had a lady last year who fell and broke her hip, and we sent her to hospital, and she had a comfort care directive, and that was just around the time that we were hearing that [hospital name] was sending people back without assessments if they had comfort care. So, I talked to the daughter about changing her ACP to medical, to get her hip treated and spoken to the physician about the hospital situation and the daughter's wish for surgery for her mom, this way everyone happy and also on the same page. The Paramedics took her and we never got any questions from the hospital or form the paramedics. (DOC; Interview: 19)

The schematic representation of the pre-conditions and components of the upgrading process are presented in Figure 6 (below). The next section describes the barriers and facilitators of the upgrading process, from the socio-ecological perspective.

Figure 6

The Process of Upgrading



Barriers to the Process of Upgrading

Several barriers inhibited nurses from being able to upgrade residents from ACP-C to ACP-M prior to hospital transfer. These barriers were analyzed from the socio-ecological perspective and are described at the family, healthcare provider, and organizational/institutional levels.

Family Level

Wish for no Hospital Transfers

Nurses in this study reported that families were not always on board with upgrading residents from ACP-C to ACP-M in order to facilitate hospital transfers, even if the nurses believed these transfers would enhance comfort. Some families were reluctant to allow residents to undergo surgical repair of hip fractures due to their dementia and/or non-ambulatory status. Families worried that the resident's mental status would deteriorate in the post-operative period. They were concerned about the delirium associated with surgical interventions and hospital transfers. As a result, these families requested only pain management for fractures, which could be provided at the LTC facility. Nurses respected the wishes of these families and never tried to persuade them to upgrade the residents' ACP levels. In most cases, these residents became heavily sedated due to the use of opioid medications for pain control. They often deteriorated faster and died sooner than expected. The following exemplars illustrate the family's attitudes toward hospital transfers:

> When she fell, I called the daughter about sending her mom to the hospital for possible hip fracture repair. She said oh no my mom is on comfort care, and I don't want her to be sent out for anything. She has dementia and she won't do good with hospital transfers. My mom is not walking for months now, and she sits in a wheelchair. I want her to be

> kept pain free without surgery. You know I get that, but I tried and I respect that. So, we were giving the resident hydromorphone for pain and she was going down and sadly died soon. We never push them to change the ACP. (Unit nurse: Interview: 14)

Healthcare Provider Level

Nurse Characteristics

Being an Internationally Educated Nurse. Internationally educated nurses interviewed for this study were aware of their professional responsibility to advocate for residents, but felt they lacked the skills to encourage families to upgrade residents from ACP-C to ACP-M. One participant shared:

> I as an international nurse honestly, I can't convince them (family) to change the ACP. I have a resident, she broke her hip. She is comfort care. She is in a lot of pain. We can't send her to hospital. That's the only thing I think I am lacking the skills on how to convince them. I know as a nurse I have to advocate for my residents because I do not know how to convince them to upgrade it to medical and we can send her to hospital to get the medical care for that. (Unit nurse; Interview: 13)

Physician Characteristics

Lack of Standardized Practices for Comfort Care Among Physicians. Participants reported that there were differing ideas and practices amongst LTC physicians as to the appropriate care for residents with ACP-C. Some physicians viewed ACP-C as EOL care, as described previously. These physicians did not send residents to the hospital for care or prescribe antibiotics for painful infections. In contrast, other physicians prescribed antibiotics to residents with ACP-C and viewed them as a comfort measure. Nurses indicated that these physicians believed antibiotics did not prolong life in these situations, but provided comfort by decreasing pain. Nurses reported that they struggled to improve comfort in residents during acute events, due to the lack of a cohesive approach among physicians with regard to ACP-C. One assistant DOC explained:

> There's no universal understanding among our doctors on ACP C. I mean, we have, you know, different doctors. Advance care plan C, may mean that no antibiotics for some. Another doctor may see advance care plan C as an antibiotic being a comfort measure. Because it's making them comfortable. It's not prolonging their life. It's just taking the pain away and it's something that we can do here. (Assistant DOC; Interview: 03)

Paramedic Characteristics

Knowledge Deficit Related to Hospital Transfers of Residents with ACP-C. Nurses reported that paramedics did not understand why residents with ACP-C were being sent to the hospital. Nurses found it challenging to field questions from paramedics and continually advocate for residents. This discouraged the nurses from wanting to engage with paramedics, as observed by this RCM:

> I would say there is problem with paramedics understanding why I was sending them. I think when explaining them I think it would work there's some nurses are hesitant because the paramedic sometime is hard to deal with because their role is different than our role right? So, for the comfort of the resident really you could send them, but they sometimes they don't understand and we are trying to explain and it doesn't help. And then that's when the confusion starts. (RCM; Interview: 05)

Organizational/Institutional Level

Lack of Universal Understanding of Comfort Care Across the Healthcare System

Nurses in this study repeatedly identified that there was a difference in the way ACP-C was understood in the acute care versus LTC settings. Nurses identified that acute care staff equated comfort care with EOL care, meaning that all residents with ACP-C would have a prognosis of six months or less. Therefore, acute care staff believed that interventions were not required for acute events. Acute care staff believed that all residents in LTC facilities should have ACP-C levels and should not be sent to the hospital under any circumstances. According to the nurses, when a resident with ACP-C was sent to the hospital, acute care staff would send the resident back as soon as possible, without providing any care; their focus was on clearing the hospital bed for another patient. The study participants argued that there was no clause written into the ACP-C to indicate that a hospital transfer was not possible. The nurses also indicated that acute care staff were not being asked to treat reversable conditions, which falls under ACP-M. As a result, the nurses felt that hospital staff were obligated to provide interventions that increased resident comfort, according to their goals of ACP-C. Due to varying interpretations of ACP-C, hospital staff often sent a note back to the facility to question the nurses' rationale for sending a resident with ACP-C to the hospital. Nurses' negative experiences with hospital staff sometimes discouraged them from sending residents with ACP-C to hospital.

The nurses reported on a number of issues that arose from the lack of a universal understanding of ACP-C across the healthcare system. In particular, some of the nurses highlighted the negative attitudes of acute care staff toward LTC residents who were ACP-C. An RCM reported that acute care hospital staff became angry and hostile after receiving a resident who was ACP-C from a LTC facility:

> The receiving end, the acute care become angry because their view if somebody is on comfort care they should not go to the hospital, period. There's a lot of hostility when a resident has comfort care, gets sent to hospital. (RCM; Interview: 06)

An RCM explained that she felt like going to the hospital herself, to explain the true meaning of comfort care to staff:

> There is no clause in the comfort care that's say, do not send them to the hospital. I feel like I should actually go to the hospital and enlighten them and say, you know what, even if they (residents) come in as comfort care, does not mean that you wouldn't treat them, except that treatment that you're going to give them, will not reverse the situation, but making them comfortable. Like, if they want to go to the hospital, once they are ACP C, oh they can't go to he hospital. If you want them to go to the hospital, you have to change the ACP to M. (RCM; Interview: 14)

Ageism

Participants reported that systemic discrimination against older LTC residents by acute care staff in hospitals was common. It was the nurses' opinion that ED staff viewed treating older residents with ACP-C as a waste of resources and wanted to get those residents out of already cramped EDs. One of the nurses voiced this opinion as follows:

> Even when I worked in emergency as a nurse, I remember people would always complain, oh why are they here– look how old this person is and why are they here. And that ageism, – you know just because they're older they feel like you know we're wasting resources, or should they be staying at the nursing home. (RCM; Interview: 10)

Similarly, another participant stated: “I think it's just a systems issue, right, because they (hospitals) are so bogged down and they see this old person coming in on the stretcher. They're comfort care, get rid of them, send them back, right” (DOC; Interview: 19).

Limited Knowledge about LTC Facilities Amongst Paramedics and Emergency Room Staff

The participants reported that paramedics and ED staff had a limited understanding of the logistics of the LTC environment, including staffing, resources, interventions, and treatments. For example, paramedics were not aware of the low nurse to resident staffing ratios in LTC, and how these ratios impacted nurses’ ability to care for acutely ill residents. One of the RCMs explained that paramedics had a limited understanding of the extent to which LTC facilities were able to care for acutely ill residents:

> They (paramedics) don’t understand what we can and can’t handle in a long-term care facility. They don’t understand, like there’s only two nurses for 40 residents, like they’re not going to be able to handle someone severely acutely ill. Like we just don’t have the capacity to do that. (RCM; Interview: 10)

Similarly, a unit nurse reported that paramedics were unaware of the limited options for oxygen delivery in LTC facilities:

> The paramedics questioning why we’re sending the person there, especially if they’re elderly … and they’re comfort care. And they don’t get that we don’t have a lot to offer them there, like even if it’s just oxygen … we can only do nasal prongs from a concentrator. (Unit nurse; Interview: 17)

A DOC reported that LTC facilities lacked appropriate medical treatments and interventions to provide acute medical care to residents. She expressed disappointed disappointment that ED staff seemed to hold the view that all LTC residents should be ACP-C and should not be transferred to the hospital for any medical care:

> I think most people in acute care facilities, particularly the emergency rooms, think that everybody in LTC should be on comfort care. And that they should not be transferred from LTC to emergency room for medical treatment. The reality is that not all diagnostics and treatments for an acute illness, can't be done in a personal care home. (DOC; Interview: 02)

In order to achieve a good understanding about the LTC environment and its' population, nurses believed it was important for other care providers to achieve a good understanding of the LTC environment, its population, and its general function. They proposed that both paramedics and medical students should have clinical rotations at LTC facilities as part their educational preparation:

> It is good for both medical and paramedics students to have some rotation at the LTC. So that they can really get to know how long-term care runs and looks. And then they can learn more about dementia and our older population, because a lot of them don't understand LTC. (Unit nurse; Interview: 17)

Lack of Standardized Education about ACP Levels Throughout Healthcare Settings

The nurses identified that problems arose from the lack of standardized education across the healthcare system about the different ACP levels. Different understandings of ACP levels caused tension between staff working in different settings and resulted in negative care outcomes for residents. Nurses believed that standardization of the ACP process across the healthcare system would improve the overall quality of patient care. In particular, they believed that universal understandings of ACP-C would allow LTC residents to receive the appropriate care in the appropriate setting, without the need for nurses to "work the system" by upgrading ACP levels prior to a hospital transfer:

> Many nurses say if I'm going to send them (residents) to hospital, I change the ACP back to M. I ask the family to do that just so I can get care. And I don't think that would necessarily need to happen if everybody understood the goals of care the same way. I also believe that the education and understanding of ACP across the board between the different facilities are different – like acute versus long-term care. I think there's a disconnect. I really do – on how it's understood, on how it's presented, how it's utilized, and I don't think that we are unified in any sense of that word, even from nurse to nurse, even within the same facility. (Unit nurse; Interview: 01)

Devaluing the LTC Sector

Nurses in this study reported that acute care staff generally had negative attitudes about the LTC system. The nurses perceived that acute care staff assigned less importance to the health conditions of LTC residents than of older adults living in the community. They also believed that acute care staff underestimated the knowledge and skills of nurses working in LTC. Nurses felt devalued by acute care staff when they questioned the nurses' decision making and judgement related to hospital transfers. Nurses blamed the unhealthy relationship between acute care and LTC settings on the ego dominance of acute care staff and the hierarchical status of acute care over LTC. According to one nurse participant, LTC residents were humans with "a body and a soul," who deserved to receive high quality and dignified care, like all other patients:

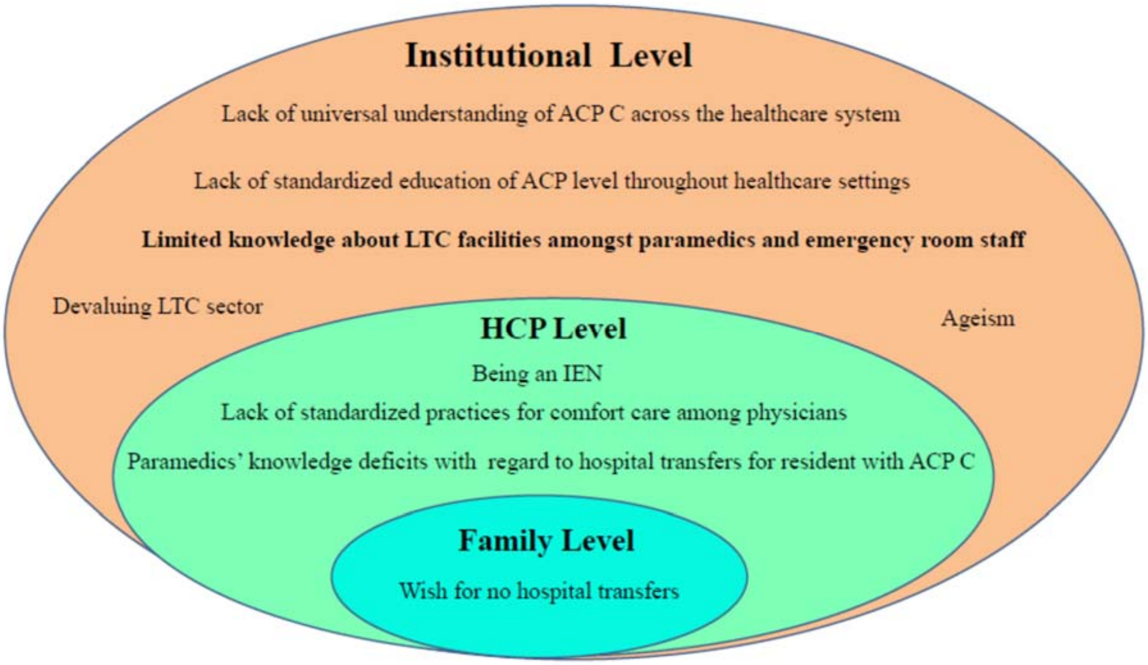
> They (residents) are human beings. They're no less than acute care. This is about any ego, right. It's about a person and a body and a soul and they deserve the same care and dignity as anyone else, and I think that there's an ego with the acute care. We are all

> people and one of the trajectories in our life and one day we need acute care and one day we'll require nursing home. (RCM; Interview: 21)

Barriers to the upgrading process were analyzed from the socio-ecological perspective and are presented in Figure 7 (below). The next section describes the facilitators of the upgrading process.

Figure 7

Barriers to the Process of Upgrading



Facilitators to the Process of Upgrading

Numerous facilitators supported the strategies that nurses used in the process of upgrading residents' ACP levels. These facilitators existed at the family, healthcare provider, and organizational/institutional levels and were analyzed using the socio-ecological perspective.

Family Level

Being Allies of Nurses

Nurses reported that the majority of families were on board with upgrading residents' ACP levels. Families understood that ACP status impacted their loved ones' level of comfort during acute events. When nurses and families were on the same page, it was easier to obtain access to appropriate hospital interventions: "I called the family. I said I think, with your permission, I will change the ACP back to M from comfort care so that we can get better accommodation at the hospital. He said absolutely" (Unit nurse; Interview: 01).

Healthcare Provider Level

Being an Advocate for the Resident/Family

Participants in this study firmly believed that residents with ACP-C had the right to receive the required care from hospital staff. As a result, nurses advocated for the residents' rights by assessing for acute medical events and promptly upgrading their ACP levels in collaboration with family members and the LTC physician. Nurses educated paramedics about the residents' conditions and strongly advocated for residents to receive necessary acute care interventions at the hospital in order to maximize their comfort:

> They (paramedics) think nobody with ACP-C should not go to hospital and then I stand firm on behalf of the resident and the family. First, I call the family and get their permission to change the ACP from C to M. Especially, if the resident is in pain, I

> strongly advocate on behalf of the resident and for their family. I won't pull back until they take the resident to the hospital. (Unit nurse; Interview: 23)

Organizational/Institutional Level

Standardized Education on ACP Levels Across the Healthcare System

The study participants believed that standardized education across the healthcare system would allow staff from different settings to have the same understanding of the ACP levels. This consensus in understanding would prevent the common misconceptions about ACP-C and EOL care. In turn, unified knowledge would allow nurses to send residents with ACP-C to the hospital without having to upgrade their ACP status. Study participants suggested that the WRHA should provide the same ACP education to staff in LTC, community, and hospital settings. They believed that standardized education would help hospital staff understand why residents with ACP-C were still being transferred to the hospital. According to one of the CRNs, standardization of ACP education and processes would get everyone on the same page

> I think it's more of the education, and I think there should be the same kind of a standard education on ACP every healthcare settings. So, if you'd be more specific on the levels, and have the same understanding, then you know, that's more effective, and I think that's one area that the WRHA can do to educate all the homes across the board so that everything is the same, everyone is on the same page. The education should happen across the board. I mean, same education in hospitals, community and nursing homes. (CRN; Interview: 07)

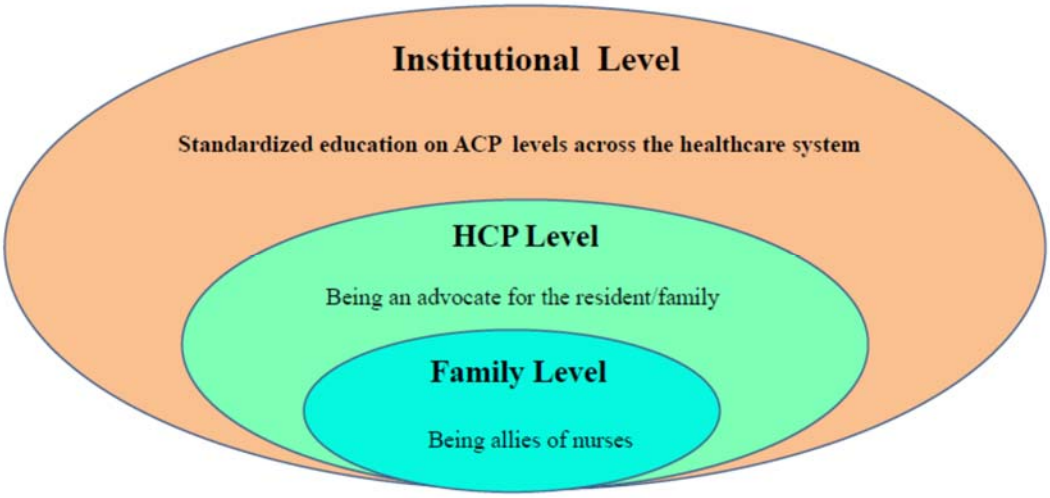
Similarly, one of the nurses believed this unity of knowledge would build her own confidence, since everyone would interpret the three ACP levels in a similar way:

> I should be able to send them (residents) with ACP-C to hospital. Again, the unity across the board. Where we understand where I have the confidence that the hospital sees the ACP level the way I do. We're all seeing it in the same way, and having the education the same way, and using it the same way. (Unit nurse; Interview: 01)

The aforementioned facilitators of the upgrading process were interpreted using the socio-ecological perspective and are presented as a schematic in Figure 8 (below). The next section describes the positive and negative consequences of the upgrading process.

Figure 8

Facilitators to the Process of Upgrading



Consequences of Upgrading

The positive and negative consequences associated with the upgrading of ACP levels occurred at the resident/family and healthcare provider levels, as described below.

Positive Consequences

Family Level

Being Satisfied with Care

According to the nurses, most families were satisfied with the upgrading process because residents' outcomes were positive. In one example, a resident's son was pleased that his father could walk again after having surgery for his hip fracture:

> The son called me and said thank you [name], my dad is doing well at the hospital after his surgery. He said, he was so happy that I asked him to change the ACP level to send him to the hospital. The son was so thrilled that his dad would walk again and doesn't have to sit in the wheelchair for ever and gets sores to his buttocks. His mom was in a wheelchair and had bad bedsores. He was glad that his dad doesn't have to go through that. (RCM; Interview: 14)

Healthcare Provider Level

Feelings of Competence and Confidence in the Decisions

Nurses reported that they felt competent making decisions to send residents to the hospital after upgrading their ACP levels. They felt confident these were the right decisions to optimize the quality of life of these residents. The nurses stood firmly behind their decisions, despite the attitudes and questions of paramedics/hospital staff. The nurses were satisfied with the residents' health outcomes, which were a direct result of their decisions. One unit nurse explained that she did not let resentment from the paramedics affect her, and indicated she was satisfied with the job she had done to facilitate the hospital transfer:

> The paramedics were upset; they said, why did you change the ACP? The resident can't go to the hospital. I said she is going, it's our decision. Yes, the resident has gone and then if the paramedics are upset you have to let that go. Because at the end of the day I've done my job. I feel comfortable that the resident went to the hospital. (Unit nurse; Interview: 23)

Negative Consequences

Resident Level

Discriminatory Treatment by Hospital Staff

As noted in the previous description of barriers to the upgrading process, nurses perceived that acute care staff viewed treating LTC residents as a waste of their time. An RCM noted that hospital staff did not provide the respect and care that LTC residents deserved, and were entitled to receive:

> When somebody comes from a nursing home the hospitals don't take them too seriously because they (hospital) think oh, they are old people and they are very sick right? How come they are sending from the nursing home? I think the perception is different when the hospital sees older people from the nursing home, and they will see this as different because usually hospital perception is nursing home residents they are here to die. It's actually not true though. They're not here to die. They are not respected like the older people from the community. No respect to nursing home residents and they do not treat them fair. (RCM; Interview: 05)

Healthcare Provider Level

Feelings of Frustration

Nurses voiced feeling extremely frustrated when residents were transferred back and forth several times between the hospital and LTC facility. They also felt that hospital staff did not treat the residents with efficiency or compassion. One of the unit nurses described how she pleaded with LTC management to support her in addressing her frustrations with hospital staff not providing care to residents with ACP-C:

> We've sent people back and forth to a hospital with a hip fracture because of the ACP C, it is incredibly frustrating when they go back and forth several times before they actually get help. That has been incredibly frustrating for me. A huge, huge frustration. The fact that I felt like I needed to tell a family can we change it to M so I can send them and get help? I don't feel that that should have to happen. (Unit nurse; Interview: 01)

Another frustrated RCM described that sending residents with ACP-C to the hospital was like a “pissing contest”:

> That's hell. It's just hell. Because we have sent a resident, I think, like two or three times. It was like, there you go again. It was a pissing contest. Back and forth. It's just crazy. Because, I think, a resident is comfort care doesn't mean you don't treat them. It's just, oh my gosh. It's so terrible. They're always worried about efficiency. Well, they should treat them when they are there. (RCM; Interview: 25)

Feeling Impotent

Nurses reported that their attempts to improve the problems associated with sending residents to the hospital were not taken seriously by hospital staff. Instead, hospital staff became angry and defensive, and refused to listen to their concerns. A DOC described herself as “feeling like a small potato” when she attempted to address these systemic issues:

> Each time the hospital send back a ACP-C resident without providing treatment, I send my concern to the senior manager from WRHA so then he can have that discussion with the hospital. Honestly when you have a conversation with the Emergency Room and they're just angry and they don't want to listen either so it's just like, well what do you do? In the big picture, I'm a small potato. (DOC; Interview: 19)

Feelings of Being Judged on Clinical Competence and Treated with Disrespect

When residents with ACP-C needed hospital transfers, paramedics questioned the LTC nurses’ judgment and treated them with disrespect. The nurses reported that their own knowledge and experience differed from that of the paramedics, and acknowledged that they both needed to remain accountable for their actions and respectful of each other's expertise. Nurses sensed that the paramedics felt they had overreacted to residents’ issues and did not take their concerns/assessments seriously: “At times I felt, they (paramedics) are not trusting our assessments and have an attitude that we are exaggerating the residents’ problems” (CRN; interview:20). Nurses wanted the residents to be treated for their conditions, not judged by the fact that they lived in LTC or by their chosen ACP level:

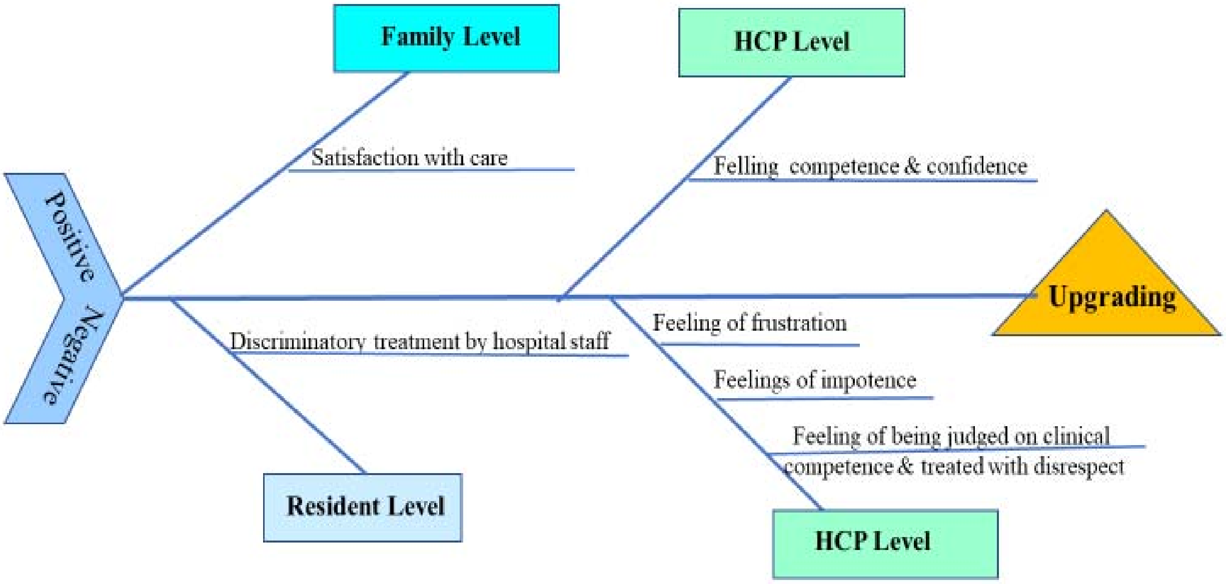
> If you are sending a resident to hospital and even though they are on comfort care I don't think that they (paramedics) should question the judgment of nurses. I think they should respect the nurse's judgment in that. They should be more sort of respectful to the nurses

> in nursing homes. Even though their knowledge and their experience is different everybody's working in the same – everybody has their responsibility right. So I think respecting each other is the important thing. I would think the resident should be treated for their condition, not as of where are they coming from or what their ACP level? (RCM; Interview: 05)

Figure 9 (below) provides the schematic representation of the consequences of the upgrading process.

Figure 9

Consequences of Upgrading



Summary

This chapter described and explained the final process of the model, upgrading of the ACP level, as well as the attendant pre-conditions and strategies associated with this process. Barriers and facilitators that influenced the nurses' abilities to orchestrate comfort, through the upgrading of ACP levels, were presented from a socio-ecological perspective. The positive and negative consequences for of upgrading ACP levels were described at both the resident/family and healthcare provider levels. The pre-conditions, nursing strategies, barriers, facilitators, and consequences of the upgrading process are described in Table 5 (below). The next chapter discusses the impact of the first wave of the COVID-19 pandemic on LTC settings, and the nurses' experiences of undertaking ACP during the first wave of the COVID-19 pandemic.

Table 5

Summary of Upgrading Process

Process of Upgrading				
Pre-Conditions	**Strategies**	**Barriers**	**Facilitators**	**Consequences**
Piecing Together the Big Picture	Assessing the resident Learning the family’s wishes for managing acute illness in residents with ACP-C Understanding the attitudes of LTC physicians/paramedics/acute care staff toward ACP-C	**Family Level**	**Family Level**	**Positive**
		Wish for no hospital transfers	Being nurses’ allies	**Family Level**
				Being satisfied with care
		Healthcare Provider Level	**Healthcare Provider Level**	**Healthcare Provider Level**
		Being an internationally educated nurse Lack of standardized practices for comfort care amongst physicians Limited knowledge about LTC among paramedics and ED staff Paramedic knowledge deficits with regard to hospital transfers for residents with ACP-C	Being an advocate for resident/family	Feeling of competence and confidence
			Institutional/Organizational Level	**Negative**
			Standardized education on ACP levels across the healthcare system	**Resident Level**
				Discriminatory treatment by hospital staff

Selling the Big Picture	Building consensus through education	**Institutional/Organizational Level**		**Healthcare Provider Level**
	Working the system	Universal understanding of ACP-C across the healthcare system Ageism Devaluing the LTC sector Lack of standardized education on ACP levels across healthcare settings		Feelings of frustration Feeling impotent Being disrespected Being judged on clinical competence and treated with disrespect

Chapter 8: Impact of COVID-19 Pandemic on LTC During the Study

Introduction

Even though none of the nurses who participated in this study encountered COVID-19 outbreaks in their LTC facilities, eight nurses shared their perspectives of undertaking ACP during the first wave of the pandemic. This chapter provides: (a) a brief overview and discussion of the impact of the first wave of the COVID-19 pandemic on LTC settings; (b) the impact of the pandemic on the researcher; and (c) the main themes that emerged from the nurses' experiences of undertaking ACP during the first wave of the COVID-19 pandemic.

Overview and Impact of the First Wave of the COVID-19 Pandemic on LTC Settings

The CIHI defined the first of wave of the COVID-19 pandemic in Canada as lasting from "March 1 to August 31, 2020, with a peak period between March 1 and June 30" (CIHI, 2021, p. 4). During the first wave of the pandemic, there were 6,080 deaths among LTC residents in Canada and 37% of residents who contracted COVID-19 died (CIHI, 2021). The second wave of COVID-19 in Canada was between September 2020 and February 2021. The second wave was bigger and broader than the first wave, reaching more areas of the country and resulting in a larger number of outbreaks, infections, and deaths in the LTC sector and retirement homes (CIHI, 2021).

Pandemic experiences varied greatly between provinces and territories as well as between different waves of COVID-19 (CIHI, 2020c). According to the CIHI report (2020c), LTC facilities had fewer physician visits, fewer hospital transfers, and less contact with visitors during the first wave than in the pre-pandemic years. The transfer of residents from LTC facilities to hospitals was not a priority during the first wave of COVID-19, as acute care beds were being reserved for patients from the community (Revera, 2021).

The first COVID-19 infection in a Manitoba LTC facility was reported on April 2, 2020, in the town of Gimli (Sanders, 2020). As of August 31, 2020, there were 1,214 lab-confirmed cases of COVID-19 infections and 14 deaths among Manitobans (Rounce & Levasseure, 2020). However, there were only 14 confirmed COVID-19 cases among LTC residents and staff in Manitoba during this period (CIHI, 2020c). In Winnipeg, the first case of COVID-19 infection in a LTC facility was reported by a staff member on April 8, 2020, followed by reports of the first case in a LTC resident on April 13, 2020 (A. Salanga, personal communication, September 13, 2021). The first COVID-19-related death in LTC in Winnipeg was reported on April 24, 2020. During the first wave of the pandemic, there were only two cases of COVID-19 infection and one death reported among LTC residents in Winnipeg (A. Salanga, personal communication, September 13, 2021).

Provincial Actions During the First Wave of the COVID-19 Pandemic

During the first wave of the pandemic, the province’s early actions in the LTC sector were to prioritize personal protective equipment (PPE) and test symptomatic residents (Rounce & Levasseure, 2020). On March 17, 2020, Manitoba Public Health officials announced an immediate suspension of all social visits to LTC facilities in an effort to reduce the transmission of COVID-19 infection; some visits were still granted on the basis of compassionate reasons (Frew, 2020). On March 31, 2020, Shared Health issued a guiding document with recommendations to limit NPs/physicians’ physical visits to LTC to only one medical provider, at a set time once a week for the entire LTC facility, while the remaining NPs/physicians were advised to do rounds on their residents through a virtual platform. This guiding document also stated that every resident transferred to hospital from LTC should be triaged first by the NPs/physicians to evaluate the need for transfer; only residents whose care could not be managed at the LTC facility would be sent to hospital for further interventions (Shared Health, 2020). In April 2020, Shared Health (2020) provided recommendations to NPs/physicians to proactively discuss ACP and GOC in the context of COVID-19 with residents/families. The COVID-19 provincial guidance for palliative care communication was issued in May 2020 (Shared Health, 2020). On-site visits by medical providers resumed on August 4, 2020. To decrease the risk of COVID-19 infection within LTC facilities, the single-site staffing model was implemented in Manitoba on May 1, 2020. According to this model, nurses and other support staff could only work at one LTC facility. This order was revised on April 19, 2021 to allow an exemption for staff members who had received at least one dose of the COVID-19 vaccine (Shared Health, 2021).

On August 19, 2020, the RestartMB pandemic response system was implemented in Manitoba to classify risks and restrictions according to community transmission of COVID-19 infection. There were four colour-coded response levels: (a) red (critical), where community spread of COVID-19 is not contained and/or there are significant strains on the healthcare system; (b) orange (restricted), where community transmission is occurring and public health orders are in place to manage the negative impacts on human health and the healthcare system; (c) yellow (caution), where community transmission of COVID-19 is occurring at low levels; (d) green (limited risk), where the spread of COVID-19 is broadly contained and a vaccine/effective treatment is available (Province of Manitoba, 2020). Winnipeg was at the yellow (caution) level of the RestartMB pandemic response system throughout the data collection period of this study. Due to a surge in COVID-19 infections, Winnipeg was placed under the red (critical) level of the RestartMB pandemic response system on November 3, 2020 (Province of Manitoba, 2020). Overall, there was minimal spread of COVID-19 infections in LTC facilities during the data collection period of this study. Both Shared Health and the province of Manitoba implemented several guidelines and recommendations to prevent and manage COVID-19 infections in LTC facilities during that time.

Impact of the Pandemic on the Researcher

Even though there were no COVID-19 outbreaks in the LTC facility where the researcher worked as an NP during the data collection period of this study, the researcher undertook many additional roles and responsibilities to prevent the potential spread of COVID-19 in the facility. The researcher collaborated with facility management to communicate the evolving COVID-19 recommendations from Shared Health and WRHA. She also helped implement pandemic protocols, such as the comprehensive clinical assessment of residents in case of an outbreak; resident cohorts and isolation plans; a COVID-19 detection protocol; a communication protocol for families in case of an outbreak; and consultations with families for proactive ACP and resident-centered COVID-19 infection treatment plans.

When physical visits were restricted to one NP/physician for the entire facility, the researcher stepped in to continue with physical visits; physicians working in the facility were then shifted to virtual visits only. As a result, the researcher's workload increased and she became the only on-site provider for the 100-bed facility, in addition to her regular work at the transitional care unit (TCU). During this time, the researcher worked in collaboration with the nurses to care for residents whose conditions were deteriorating and discuss ACP with their families. Because residents were socially isolated from their families, staff observed an increase in behavioural and psychological symptoms of dementia in some residents. The researcher was involved in developing and implementing interventions and resources to maintain the safety and well-being of these residents.

The researcher played a pivotal role in providing emotional support and education to staff and families. Most of the staff were overworked and feeling anxious about contracting COVID-19 infection and spreading it to the residents. The researcher helped ease the staff's fears by educating them on the proper use of PPE, role modeling and clarifying misconceptions about COVID-19 infection, and actively listening to their concerns and feelings. The researcher spent time mentoring nurses to enhance their assessment skills and build their confidence in EOL care. She also volunteered to extend her work hours and be on call to address the staff's concerns. The researcher spent a large part of her time supporting the residents' families, whose visits to the facility had been restricted. In collaboration with the nurses, she kept families in the loop by providing updates on the residents' status and plans of care as well as general education on COVID-19 and the strategies for prevention and management. The researcher tried to mitigate the spread of COVID-19 by restructuring her workload and schedule while continuing to work at two sites (TCU and LTC). It was challenging to manage these changes while also trying to balance the needs of staff/residents/families and stay up-to-date with rapidly changing recommendations from Shared Health/WRHA.

Nurses' Experiences of ACP Conversations During the First Wave of COVID-19

None of the LTC facilities that participated in this study had any COVID-19 infections during the data collection period. However, the context of the pandemic did appear to impact the nurses' ACP conversations. Eight of the 25 nurses interviewed in this study shared their perspectives and experiences with ACP during COVID-19. The three main themes that emerged from these interviews were: (a) easier downgrading of the ACP level, (b) forward triaging of residents prior to hospital transfer, and (c) use of telephone family meetings. The following sections describe these findings in detail.

Easier Downgrading of the ACP Level

During the COVID-19 pandemic, nurses found that families were hesitant to send their loved ones to hospital for appointments and treatments, and preferred to keep them at the facility to monitor their conditions. The nurses reported that some families were scared their loved ones would acquire COVID-19 infection from the hospital, while others did not want their loved ones to transmit COVID-19 infection to others upon their return to the facility. The following quotes illustrate the nurses' experiences with hospital transfers during COVID-19:

> I think lots of people are scared to go to the hospital right now and they are scared getting COVID to their loved ones from hospital and I think that is making or influencing chances and decisions in ACP levels. That's my experience (Unit nurse; Interview: 20); and
>
> One daughter said to me at one point, "You know I'm changing my dad to no transfer to hospital because you know what I don't want him" and she goes, "I could never live with myself if he came back, you know, with whatever's going on and he brought COVID into your home. She goes, my dad was somebody that's a giver and would want us to do the right thing and would never want to be responsible for that. (RCM; Interview: 23)

The nurses reported that families were more open to ACP conversations during the COVID-19 pandemic than they were previously. Many families readily downgraded residents' ACP levels from resuscitative/medical to either medical with no hospital transfers or comfort care. The nurses noted that families required less persuasion than prior to the pandemic:

> I think that all along, you know, – nobody like to talk about it (ACP) but I think that with COVID more people are open to it in my opinion. I have found that people are a lot more open to listening about goals of care and, you know, what their plans are, a lot more

> involved. But I have to say with COVID what's happened is that people really truthfully now mostly go from medical with transfer to comfort care is what I'm finding (Unit nurse; Interview: 24); and
>
> Like a lot of the people who were medical with transfer, so would go for anything, were changed to medical no transfer. And we even had some families who have very elderly and very sick family members here with us that were resuscitation that they changed to medical either with no transfer or comfort care. (RCM; Interview: 23)

Some facilities responded to Shared Health's recommendations to proactively discuss ACP and GOC by having the medical director/attending physician persuade families to downgrade residents' ACP levels. They discussed the risks of sending residents to hospital during the COVID-19 pandemic, and families willingly downgraded the residents' ACP from medical/resuscitative to medical without hospital transfer or comfort care:

> During the COVID, the doctor called the families to change the ACP from M to C. The doctor wants to let the family know about the risk of sending someone out to hospital during this pandemic you know, like exposure and everything, and like they said there might be of an exposure of COVID at the hospital if you send someone out to hospital. (Unit nurse; Interview: 18)

Forward Triaging of the Residents Prior to Hospital Transfer

Forward triaging refers to the physician/NPs' determination of the residents' acuity level and the best setting of care for meeting their needs prior to hospital transfer. The nurses reported that, prior to the pandemic, any change in a resident's status resulted in the resident being transferred to the hospital, without notifying the NP/physician. Conversely, during the COVID-19 pandemic, nurses had to notify the NP/physician prior to a resident's hospital transfer to solicit their assessment, and determine if the resident required the hospital transfer or could be managed at the facility. If the resident needed a transfer, the NP/physician engaged in direct communication with the hospital emergency room physician. Nurses believed that the NPs/physicians' role in hospital transfers during the COVID-19 pandemic significantly reduced unnecessary hospital transfers and improved ACP communication between families and healthcare providers. In addition, their consultation with emergency room physicians and residents' family members was helpful in developing appropriate treatment and EOL care goals. These consultations also seemed to reduce tension and conflict, which was commonplace prior to the pandemic, between the LTC facility and hospital about transfers. The following quotes illustrate these findings:

> Like pre-COVID, if they (residents) were an ACPM or R, we'd transfer out and when the condition changed usually we would just send them to the hospital. Now, with the COVID-19, there's an extra phone call. The physician or the nurse practitioner needs to be notified. And that physician or nurse practitioner decides can we treat this in facility? Should we send them out? And they kind of have more of a role in trying to help decide. If we do send them out that the nurse practitioner or physician is phoning the emergency room to let them know that they'(residents) are coming (CRN; Interview: 15); and
>
> I think we're not sending out as much and we're being more honest and realistic with the families about what the outcomes would be sending them to acute care. And I really think it's pushed us to have those conversations and be honest with them about end-of-life and with our families. I definitely think it's better now and reduces unnecessary hospital transfers. (RCM; Interview: 25)

Use of Telephone Family Meetings

Nurses reported that the pandemic-related visitor restrictions forced them to conduct resident admission and annual family meetings as teleconferences rather than in-person. Prior to the COVID-19 pandemic, nurses reported that their ACP conversations were mostly directed toward the resident's POA and that only family members who were geographically close could attend the family meetings. With teleconferences, the nurses noted that all family members, regardless of their geographic location, were able to participate in family meetings and learn about the resident’s status directly from the healthcare team. The nurses believed that telephone family meetings helped get everyone on the same page by improving the family’s collective understanding of the resident’s status, as evidenced by the following quotes:

> With COVID we had the visitor restrictions so we've had to do quite a bit on the phone. We have had a lot of family phone conferences, so me, the CRN, admission coordinator and the other manager, have actually done like a group phone conversation on the speaker phone and conferenced other family members in so that we could have, you know, like a – everybody on board who needs to help make the decisions (RCM; Interview: 25); and
>
> Before what happens is I would often call the primary contact, always, to talk about goals of care. And so I think our team has found that if we do a phone conference and, you know, and have all the siblings there, you know on the phone, or the key players, and explain it to them all on the same page again. I think that that has been very beneficial. (CRN; Interview: 20)

Some nurses found it challenging to build relationships/rapport with families during teleconferences, while others perceived the virtual conference as a gift from the COVID-19 pandemic. These nurses felt that teleconferences significantly improved the quality of ACP conversations and decision making between families and the healthcare team. For instance, one of the nurses stated, “I think the thing that I found that phone conferences have been very, very helpful and that was kind of a gift of COVID in regard to having effective family meetings” (CRN; Interview: 20). Another nurse affirmed this by stating:

> I’m finding that time is very difficult nowadays, so I’d say now since COVID but now it’s actually getting to know people over the phone which is a new modality to get used to. I find it so – not conducive to good person rapport but that’s the new reality. (Unit nurse; Interview: 24)

Summary

In summary, the nurses in this study found that residents’ family members were more willing to engage in ACP conversations and downgrade residents’ ACP levels with less persuasion than prior to the COVID-19 pandemic. During the pandemic, unnecessary hospital transfers were reduced by a combination of forward triaging residents prior to hospital transfer and enhanced NP/physician consultation with families and ED physicians. Nurses found that family meetings conducted via telephone were the ideal platform to get everyone on the same page. Families were found to be more open to conversations about ACP and more realistic about treatment plans during the first wave of the pandemic when compared to pre-pandemic.

The second wave of the COVID-19 pandemic resulted in a larger number of outbreaks in LTC facilities and resident deaths when compared to the first wave (CIHI, 2020c). Thus, the nurses’ perspectives and experiences with ACP would likely have been different if the study was conducted during the second wave. The second wave of the pandemic in Manitoba began on September 1, 2020. Inadequate medical support, staffing shortages, and subpar infection control measures significantly and negatively impacted the LTC population in Winnipeg during the second wave (Revera, 2021). The grim visual images of deaths in LTC facilities in Europe, the US, and Canada during the second wave of the COVID-19 pandemic remained etched in people's minds worldwide. In addition, and families and staff were forced to deal with abrupt losses while continuing to provide care to family members and residents (Estabrooks et al., 2020). The second wave of COVID-19 struck a devastating blow to the LTC sector. Many frustrated families resorted to voicing their concerns to the media and/or chose to assume the role of primary caregiver for their loved ones, even if it meant forfeiting their employment to accommodate this role (Revera, 2021). More than 80% of all COVID-19 deaths in Canada occurred in the LTC sector (CIHI, 2020c). As a result, future research is warranted in the Canadian LTC sector to better understand the process of undertaking ACP during the COVID-19 pandemic, and any future pandemics. The final chapter discusses the findings of this study within the context of the existing empirical literature, and examines the strengths, limitations, and implications of the study, along with potential approaches for knowledge translation.

Chapter 9: Discussion and Conclusion

Introduction

This CGT study sought to address an important gap in the literature. The study's inductively-derived empirical model aimed to understand the experiences of nurses working in LTC facilities, specifically with regard to their engagement in the process of ACP. A theoretical model emerged that captured the experiences, processes, and strategies of nurses trying to address the identified social problem: *orchestrating comfort: getting everyone on the same page*. This chapter situates the study findings within the existing literature and provides reflections on the theoretical perspectives that guided this study. In addition, this chapter outlines the strengths and limitations of this study as well as its education, practice, and policy implications, and provides suggestions for future research. Approaches for knowledge translation activities are also proposed.

Relationship of the Model's Concepts to the Literature - Orchestrating Comfort: Getting Everyone on the Same Page

The core category that emerged from the data was that of *orchestrating comfort: getting everyone on the same page*. This core category accounted for the variations in nurses' patterns of behaviour, the study's other categories, and their properties are related to it. When we think of *orchestrating,* the mind conjures up many actions (e.g., writing a piece of music to be played by an orchestra, arranging something to achieve a desired effect, planning something secretly, or organizing an event). These actions evoke the feeling that strategies are being arranged to achieve a positive outcome. The Collins dictionary defines 'orchestrating' as organizing a situation in a way that produces the result the person wants (Collins English Dictionary, n.d).

Similarly, many different images come to mind when we think of *comfort,* namely feeling relaxed, secure, and free of pain. Central to these images is the alleviation of pain and suffering. The Collins dictionary defines ‘comfort’ as the state of being physically relaxed with no pain or other unpleasant sensations (Collins English Dictionary, n. d). The nurse theorist Kolcaba (1994) defined comfort “as the satisfaction actively, passively, or cooperatively of basic human needs for relief, ease or transcendence arising from healthcare situations that are stressful” (p. 1178). Comfort has been identified as a noun, verb, adjective, process, product, cause, and effect (Kolcaba, 1994).

It was not surprising that the concept of *orchestrating comfort* emerged as a key goal for nurses in this study, given that the provision of comfort is a central goal of nursing care (Kolcaba & Kolcaba, 1991; Kolcaba et al., 2006). In their joint position statement, the CNA, CHPCA, and CHPC-NG (2015) endorsed that nurses strive to foster comfort, alleviate suffering, provide adequate pain and symptom relief, and support a dignified and peaceful death.

The concept of *orchestrating comfort* was also identified in an ethnographic study conducted by Hyland and Morse (1995), to describe the role of funeral directors in dealing with the bereft. Funeral directors orchestrated comfort to ease the burdens of the bereaved families and mourners. They orchestrated a good funeral by providing mechanistic comfort, personal comfort, and technical comfort to families. Funeral directors provided mechanistic comfort to the family by taking control of the funeral and, thus, enabling family members to focus on their own feelings without worrying about hosting the event. Personal comfort was ensured by guiding the family through the different processes and procedures of the funeral, while also honouring their wishes. Technical comfort was ensured by restoring the appearance of the deceased person to their natural repose, which helped families view death as a peaceful state and allowed them to focus on good memories of the deceased person (Hyland & Morse, 1995).

Similarly to the funeral directors in Hyland and Morse's study (1995), the nurses in this study provided personal comfort to both the residents and their families. In the current GT study, nurses eased the pain and suffering of frail and older LTC residents. They provided personal comfort to the residents, both at EOL and during uncomfortable acute events, by orchestrating realistic ACP levels. They provided families with information about the residents' status and educated family members on the importance of downgrading and upgrading ACP levels to achieve comfort at EOL and during acute events.

When we ponder the meaning of *getting everyone on the same page*, the primary actions that come to mind are: all parties reaching agreement on a specific subject and/or a group of people who have the same knowledge, ideas, or understandings of a specific topic. These actions require consensus amongst multiple people around a given issue. According to the Collins dictionary, 'on the same page' means being "in agreement about what you are trying to achieve" (Collins dictionary, n. d). The dictionary definitions of 'comfort' and being 'on the same page' were a direct reflection of the nurses' intentions in this study when they undertook the process of ACP with residents and their families. Nurses orchestrated strategies for easing/alleviating residents' pain/suffering at EOL and during acute illness. They accomplished this goal by working to facilitate a common understanding of optimal ACP levels among residents, families, and healthcare providers, based on the residents' condition and the nurses' own perceptions/assessments.

In this study, the concept of *getting everyone on the same page* captured the nurses' strategic and targeted efforts to develop a shared understanding of the resident's big picture. The nurses tried to work with all key stakeholders to ensure that a realistic ACP level was selected for the resident. The concept of *getting everyone on the same page* has been noted in the empirical literature and is consistent with the shared mental model (SMM) developed by Floren (2018). The SMM has been defined as "an individually held, organized, cognitive representation of task-related knowledge and/or team-related knowledge that is held in common among healthcare providers, who must interact as a team in the pursuit of common objectives for patient care" (Floren, 2018, p. 506). The SMM provides a shared understanding among team members and keeps all members on the same page. The concept of SMM has been noted to be a critical component of successful teamwork and collaboration in healthcare settings (Liaw et al., 2018). The challenges associated with not having SMM in teamwork include: inaccurate refection of the current reality among team members, disagreement among team members about the team goal(s), and lack of shared knowledge among team members (Floren, 2018). More specific examples of situations that can be challenging in the absence of an SMM include: training in interprofessional rounds (Liaw et al., 2018), creating a single multidisciplinary pre-procedure checklist to enhance patient safety (Devaux et al., 2009), and taking steps to achieve good EOL care in NHs (Bern-Klug, 2004). The following sections situate the major components of the theoretical model from this study within the extant literature.

Processes, Pre-conditions, Strategies, Barriers, Facilitators, and Consequences Identified in the Model: Relationship to the Literature

Processes of the Model: Relationship to the Literature

The processes of *downgrading* and *upgrading* captured the alterations nurses made to residents' ACP levels to orchestrate comfort, and were based on nurses' assessments of their overall condition. The notions of upgrading and downgrading have been mentioned in descriptions of military operations and in the healthcare literature. In healthcare, '*slow codes'* are used to minimize medical futility. During slow codes, the healthcare team symbolically appears to conduct advanced cardiac life support, but do not provide full resuscitation efforts (Piscitello et al., 2021). Similarly to the downgrading of resuscitation efforts, the downgrading of ACP levels in this study helped reduce suffering in LTC residents.

Ferreira et al. (2020) proposed a pediatric urological surgery readiness condition (PedsUROCON) for different alertness levels, "ranging from a fully functional hospital capacity (level 5) to when maximal hospital capacity has been reached, and even life/limb threatening surgeries cannot be performed (level 1)" (p. 291). The PedsUROCON is an example of a decision making algorithm that can guide decisions to either downgrade or upgrade levels of care and offer or restrict specific treatment options, depending on the clinical situation (Ferreira et al., 2020). Similarly, the US Pentagon uses the five-level Defense Readiness Condition (DEFCON) to indicate perceived levels of threat and determine the readiness for and extent of potential military response (Oxford University Press, 2002). The DEFCON system consists of protocols that prioritize procedures based on hierarchy and formally establish triggers that guide personnel when upgrading or downgrading DEFCON levels. In this study, nurses' awareness of the residents' health status (i.e., their big picture) enabled them to identify perceived threats, triggers, and changes that necessitated the downgrading or upgrading of ACP levels in order to optimize comfort.

Pre-conditions of the Model: Relationship to Literature

Nurses used a variety of strategies to piece together the resident's and family's big pictures. Awareness of the residents' big picture facilitated realistic ACP-GOC and achieved a shared understanding of the resident's clinical situation. The pre-condition, *piecing together the* *big picture*, has been described in previous medical and nursing literature. In their interpretative phenomenological analysis, Anderson et al. (2018) reported that New Zealand emergency ambulance personnel pieced together the big picture for out of hospital patients in order to establish appropriate resuscitation efforts. They considered the patient's advanced age, disabilities, comorbidities, functional status, presence of any terminal illnesses, and involvement of palliative/hospice care. They assessed the understandings, expectations, and wishes of family members as well as the perspectives of bystanders at the scene. Thompson and McClement (2019) conducted an interpretive descriptive study that identified the activity of *piecing together,* which described the critical behaviours that nurses and HCAs engaged in while caring for NH residents dying with dementia. The researchers reported that nurses and HCAs used their familiarity with residents' normal behaviours to piece together the various and individualized symptoms of decline that were "beyond the textbook signs" (Thompson & McClement, 2019, p. 6).

In the current study, nurses pieced together the big picture using the following strategies: assessing residents' overall condition; considering the residents' diagnoses, illness trajectory, and functional status; and assessing residents' tolerance for aggressive interventions. Nurses made a conscious effort to understand the residents' families. The nurses assessed family members' knowledge about the residents' condition, the purpose of ACP, and their perspectives of the residents' desired treatment goals. They also considered families' dynamics, emotional readiness to engage in ACP discussions, and level of attachment to the residents. Finally, in piecing together their big picture, nurses also considered the practices of LTC physicians regarding comfort care and the attitudes of acute care staff/paramedics toward the LTC population and ACP-C.

The nurses in this study conducted regular assessments to identify residents' declining status in the physical (e.g., pain, reduced oral intake), psychological (e.g., low mood), and social domains (e.g., withdrawal from activities), and collaborated with other members of the healthcare team as appropriate. These findings were similar to those reported by Åvik Persson and colleagues (2018), who completed a focus group study to explore multidisciplinary teams' experiences of early and late signs of impending death in four Swedish NHs. The study participants portrayed residents' declining health toward EOL as 'going into a bubble,' which was characterized by their withdrawal from the surrounding world, low mood, increased sleep, new onset of confusion, decreased physical ability, and decreased appetite (Åvik Persson et al., 2018). Piecing together the resident's big picture helped nurses understand that a continued decline in health was expected to occur up until the resident's death. With this understanding, nurses were able to engage in more structured discussions with families about their GOC.

In addition, piecing together the family's understanding of the big picture allowed nurses to gauge family members' perceptions of the resident's overall state of health and well-being. Family characteristics appeared to influence family members' understanding and responses to the resident's big picture. The nurses appreciated that family members' emotions could influence the extent to which they were able to absorb and process information about the resident's declining condition. Thus, families had variable responses to receiving such information.

This finding is consistent with Timmermans's (1994) observation that families' awareness is context-dependent, and based on their emotions and cognitions. As a result, emotional crises can block out the information being provided to them. Timmermans (1994) considered families' abilities to emotionally cope with their loved ones' terminal diagnoses by dividing Glaser and Strauss's (1965) open awareness context into three subcategories: (a) suspended open awareness, (b) uncertain open awareness, and (c) active open awareness. In this study, family members who were “holding on/ angry”, had a healthcare provider background, and/or were deeply rooted in religious beliefs had perspectives most consistent with the suspended open awareness stage (Timmermans, 1994). This stage was associated with overly pessimistic attitudes, refusal to engage in ACP conversations, denial of the resident’s big picture, and placing higher value on quantity rather than quality of life.

Nurses in the current study noted that religious, Jewish, and Asian families were particularly reluctant to engage in ACP conversations, as they were more focused on prolonging their loved ones’ life for as long as possible. The Jewish legal system, or *Halacha*, places extraordinary value on human life and indicates that life’s value is absolute and supreme, irrespective of its quality (Cohen et al., 2018). According to Judaism, life possesses intrinsic value as a divine gift of creation. Therefore, *Halacha* mandates that humans do everything in their power to heal when ill and obligates that they act to save the lives of others (Jotkowitz et al., 2005). *Halacha* does not allow for the hastening of death, even in those who are terminally ill (Cohen et al., 2018).

The topic of death and dying is considered to be taboo among the South Asian community, and is often avoided in conversations for fear that speaking about it will hasten death (Arthur & Seymour, 2013; Biondo et al., 2017; Con, 2007; Venkatasalu, 2013). Venkatasalu et al. (2013) conducted a CGT study in East London to explore older South Asians’ perspectives of death and dying. The study found that the South Asian community generally avoided talking about death for two major reasons: (a) due to the cultural norm, and (b) to protect family members from emotional burden and distress (Venkatasalu et al., 2013).

Similarly, death and dying remains taboo in Chinese communities and is not to be discussed for fear of invoking bad luck. In order to postpone the bad luck associated with death, Chinese people will try to prolong life as much as possible (Hsu et al., 2009). Yick and Gupta (2002) conducted a qualitative focus group study in New York to learn about Chinese immigrants' attitudes and practices around death, dying, and bereavement. Participants from this study indicated that death was a taboo topic and that death was usually only spoken about indirectly, using euphemisms (Yick & Gupta, 2002). Mjelde-Mossey and Chan (2007) conducted a telephone survey in Hong Kong to assess Chinese peoples' attitudes and beliefs around death, dying, and EOL care. In that study, participants believed that death could be hastened by talking about it with a dying person.

In contrast, the families in this study who were identified as "letting go /resigned," non-religious, and/or actively engaged in visiting with the residents demonstrated perspectives that were most consistent with Timmermans' (1994) active awareness stage. According to Timmermans (1994), families in the active open awareness stage could accept information about the patient's condition and act accordingly. These families understood and accepted the nurses' big picture about the resident and valued quality of life over quantity of life. Overall, these families more easily acquiesced to the nurses' recommendations regarding ACP levels. After the nurses pieced together the resident's big picture, they had to construct their understanding of the resident's '*possible dying'* (Bern-Klug, 2009). The nurses used different selling strategies to build an *active open awareness context* (Timmermans, 1994) to discuss the resident's '*possible dying'* with the family and gain their acceptance of ACP-C.

Research has indicated that both ACP-C and DNH orders can help avoid unplanned and unnecessary transfers to hospital for NH residents (Teno et al., 2004; Travis et al., 2001). In order to avoid burdensome interventions and elicit comfort-oriented care for people with advanced dementia, Quinn et al. (2017) asked healthcare providers to pause and think critically before beginning disease-directed therapies for these patients. The researchers proposed that healthcare providers simply ask families, "'what is your understanding of your loved one's prognosis?' and 'what are you hoping for?'" (Quinn et al., 2017, p. 16). In this study, nurses believed that their actions played an important role in shifting the family's big picture and moving toward successfully orchestrating comfort for the residents. Nurses used the strategy of *selling the big picture* to direct family members' attention to the resident's big picture, as understood by the nurses. They also used this strategy to establish ACP-C care plans to preclude any unwanted and/or harmful interventions. These findings were in alignment with those of Quinn et al. (2017).

Nurses in the current study enacted various strategies to increase family members' death literacy and awareness of the resident's big picture. Death literacy has been defined as "a set of knowledge and skills that make it possible to gain access to, understand, and act upon EOL and death care options" (Noonan, 2016, p. 32). According to Timmermans (1994), families' emotions can supersede logical thinking. Therefore, the pre-condition *selling the big picture* helped the nurses improve both death literacy and awareness of context among key decision makers. Families were then able to achieve active open awareness of the resident's big picture, such as *possible dying,* and choose realistic treatments goals.

Nursing Strategies: Relationship to Literature

Strategies Used in Downgrading. Nurses used various strategies to help families achieve an active open awareness of the resident's big picture. Nurses who participated in this study used persuasive strategies as a "selling mechanism" (Fisher, 1982, p. 6), whereby they convinced family members to follow their own perceptions of optimal ACP levels. Persuasion has been recognized as an essential skill for healthcare professionals (Davidhizar & Eshleman,1999). It has been appreciated as a form of communication that can be used to alter beliefs (what one knows about something), attitudes (how one feels about something), behavioural intentions (the intent to act on something), and behaviours (how one acts toward something) (Cheng & Powers, 2012). When nurses wanted to downgrade residents to ACP-C, they used strategies of gentle persuasion, team persuasion, and drawing a line in the sand: enough is enough in order to sell their big picture.

Persuasion can be traced back to ancient philosophy, when Aristotle proposed three modes of persuasion: logos, pathos, and ethos. Logos is an appeal to reason, pathos is an appeal to emotion, and ethos is an appeal to character and credibility (Demirdogen, 2010). In this study, nurses utilized all three modes of persuasion in their selling mechanism.

Logos is defined as the speaker's effort to convince the audience using logic and reason (Demirdogen, 2010). During their interactions with families, nurses strategically used their authority and clinical knowledge to persuade families to share the nurse's understanding of the big picture. Fisher and Todd (1986) described two interrelated persuasive strategies: the selective presentation of (scientific) information and the selective use of authority. By selectively presenting information to patients, healthcare providers offer different levels of information or colour the medical presentation to enhance the patients' acceptance of the provider's desired choices (Fisher & Todd, 1986). This may be accomplished by focusing on the positive effects and downplaying the negative effects of a preferred option, or magnifying the negative side effects and understating the potential positive outcomes of unwanted choices. In selective use of authority, healthcare providers use authority figures/medical guidelines to increase patients' trust and, ultimately, persuade them to accept the providers' preferences (Fisher & Todd, 1986). Nurses from this study engaged selective use of authority by having physicians and managers persuade complex families and achieve the desired outcome of comfort care.

Pathos means appealing to the audience by arousing their emotions (Demirdogen, 2010). With the help of pathos, the speaker can become emotionally connected with his/her audience (Demirdogen, 2010). In the current study, nurses facilitated the downgrading of ACP levels by evoking emotions in family members. The nurses selectively presented information about dementia and its trajectory, the burdens of hospital transfers, and the different ACP levels to residents' families. The nurses graphically depicted the negative aspects of hospital transfers and asked family members to picture themselves in the same situation as their loved one. Graphic representations of the risks of hospital transfers enhanced certain family members' acceptance of comfort care. In addition, the nurses focused on the positive impacts of comfort care (dignified and peaceful death at the facility) and magnified the negative effects of extending life with burdensome interventions and uncomfortable hospital transfers.

Ethos represents the audience's perception of the speaker's credibility and authority over the subjects to which s/he is speaking (Demirdogen, 2010). The speaker's credibility can be acquired through his/her personality, character, intelligence, virtue, good will and sensitivity, (Demirdogen. 2010). If nurses had concerns that family members were unable or unwilling to accept the big picture, they used team persuasion to change family members' attitudes and behaviours toward the resident's big picture. As stated by Grass and Seiter (2011), persuasive communication "involves one or more persons who are engaged in the activity of creating, reinforcing, modifying, or extinguishing beliefs, attitudes, intentions, motivations, and/or behaviours within the constraints of a given communication context" (p. 33). Nurses used team persuasion (i.e., by working together, involving others, calling family meetings, and leveraging the opinions of hospital staff) to fully convince family members that the resident's status was declining and their ACP level needed to be downgraded. Nurses' collaborative efforts and use of authority figures (physicians/hospital staff) were enhanced by the logos and ethos of their persuasion. Leveraging the opinions of hospital staff provided families with clarity and a sense of comfort, because they assumed that all care options had been considered. This enabled all key stakeholders to connect and unify around the big picture, which ultimately facilitated safe ACP and the outcome of a dignified death for the resident.

Persuasion has been described as a symbolic activity that aims to affect the internalization or voluntary acceptance of new cognitive states/patterns of overt behaviour, through the exchange of messages (Smith, 1982). In order for an activity to be considered 'persuasive,' the sender, the means, and the recipient must meet certain requirements. First, persuasion involves a goal and the intent to achieve that goal on the part of the message sender. Second, communication is the means to achieve that goal. Third, the message recipient must have free will (Smith, 1982). In this study, nurses initiated conversations with families as soon as they identified triggers of decline in residents. Nurses aimed to set the stage and provide a context within which to anchor future communications. Their ultimate goal was to shift families' perceptions of the big picture to be congruent with their own, and convince families to agree to downgrade residents to ACP-C. During gentle persuasion, nurses were providing families with space and time to reduce their feelings of guilt and ease the burdens of decision making. At the same time, nurses were actively persuading these families to consider less aggressive interventions and accept comfort care for their loved ones. It is important to distinguish that the nurses never coerced families to choose comfort care. In addition, the nurses always respected and followed the families' wishes, even if they caused pain and suffering for the residents and moral distress for the healthcare providers.

It has been argued in the literature that the appropriateness of persuasion is context-dependent (Dubov, 2015; Shaw & Elger, 2013). Dubov (2015) stated that patients and families will not always clearly understand the risks and may make decisions that contradict long term goals. When this occurs, healthcare providers should assume the responsibility of recognizing and modifying the personal/contextual factors and biases that influenced patients/families' choices, and assist them to reach their desired outcomes. According to Dubov (2015), healthcare providers have a duty to persuade and can be considered morally blameworthy if they do not attempt to persuade their patients to accept interventions deemed medically necessary.

Patients and families often make irrational decisions, especially in emotionally charged situations. Healthcare providers have the power to inadvertently influence these choices through the use of persuasion. Therefore, persuasive communication has been viewed as a powerful tool for motivating patients and families, achieving desired patient outcomes, and accomplishing the healthcare providers' goals (Dubov, 2015; Shaw & Elger, 2013). In this study, family members often made irrational decisions about residents' ACP levels without understanding the resident's big picture. The nurses employed different persuasion strategies to sell the resident's big picture to the family and reach consensus between the family and nurses about comfort care. This consensus facilitated the nurses' goal of shifting care from aggressive curative interventions with hospital transfers to comfort care at the facility.

Clear, frequent, honest, and open communication with families about the resident's big picture helped families experience an active open awareness of the resident's condition. This type of communication from the nursing team also promoted realistic, resident-centered, and family-focused ACP. The results of this study suggested that supportive communication played the most prominent role in promoting families' understandings of the big picture and enhancing comfort for LTC residents. Nurses viewed ACP as a process and tried to engaged in ACP communication with families as early as possible, namely at the time of the resident's admission to LTC, rather than waiting until EOL. Supportive communication and shared decision making between the nurses and families promoted trust, partnership, and realistic ACP discussions.

The 2019 Pan-Canadian Framework for ACP (CHPCA, 2020) supported and encouraged shared decision making practices to engage people with cognitive impairment in ACP. Shared decision making can be used to discuss ACP in a participative and informed manner. Shared decision making is the process by which residents/families and healthcare professionals make decisions together, using the best available evidence (Elwyn et al., 2010). Shared decision making is particularly relevant in ACP because it embodies the principles of resident-centered care, which seeks to provide high quality care by acknowledging the personhood of residents in all aspects of their care (Goossens et al., 2020). The benefits of shared decision making include improved knowledge on healthcare topics, increased participation in decision making, and reduced decisional conflict (Frosch et al., 2012), all of which were observed in the current study. A cross sectional survey explored the perceived level of shared decision making during ACP conversations between healthcare professionals and family members/residents with dementia in Belgian NHs (Goossens et al., 2020). The results of the survey highlighted the importance of education programs for NH staff on the concept of shared decision making. In addition, the survey findings indicated that team-based collaboration can increase the level of person-centered care in LTC settings (Goossens et al., 2020).

Nurses in this study helped families understand the impact of burdensome interventions on the residents' quality of life and guided them to make rational decisions about terminal hospital transfers. The nurses incorporated the negative impacts of hospital transfers and other burdensome interventions when piecing together the resident's big picture. According to the nurses, hospital transfers and ambulance transport would cause marked discomfort and suffering for frail residents with multiple comorbidities and dementia. The nurses' perspectives about the burdens of hospital transfers were supported by numerous studies in the literature (Crilly et al., 2012; Grant et al., 2020; & Ouslander et al., 2011).

The findings of the current study were consistent with those of Lopez et al. (2017) in that nurses were very aware and concerned about the risks of hospitalization, and actively reminded families about previous negative experiences with such transfers. The nurses advised families that the hospital had little to offer to improve residents' quality of life and that comfort care in the LTC facility was the optimal approach. The Zurich Life and Death with Advanced Dementia (ZULIDAD) study examined nurses' attitudes toward burdensome medical interventions on NH residents with dementia in Switzerland (Riese & Eicher, 2017). In contrast to the current study, the ZULIDAD study found that nurses were more favorable of burdensome interventions and less focused on a palliative approach than the residents' healthcare proxies. The authors stated that further research is required to investigate the reasons nurses favoured a more aggressive treatment approach (Riese & Eicher, 2017).

While piecing together the family's big picture, nurses evaluated the family's understanding of the medical information they had received and tried to deliver information and explanations in lay person's terms. Nurses also believed that providing information in the family's first language facilitated their understanding of both ACP and the resident's health status. Furthermore, health literacy is a strong predictor of advance directive completion. A national adult literacy survey from the US noted that 48% of Americans lack the necessary literacy to comprehend and process health information (Melhado & Bushy, 2011). Sudore et al. (2007) reported that an advanced directive written at the fifth grade reading level, with graphics, was favored by patients of both adequate and limited literacy. The use of this advance directive was associated with increased advance directive completion rates (Sudore et al., 2007). Ladin et al. (2018) recommended that, in order to sell the resident's big picture, nurses take steps to reduce the health literacy demands on families by aligning their educational approach with the family's ability to understand the information. Ladin and colleagues (2018) asserted that clear communication in EOL care can reduce literacy demands so "patients of all functional literacy levels can fully engage in care" (p. 7).

Nurses from this study believed care conferences were excellent arenas in which to persuade the family because these meetings allowed all team members to present a consistent big picture of the resident. Consistent messaging facilitated getting the family on the same page as the healthcare team and helped encourage the choice of ACP-C, which was consistent with the resident's big picture. Similarly, a Canadian study from Ontario NHs reported that multidisciplinary attendance at family care conferences promoted collaboration and communication, and was associated with positive EOL outcomes. Care conferences allowed the team to negotiate common GOC with families and assist them to maintain realistic and feasible expectations for EOL care (Durepos et al., 2018). Similarly, a study by Durepos et al. (2018) emphasized the importance of HCAs' and physicians' attendance at family care conferences. A more recent study by Rainsford et al. (2021) showed that care conferences provided families the opportunity to engage with a cross-section of the healthcare team to discuss, ask questions, and hear perspectives about their loved ones. This type of engagement helped families gain a sense of their loved ones' upcoming health journey, the available care options, and the feasible interventions that would facilitate comfort.

Nurse participants viewed futile care as problematic. They acted as mediators when negotiating futility with families and physicians through the strategy of *drawing a line in the sand: enough is enough*. Futility was defined as "treatment or clinical interventions that are not likely to result in benefit to the patient or produce the expected outcome" (Terra & Powell, 2012, p. 103). Jacobs and Taylor (2005) argued that the healthcare team may use their own experiences to prognosticate futility; if a treatment proved to be useless in a healthcare provider's previous experiences, the intervention should be judged as futile. The concept of futility encourages physicians to use their judgment and empirical evidence to gauge the appropriateness of a treatment, which affects the way they present information to patients and families (Jacobs & Taylor, 2005). In this study, nurses alerted families and physicians about futile antibiotic treatment for reoccurring aspiration pneumonia, specifically in residents with dementia and swallowing problems. As a result, the physicians felt obligated to withhold antibiotics and pursue comfort care instead.

Similar findings were identified in an observational cohort study from 61 NHs in the Netherlands, where it was a common practice to withhold antibiotic treatment for pneumonia in residents with severe dementia, severe pneumonia, poor oral intake, recurrent aspiration pneumonia, and dehydration (van der Steen et al., 2002). The Netherlands study affirmed that ACP with family needs to include discussions about antibiotic treatment (van der Steen et al., 2002). Evidence has shown that antibiotic treatment for pneumonia does not improve comfort in advanced dementia (van der Steen et al., 2012) and prolongs the dying process (Givens et al., 2010).

Findings from a recent Canadian study (Bravo et al., 2021) highlighted the challenges associated with antibiotic treatment for pneumonia with comorbid dementia. The researchers urged healthcare providers to initiate ACP decisions in the early stages of dementia to help residents and their families prepare for anticipated future complications and treatment goals (Bravo et al., 2021). Van der Maaden et al. (2015) conducted a systematic review to examine the use of antibiotics in residents with dementia. They identified that the failure to recognize dementia as a terminal condition, or pneumonia as part of the natural death process in severe dementia, contributed to unnecessary antibiotic treatment in NH residents. Similar findings were presented in the current study as well.

Antibiotic use tended to vary between countries due to differences in legislation, physicians' practices, and care providers' competences with regard to dementia and EOL care (van der Maaden et al., 2015). A cross-cultural study showed that physician-perceived roles regarding pneumonia treatment in NH residents were influenced by the physicians' involvement with residents and families (Helton et al., 2006). Dutch physicians assumed active, primary responsibility for treatment decisions; their decisions were based on intimate knowledge of the residents and their own perceptions of the residents' best interests. Conversely, physicians from the US (Helton et al., 2006) and the current study were described by nurses as taking an easy path. The nurses felt that physicians assumed a passive stance in making treatment decisions, due to their own limited knowledge of the residents and their perceived threat of blame from families. Nurses believed that physicians went along with families' wishes even when the treatment was inappropriate.

Decisions about potentially futile treatments, such as antibiotics, often had a variety of consequences for the nurses. A modified GT study was conducted with different healthcare providers from 16 ICU units across Ontario, Canada (Sibbald et al., 2007). The study found that nurses were generally less satisfied with EOL decision making when compared to their physician counterparts. Physicians were known to offer treatment to patients with a poor prognosis, which instilled false hope in patients and families (Sibbald at al., 2007). Nurses often predicted mortality more accurately than physicians, and were usually the first members of the team to perceive when life support should be withdrawn (Sibbald at al., 2007). Similar to the findings of the current study, a recent prospective qualitative study found that experienced nurses in Greece (n=16) were frequently confronted with situations in which they believed that further treatment had no foreseeable benefit and was likely to cause undue suffering (Voultsos et al., 2021). As in the current study, nurses played a critical role in decision making and (Demirdogen, 2010). acted as mediators between physicians and patients with regard to futile care (Voultsos et al., 2021).

The strategies and behaviours used by nurses in the downgrading process in this study were previously reported in the literature. Thompson and McClement (2019) performed a qualitative examination of behaviours among nursing and HCA staff caring for NH residents dying with dementia. They identified the following critical behaviours: salience of recognizing and responding to changes in a resident's pattern of behaviour; working with the family; and engaging with others (Thompson & McClement, 2019). A descriptive exploratory study examined critical behaviours in nurses caring for dying residents in NHs (Wowchuk, 2004). The study identified several critical behaviours including: the importance of educating family members about the potential burdens and benefits of different treatments; facilitating decision making; informing family about a deterioration in the resident's condition; vocalizing concerns about burdensome/futile interventions to family and physicians; preventing terminal hospital transfers; and advocating to keep the resident at the facility (Wowchuk, 2004). The critical behaviours identified among HCAs and nurses caring for dying residents in the aforementioned qualitative studies (Thompson & McClement, 2019; Wowchuk, 2004) were similar to the nursing strategies used in the downgrading process in the current study.

Similar to this study, Terzakis and MacKenzie (2018) found that healthcare providers assessed families' awareness, acceptance, and planning in the cognitive (knowledge of illness/prognosis), affective (feelings, emotions, and readiness), and behavioural (ACP/estate planning) dimensions. Assessment of families' functioning across these dimensions helped the provider adequately prepare family members for the residents' death in LTC. In order to prepare families for the death of their loved one, healthcare providers ensured that the residents' prognosis was clearly disclosed and that all information was tailored and repeated according to the families' emotional state/desires (Terzakis & MacKenzie, 2018).

As in the current study, other research has demonstrated that nurses used strategies and activities to shift patient and family goals from acute curative treatment to realistic palliative treatment in order to facilitate a good/dignified death (Norton & Bowers, 2001; Thompson et al., 2006). The strategies used by nurses in this study, as well as in other studies, included: cueing people (family and physicians) about a decline in the patient's status; educating family about salient changes in the dying process; pushing physicians to change the patient's resuscitation orders to avoid aggressive and futile interventions; being honest with family about the patient's poor prognosis; using perspective taking to get the family to consider their loved one's EOL wishes; (Thompson et al., 2006) working together; involving others; and conducting family meetings to lay the groundwork (Norton & Bowers, 2001).

Strategies Used in Upgrading. In the current study, nurses used the strategies of *building consensus through education* and *working the system* to upgrade residents' ACP levels. Collaboration and networking between LTC nurses and hospital staff assisted the downgrading process. Using these strategies, the LTC nurses were able to successfully leverage the knowledge and authority of acute care staff in order to persuade families to proceed with ACP-C.

Staff perceptions of ACP-C differed between acute care and LTC settings. Acute care staff's indifferent attitudes toward residents with ACP-C caused significant issues for LTC nurses during acute events. The hospital staff believed that residents who were ACP-C were dying and that hospital transfers were not needed for these patients. Care practices and working conditions within the two sectors were strongly influenced by two different mindsets. These differences caused conflict about the residents' treatment goals and prevented staff from providing resident-centered care. Nurses in this study believed there was a power imbalance between acute care and LTC staff, whereby acute care staff had a sense of superiority over LTC staff. This power differential meant that staff had little interest in working together to share residents' care, which resulted in many disagreements between the two teams. The lack of understanding of each other's professional viewpoints, work requirements, and professional responsibilities contributed to strained working relationships between LTC and acute care staff. The nurses in this study reported there was a lack of mutual respect and trust between the LTC and acute care teams.

Previous research has highlighted the different perspectives and organizational structures between these two sectors (Horwitz et al., 2009; Laging et al., 2015; Purdy, 2002). The whispered tensions between the LTC and acute care sectors were recognized in previous studies, where it was uncovered that this tension has been normalized (Horwitz et al., 2009; Purdy, 2002). Nurses who transferred residents to the hospital fully expected that the residents would return to LTC with the same health issues and concerns as when they left. According to McCloskey (2011), acute care staff's beliefs that LTC residents gained little benefit from hospital transfers, without considering the issues that prompted their transfer, could be explained through mindlessness and premature cognitive commitment ideologies. These ideologies also explained the staff's beliefs that LTC residents were "problematic," because they were already dying and "wasted resources that could be used for others" (McCloskey, 2011, p.167) Mindlessness occurs when people unconsciously commit to specific views or ways of understanding the world (Langer, 1989). According to Langer (1989), mindlessness occurs when people form a mindset on the first exposure to a situation and then cling to that mindset during subsequent encounters with the same situation. This type of mindset is formed without much critical thought and is referred to as a premature cognitive commitment.

It was evident in this study that the LTC and hospital settings represented 'two worlds' with separate cultures and identities. According to the work of Petersen et al. (2019), nurses working in 'two worlds' required different skill sets and had different care priorities, workplace tasks, and goals. This study demonstrated that staff in these two settings had very different perceptions of ACP-C and lacked a shared understanding of comfort care. The different objectives and approaches to care across these 'two worlds' challenged LTC nurses' ability to provide realistic comfort care to residents during acute events. Therefore, LTC nurses developed specific strategies to avoid the misconceptions that surrounded ACP-C, and subsequent disagreements with acute care staff about optimal care for residents. The nurses learned to 'work the system' to sell the big picture to acute care staff and improve residents' comfort during acute events.

It was evident from this study that packaging and handing residents off to EDs for comfort-oriented interventions involved complex communication skills. In order to achieve their objectives, the nurses used the same persuasion strategies with acute care staff as they did with the residents' families. The notion of 'selling the patients' has been identified in research conducted in ED settings, where emergency physicians were pressured to sell admissions by persuading inpatient staff to accept patients (Hilligos et al., 2015). Nugus et al. (2017) argued that effective selling involved minimizing or maximizing aspects of the patients' concerns, either by spinning stories or overselling patients' issues to avoid pushback from inpatient physicians. The winner of these competitive interactions was the provider who argued most persuasively or who effectively mobilized institutional power to achieve a desired outcome (Nugus et al., 2017). As stated by an attending in the ED, "it doesn't necessarily mean the patient goes to the best service, but maybe just the weakest personality caves" (Hilligos et al., 2015, p. 135).

When ED physicians experienced pushback and were unsuccessful in their attempts to 'sell the patient,' they revised and strengthened their approach by invoking the desires of a third party. Hilligos and colleagues (2015) found that physicians could persuade inpatient units to accept patients by explicitly stating that the admission was "what the attending wants" (p. 138). Similarly, nurses in the current study experienced pushback and hostility from acute care staff and paramedics regarding resident transfers. In the same way as the ED physicians, the nurses modified their selling technique by invoking the wishes of a third party—that of the resident's family. The nurses' discussions with acute care staff and paramedics clearly communicated that "transfer to hospital was the wish of the family." Nurses in the current study valued the family's support for transferring residents with acute medical events to the hospital. Family members played a critical role in advocating for their loved ones with hospital staff. As a result, the nurses encouraged family members to accompany residents to the hospital to ensure they received the required care. Nurses perceived family members as a “gap filler” (Pulst, et al., 2019, p. 11) between the nurses and acute care staff; the nurses noted that, when families forcefully advocated for their loved one’s comfort, their efforts ultimately benefited both the resident and the LTC nurses.

Nurses in this study not only invoked the wishes of family members to sell residents’ transfers to hospital, but also admitted that they intentionally and unilaterally altered residents’ ACP documents. The nurses knew that residents sent to hospital with an ACP-C would immediately be sent back to the LTC facility. As a result, they learned to sell the resident to the hospital by manipulating the ACP level prior to transfer and upgrading it to ACP-M.

In this study, nurses tried to convince LTC physicians about the futility of treating recurrent aspiration pneumonia in residents, with the goal of downgrading the residents to ACP-C. When physicians refused to treat painful infections, especially urinary tract infections, in residents who were ACP-C, nurses again ‘worked the system’ by creating an upgraded level of ACP-C – ACP M without hospital transfer – to compel the physician to order antibiotics. Nurses in this study identified that decisions to prescribe or forgo antibiotic treatment were heavily influenced by ACP levels. A survey study from US NHs indicated that only 10% of key medical decision makers were perceived to discourage antibiotic therapy for residents with end-stage dementia; conversely, 41% of medical directors, 59% of directors of nursing, and 57% of administrators actively encouraged antibiotic use (Lacey, 2005). These findings suggested that key medical decision makers in NHs held attitudes and perspectives that were inconsistent with the recommendations of dementia and palliative care experts (Lacey, 2005). Research has shown that antibiotics are mainly prescribed because healthcare providers and family members believe this approach will improve residents’ comfort (Forbes et al., 2000; van der Steen et al., 2002). However, a study by van der Maaden et al. (2016) suggested that antibiotics may not make a difference in residents’ overall comfort levels if they were given access to effective symptom management.

Unfortunately, working the system encouraged the nurses in LTC and acute care to work against each other rather than with each other. Consequently, it was difficult to achieve resident-centered care between the two settings. The fact that the healthcare system has not yet been structured to align ACP goals and integrate the needs of LTC residents suggests that there may be more fragmentation across the care continuum than has been previously understood.

In order to successfully upgrade and downgrade ACP levels, nurses needed to have both contextual and communicative competence. Contextual competence has been defined as the capacity to recognize, critically reflect on, and manage the relationship between individual attitudes and behaviours in addition to the broader network of positional, departmental, and organizational circumstances (Charaudeau, 2002). Whereas the communication competence relates to the immediate situation in which a person (the ‘interactant’) is communicating. To achieve communicative competence, interactants must understand the role and position of their interlocutor and their relationship with that person, the aim of the interaction, the thematic relevance of their communication (Charaudeau, 2002). In order to bring the key decision makers to the same page to orchestrate comfort and achieve a realistic ACP level for the residents, nurses utilized both communication and contextual competencies in piecing together and selling their big picture.

In this study, nurses appeared to be motivated by the desire to do ‘what is best’ for the resident, but their views did not always coincide with the family’s preferences for the resident during acute illness and/or at end of life. When disagreements occurred, nurses used several strategies to help the family understand the resident's big picture and to ultimately choose the best ACP level which would promote comfort for the resident. Othering, at the level of nurse-family interactions, was manifested in this study. Othering is a process through which people construct their own identities in reference to others. A critical aspect of Othering requires that the prevailing group hold a clearly defined standard of acceptable behavior, which is a standard constructed and maintained for the group, by the group (Canales, 2000). The standards of care that are set for nurses are: to foster comfort; to alleviate suffering and advocate for adequate relief of discomfort; to support a dignified and peaceful death (CHPC-NG, 2015). The code of ethics for registered nurses provides a framework for ethical decision-making and guides the actions of nurses, who are expected to uphold these ethical principles in their practice and promote the welfare of their patients as well as the profession of nursing (CNA, 2017). It is in reference to this accepted standard that Othering takes place. In this study, Othering occurred when the family did not conform to the agreed standard of care set by the nurses and/or the nurses perceived the family members as difficult and challenging to work with.

According to Canales (2000), the two distinct sets of Othering practices in healthcare are exclusionary and inclusionary. Exclusionary practices are characterized by the use of power in the relationship to differentiate the other and maintain a sense of distance. This can result in exclusion, neglect and even oppression of the other. Healthcare providers who ignore the needs or preferences of those patients who do not conform to their expectations, or who withhold information from patients who are perceived as difficult or challenging to work with, are examples of exclusionary Othering practices (Canales, 2000). In contrast, inclusionary Othering practices use power in the relationship to build a sense of connectedness and promote inclusion and support. Inclusionary practices recognize the importance of fostering relationships and working collaboratively with patients/families to include them in the decision making. Healthcare providers who actively seek out and incorporate the input and feedback of patients and their families, and who provide support and information to patients and families who are facing challenging health situations are examples of inclusionary practices (Canales, 2000).

The Othering practices demonstrated by the nurses in this study were inclusionary Othering. Once the nurses understood what was best for the resident, they used several strategies to educate families and to encourage them to choose the best ACP level that had been decided by the nurses. Nurses decided on what was best for the resident through: their knowledge of the resident; piecing together the big picture of the resident; using relational knowing to piece together the family's understanding of the resident's big picture; using their knowledge of other characteristics of the family. This study highlighted the importance of 'knowing the resident' and 'knowing the Other's world' to orchestrate comfort for residents. The nurses used inclusionary Othering practices to find common ground with the family and to build a coalition based on mutual respect and understanding. By cognizing and challenging their own biases and assumptions, the nurses in this study tried different strategies to overcome the barriers that caused division between them and the family. The nurses promoted inclusive, relationship-based Othering practices to advocate for what was best for the resident, as well as to get everyone on the same page in order to promote comfort for the resident.

It was encouraging to hear that the nurses in this study felt confident and satisfied with the outcomes of their decisions and the level of ACP they promoted for the resident. None of the nurses from this study ever voiced the possibility that they made the wrong decision for the resident. The absence of reported decisional regrets from the nurses suggested that the nurses believed the process of downgrading or upgrading the ACP levels was conducted in a thoughtful and effective manner with the residents' comfort and best interests as the top priority. Decisional regrets in healthcare refer to feelings of disappointment, guilt or remorse that individuals experience after making a particular healthcare decision. These regrets may stem from a variety of factors, including the outcome of the decision, the decision-making process itself and the available information at the time of the decision (Courvoisier et al., 2011).

In this study, shared decision making and active participation and collaboration between the nurses and the families were evident. This approach recognized the importance of informed decision making, where family was provided with information about the resident's "big picture", including the benefits and risks of interventions to promote comfort for the resident through the nurses' strategy of selling the "big picture". Through the shared decision making, nurses respected the resident's/family's wishes and nurses' decisions were based on the best available evidence. They also work collaboratively with the family to get a feel of the family to determine the best way to sell the "big picture" of the resident based on the unique characteristics of the family. In this study the nurses' decisions were grounded in the four key principles of healthcare ethics: respect for autonomy, beneficence, nonmaleficence and justice (Beauchamp & Childress, 2009). Nurses acted in ways to preserve the autonomy of the resident when resident wishes were known, acted on what the nurses' perceived to be the best interests of the resident (beneficence), acted in ways to prevent harm to the resident (nonmaleficence) and advocated for the fair and equitable treatment and distribution of healthcare resources (justice) for the resident from acute care staff and paramedics. The nurses' emphasis on good communication, relationship building, and knowing the resident and family, along with upholding the principles of healthcare ethics and collaborating with family, may have helped to minimize the possibility of decisional regret in this study.

The nurses' confidence in feeling that they were best placed to determine what was in the residents' best interests is interesting. By definition, the best interests standard "protects an incompetent person's well-being by requiring surrogates to assess the risks and benefits of various treatments and alternatives to treatment" (Beauchamp & Childress, 2009, p. 138). The family often brings to the best interests discussion an understanding of the residents' values, beliefs, and previously expressed wishes. The nurses in this study believed that they had a fuller understanding of the "big picture" for the resident than others (e.g., the family, physicians), including the risks and benefits of possible interventions. As a result, the nurses believed they were in a strong position to make judgements about residents' best interests and, by extension, the optimal ACP level for residents. They did not speak about the possibility of "getting it wrong" in terms of these best interests judgements, but this is something that could be explored in future studies.

Why might nurses in this study not have talked about the possibility of "getting it wrong" when deciding on the optimal ACP level for residents? This was not a distinct line of questioning that occurred during participant interviews, thus it is possible that because nurses were not asked about it, they chose not to disclose situations in which they believe this might have occurred. It may be argued that making a wrong decision on a resident's ACP level would create cognitive dissonance among nurses. Cognitive dissonance is defined as the mental discomfort or psychological tension that arises when a person's attitudes or beliefs conflict with their behaviors or other beliefs (Ploger et al., 2021). Cognitive dissonance can lead to feelings of discomfort, guilt, or shame, as well as questioning of one's competence and professional identity (Ploger et al., 2021). Thus, the associated psychological discomfort of experiencing cognitive dissonance may be a possible explanation for why nurses did not talk about the possibility that their clinical decision making about the optimal ACP status for residents was in error.

The next section explains the barriers and facilitators that enabled nurses to achieve a realistic ACP level and enhance residents' comfort. followed by the utility of the theoretical perspectives that were used in understanding the process through which nurses undertook ACP.

Barriers and Facilitators: Relationship to the Literature

Factors that either constrained or facilitated the nurses' ability to downgrade or upgrade residents' ACP levels were classified and analyzed from a socio-ecological perspective. The following section provides an overview of the barriers and facilitators identified in this study and describes them in the context of the available literature. New insights about the barriers and facilitators that have not been previously explored in the existing ACP literature are also discussed.

Resident and Family Level. This study identified that families' and residents' behaviours/beliefs were factors that impacted the nurse's ability to upgrade or downgrade ACP levels. Similar findings were reported by Jimenez et al. (2018), Gilissen et al. (2017), and Risk et al. (2019). Barriers that hindered the downgrading process at the resident/family level included: younger age of the resident; resident being under PGT; prognostic uncertainty; family dynamics; acting in the best interests of the family; family member(s) with a healthcare background; family members' knowledge deficits; and the family's culture/religion.

In the current study, younger age of the resident was found to be a barrier to downgrading ACP levels. Interestingly, a meta-synthesis by Ke et al. (2015) reported that older age was a barrier to ACP because older people believed that talking about death and dying could have negative effects, including abandonment by healthcare providers. In the current study, culture rather than age was identified as a barrier to conversations about ACP, due to fears of hastening death. In this study, when the resident’s big picture was cloudy, it was difficult for nurses to forecast a time frame for EOL. This prognostic uncertainty stalled nurses’ efforts to downgrade residents’ ACP levels. Similarly, in a study by de Velminck and colleagues (2014), prognostic uncertainty led to prognostic paralysis – a situation in which the general practitioner avoided discussions about future care and limited ACP conversations. Similar findings concerning the impact of prognostic uncertainty were echoed in a recent scoping review (Carlini et al., 2021), a recent systematic mixed methods review (Ellis-Smith et al., 2021), and in several other studies (Kastbom et al., 2019; Lamahewa et al., 2018; de Velminck at al., 2014).

The clinical uncertainty of NH residents’ health status was described several decades ago in the literature as ‘*prolonged dwindling’* (Lynn et al., 1995) and ‘*possible dying’* (Bern-Klug, 2006). These terms were used to underscore the uncertainty of time until death for many NH residents with multiple chronic and progressive illnesses (Bern-Klug, 2006). Nurses in the current study described the ‘*roller coaster ride’* of prognostic uncertainty, during which time residents recovered from their illness and kept living. Participants from another study by Hall et al. (2011) described a similar situation in which residents lived much longer than expected and defined this phenomenon as *‘bouncing back*’.

Even though several prognostication tools have been made available to predict mortality and facilitate ACP conversations, their use has been neglected in clinical practice (Heckman et al., 2021). The current study found that many LTC nurses were not aware of the CHESS score, collected quarterly for every resident, or its clinical use (Heckman et al., 2021). Mortality-risk communication tools report personalized mortality risk and survival and include the Risk

Evaluation for Support: Predictions for Elder-Life in the Community Tool (RESPECT) (Hsu et al., 2021) and the ‘double surprise question’ (Veldhoven et al., 2019). These tools were found to predict older adult’s mortality risk as well as life expectancy to inform providers of ‘possible dying’ (Bern-Klug, 2006) and guide the initiation of ACP and EOL care.

There is a lack of consensus in the literature regarding the influence of the PGT’s engagement in ACP for LTC residents. Nurses who participated in this study found that it was difficult to establish realistic ACP levels and have timely ACP conversations with residents under the PGT. Until such conversations occurred, the residents remained ACP-R and experienced many unnecessary hospital transfers. In these situations, only residents who were actively dying had their ACP levels downgraded. Findings from the current study were consistent with other studies from the US (Cohen et al., 2015; Sager et al., 2019) and Canada (Chamberlain et al., 2020), in which unbefriended adults under the PGT experienced delays in the transition to EOL care and received medically unnecessary care. Chamberlain et al. (2020) completed a qualitative cross-sectional descriptive study with 39 LTC staff and three PGTs at seven different LTC facilities in Alberta, Canada. The study revealed significant issues with unbefriended residents’ GOC, EOL care, and quality of life. The authors reported there were two different groups of unbefriended LTC residents: (a) those with no living conjugate partner or children; and (b) those with histories of substance use, homelessness, and estrangement from their family. Unbefriended residents were found to have more aggressive GOC than residents who had a family or friends. In addition, PGTs were more likely than family members to request that residents be transferred to hospital (Chamberlain et al., 2020). The study participants indicated that unbefriended residents were more likely to receive aggressive interventions, such as resuscitative measures and hospital transfers, while residents with families/friends more often received comfort-focused and palliative care interventions. As in the current study, Chamberlain and colleagues' study (2020) noted that the PGTs' tendency to choose more aggressive interventions stemmed from their limited contact with the residents and their lack of knowledge about the residents' values and wishes.

In contrast, a retrospective cohort study by Cohen et al. (2021) did not find statistically significant differences in the provision of high-intensity treatments among NH residents with moderately severe or severe dementia, regardless of the type of guardianship. Cardiopulmonary resuscitation, mechanical ventilation, and intensive care admissions were more common among NH residents with professional guardians, while feeding tube placement, terminal hospital transfers, and hospital deaths were more common among residents without professional guardians (Cohen at al., 2021). In the current study, residents under PGT were often designated as ACP-R, so they were more likely than other residents to receive aggressive interventions like CPR, admission to ICU, and hospital transfer.

In Canada, PGTs are employees of the provincial offices of PGT. Conversely, American PGTs are a mix of private and for-profit agents who can be employed by agencies, volunteer organizations, and law firms (Chamberlain et al., 2020). There is no standard framework for decision making at EOL for unbefriended individuals in Canada or the US (Cohen et al., 2015). In addition, there are conflicting opinions and guidelines regarding the treatment of unbefriended individuals (Sequeira & Lewis, 2017). As identified in the current study, the lack of a standardized approach to ACP engagement, along with the lack of guidelines for ACP decision making for residents under PGT, were significant barriers for nurses to orchestrate residents' comfort.

In the current study, facilitators at the resident level that assisted with the downgrading of ACP levels and enhancing comfort included: declining health status, the presence of a HCD, and involvement of the resident in ACP discussions. Nurses in this study identified that the existence of a living will, or HCD, made the downgrading process easier and helped families choose less aggressive care options. This finding is consistent with the results of two systematic reviews (Brinkman-Stoppelenburg et al., 2014; Gilissen et al., 2017) that examined the barriers and facilitators of ACP, and noted that the presence of a living will/HCD led to increased use of comfort care measures and decreased rates of hospital deaths among NH residents. Similarly, an evidence-based article published in 2022 stated that written advance directives were associated with increased enrollment in hospice/palliative care and increased use of comfort care (Amkraut et al.).

In the current study, nurses reported that the involvement of residents in ACP discussions improved ACP engagement; however, impaired decision making capacities precluded the involvement of many residents with dementia. Similarly, Stewart et al.'s (2011) qualitative explanatory study reported that NH staff and families identified residents' lack of cognitive capacity as a barrier to ACP. These findings were consistent with those of other studies that examined the barriers and facilitators of ACP in residents living with dementia (Ali et al., 2021; Phenwan et al., 2020; Tilburgs et al., 2018).

The gradual decline in residents' mental capacity often delayed ACP conversations to the point where individuals living with dementia no longer had the capacity to express their wishes (Ali et al., 2021; Phenwan et al., 2020; Tilburgs et al., 2018). Thus, healthcare providers needed to initiate ACP conversations with residents and their families in the early stages of dementia (Phenwan et al., 2020; Tilburgs et al., 2018). Consistent with the findings of the current study, one of the pre-conditions highlighted in Gilsissen et al.'s (2017) systematic review of successful ACP in NHs was that residents needed to have the cognitive capacity to engage in ACP. If ACP was initiated when the patient was well, it eased EOL decision making and provided guidance to substitute decision makers and healthcare providers in future moments of crisis (Gilissen et al., 2017; Phenwan et al., 2020; Tilburgs et al., 2018).

Declining health or changes in the resident's clinical status were reported as facilitators for downgrading the ACP level. This finding is consistent with a narrative review (Phenwan et. al., 2002) and systematic review (Lord et al., 2015) about the barriers and facilitators of ACP in people living with dementia. A qualitative study conducted by Black et al. (2009) reported that failing health and progressive declining health served as catalysts for surrogates to execute ACP for patients with dementia. Consistent with the findings of the current study, Black et al. (2009) indicated that familiarity with the resident and strong assessment skills were prerequisites for nurses to detect subtle changes in the residents. A critical ethnography study by Laging et al. (2018) identified the value of timely recognition and assessment of a resident's deterioration by NH staff. Their findings reinforced the need for a more clearly defined philosophy of care to ensure that nursing assessments are relevant and focused on the residents' best outcomes. Laging et al. (2018) also reported on the importance of collaborative decision making and building clinically strong nurses by elevating their assessment skills, supporting their authority to make decisions, and giving them the freedom to act in accordance with their professional knowledge.

Barriers identified at the family level in the current study were consistent with those reported in the ACP literature, and included: family member's lack of knowledge regarding dementia, comfort care, palliative care, and ACP (Ashton et al., 2016; Gilissen et al., 2017; Stewart et al., 2011); family dynamics such as disagreement among family members (Ke et al., 2015; Sharp et al., 2013; Stewart et al., 2011); guilt among family members over the appropriate ACP level (Dening et al., 2011; Gilissen et al., 2017; Kastbom et al., 2020); denial of the resident's diagnosis (Gilisen et al., 2017); avoiding ACP conversations (Lovel & Yates., 2014; Seymour et al., 2010); family members holding onto the resident (Baughman et al., 2012; Gutierrez et al., 2012; Jeong et al., 2010; Ke et al., 2015; Thompson et al., 2003); and family members overriding the resident's wishes (Erel et al., 2017; Jeong et al., 2010; Ke et al., 2015). Other barriers identified in the current study, including families' lack of awareness of LTC as last resort, family members with a healthcare background, the arrival of long-lost family members, and families who put their own interests first, were not mentioned in the LTC ACP literature.

Nurses in the current study reported that families often lacked the awareness that LTC was the last place of residence for their loved ones. The nurses reported that resident navigators played a crucial role in following and supporting the resident and family during their transition from the community to LTC. Resident navigators were able to work in conjunction with the health system to ease some of the burdens of this transition. Similarly, Alden (2003) envisioned that home care nurses would be the ideal resident navigators, since they had direct contact with the patient and were often the first ones to recognize when patients were ready to transition to NHs for more intensive care. Home care nurses established personal contact with patients and family members that increased their awareness of family dynamics, and allowed them to be a valuable resource for decision making during the transition to LTC. Alden (2003) claimed that home care nurses could help support and ease the transition process and that it was unnecessary to involve any "outside" experts.

Nurses in the current study reported that, in general, families had difficulty engaging in timely ACP conversations when residents were admitted directly from the community or hospital, rather than from another NH. Nurses appreciated that the residents' admission to LTC impacted the families' emotional readiness to engage in ACP discussions. Nurses described that families were often in denial of the fact that their loved one could no longer live with them and/or could not return to their previous living environment and, therefore, were not prepared to discuss ACP during admission to LTC. This transition period has been described in the literature as a time filled with pressure, limited choices, and lack of control (Merla et al., 2018). A scoping review reported that the families of residents admitted to a NH directly from the hospital felt "rushed by the system," pushed along a track set out by formal caregivers and health professionals, and "forced to jump hoops" (Merla et al., 2018, p. 6). It has also been noted that rates of ACP completion among frail older adults in acute care hospitals are very low (0.5 to 5.4%) (Hopkins et al., 2020), and that families may have limited exposure to ACP. It was encouraging that the nurses in this study were cognizant of the resident's prior place of residence and families' emotional readiness when engaging in ACP discussions.

In this study, family members with a background in healthcare were seen as barriers to ACP engagement. This finding had not been previously identified in the ACP literature. Nurses reported that family members who were healthcare providers themselves tended not to listen to the nurses' recommendations and, instead, had an attitude that they knew everything about the resident and ACP process. The nurses reported that these types of family members tended to choose aggressive interventions and attribute less importance to the resident's quality of life. Past research has noted that caring for a critically ill patient with a physician-/nurse-family member presented challenges for the healthcare team (Arnold, 2019; Giles & Hall, 2014). It was recognized that these types of family members suffered from intense and complex emotions in relationship to their loved one's illness, and were likely to want more control and information than other family members (Arnold, 2019). Salmond (2011) conducted a qualitative study to explore the experience of being a nurse-family member of a relative hospitalized with a critical illness. The findings indicated that the nurse-family member's knowledge base forced them into an ongoing role of guarding and protecting their loved one. A qualitative systematic review examined how healthcare providers can support family-centered care in the presence of healthcare provider-family members (Giles & Hall, 2014). The researchers recommended that healthcare providers make a conscious effort to recognize the unique needs of healthcare provider-family members by acknowledging their specialized knowledge, empathizing with their emotional experiences, and partnering with them in patient advocacy (Giles & Hall, 2014). In the current study, nurses provided extra care and support to these families by directing their communication toward them and working in partnership with them to promote the residents' best interests.

The arrival of a long-lost family member was not identified in the available literature as a barrier that could hinder EOL care. In this study, the involvement of an out-of-town family member was a significant barrier to downgrading a resident's ACP level. This finding resembled what Molloy and colleagues (1991) characterized as '*the daughter from California syndrome,'* which could also be referred to as '*the daughter from Ontario syndrome*' or '*the daughter from New York syndrome,'* depending on the family's location (Molloy et al., 1991). According to Molloy et al. (1991), this syndrome was characterized by the out-of-town daughter directing her acute denial, anger, and resentment at her mother's healthcare providers while refusing to come to terms with her mother's condition, demanding inappropriate aggressive care, and impeding the management of her care (Molloy et al., 1991). The out-of-town daughter (or other family member) disrupted plans that had been developed after considerable discussion and effort with the resident's POA. The daughter may have hoped that her mother would recover enough to "make her peace" (Molloy et al., 1991, p. 397). In the current study, nurses resolved the issues associated with re-entry of a long-lost family member by directing them to the resident's POA. The nurses in this study were better able to navigate challenging situations and communicate with families when they developed a relationship with the family's spokesperson and gained awareness of the family's dynamics.

Nurses who participated in this study reported that family members would sometimes act according to their own interests, rather than the best interests of the resident, when making decisions about ACP levels. This finding was not directly mentioned in the available LTC ACP literature. Family members who acted according to their own best interests caused distress for both the residents and the nurses. The nurses felt trapped because they needed to act according to the residents' best interests but also wanted to honour the family's wishes. A mixed methods study investigated the EOL decision making process of community-dwelling older adult partners (Batteux, et al., 2020). The results showed that surrogate decision makers who had egocentric perspectives preserved their own interests by pushing for life-saving treatments for their loved ones, even when these decisions would diminish quality of life. In the current study, family members who took an egocentric perspective were characterized as the *'complex ones.'*

In the current study, families who had a different conception of the resident's big picture than the nurses often preferred non-beneficial hospital transfers, refused to acknowledge that their loved one was approaching EOL, and were not open to having ACP conversations. This resulted in conflict between the nurses and families, as nurses felt that family members were prioritizing their own interests over those of the resident. A similar finding was noted in a systematic review that examined the experiences and involvement of family members in transfers from the NH to hospital (Pulst et al., 2019). The review identified that family members' attitudes toward hospital transfers were dependent upon their individual positive and negative experiences of NHs and hospital care (Pulst et al., 2019). If the family was satisfied with NH care and trusted the NH staff, they assumed the NH was a more suitable environment for their loved one than the hospital. Family members who were unsatisfied with NH care perceived that physicians were unavailable and that the facility was understaffed, or staffed with providers who lacked adequate qualifications, and tended to prefer hospital transfers (Pulst et al., 2019).

The nurses in the current study believed that families did not act in the residents' best interests when they disagreed with the nurses' recommendations for hospital transfer during acute events, such as fractures, in order to optimize residents' comfort. In LTC, hospital transfers were commonly related to pressure from the family (Pulst et al., 20190. Interestingly, the findings of this study showed that families resisted hospital transfers for acute events, particularly when the resident was ACP-C. The divergent perspectives of nurses and family members regarding GOC in acute events made it challenging for nurses to upgrade residents to ACP-M for hospital transfers. In this study, families who lacked an understanding of the implications of fractures, especially regarding the pain from hip fractures, thought that ACP-C meant the resident would be kept at the LTC facility. These findings were supported by those of a systematic review of qualitative studies in which families objected to hospital transfers if they viewed the residents' condition as non-life-threatening or did not clearly understand the severity of the residents' symptoms (Pulst et al., 2017). When families did not understand the impact of acute events on residents' comfort, nurses worked to build consensus about the hospital transfer with the family. In these cases, the nurses tried to educate families about the negative impacts of acute events on their loved ones' comfort as well as the implications of an ACP-C designation during hospital transfers. These actions facilitated the upgrading of ACP-C to ACP-M for hospital transfers.

The results of this study demonstrated different levels of ACP engagement between younger and older generations within the same culture; however, these findings were not directly reported in the available LTC literature. A study by Lee et al. (2017) noted a generational gap in attitudes about ACP among older and younger Chinese Americans. Findings from the current study echoed those of Lee et al. (2017) in that it was easier to discuss ACP with younger generations because ACP conversations were more acceptable to them. In contrast, older generations needed more information about ACP and required that the information be repeated several times. This generational gap may be due to the acculturation of younger generations to American mainstream culture, which has resulted in fewer cultural beliefs about death and dying, better English-language communication skills, and greater knowledge about ACP (Lee et.al., 2017).

In the current study, ACP discussions were found to be easier with families who had lived in Canada for generations when compared to those who had immigrated more recently. This difference was thought to be due to the possibility that Canadians who had more exposure to the ideas of ACP and LTC over generations may have accepted the ideas more readily. A similar finding emerged from a cross-sectional survey that examined the role of immigrant status on ACP engagement among older Chinese Americans (Pei et al., 2021). It was noted that US-born Chinese Americans were more likely to engage in ACP than those who were foreign-born (Pei et al., 2021). This difference may be explained by the fact that foreign-born Chinese Americans have less proficient English-language skills, lower levels of acculturation, and less knowledge about ACP and the healthcare system than their US-born counterparts (Pei et al., 2021). Similarly, a descriptive cross-sectional survey of Iranian-American older adults found that those who had greater levels of American acculturation also had more favorable attitudes toward EOL and ACP (Rahemi, 2019).

The facilitating factors identified at the family level in this study that were supported by the scholarly ACP literature included: the letting go family (Jenog et al., 2011; Ke et al., 2017) and family's level of knowledge about ACP (Ashton et al., 2016; Gilissen et al., 2017; Stewart et al., 2011). No specific ACP literature examined the effects of family's visitation frequency on their engagement in ACP discussions. The nurses from this study claimed that frequent visitation helped families see the resident's big picture more clearly and led to more frequent, open communication with the nurses. This finding was supported by a family satisfaction survey from NHs in the US (Roberts & Ishler, 2018), which showed that families who visited more frequently and engaged in more communication with facility staff had higher perceptions of their loved ones' quality of life. Family visitation has also been shown to improve person-centered care (Boise & White, 2004) and help staff gain a better understanding of the resident (Bern-Klug & Forbes, 2008). As a result, it is possible that family visitation facilitated the downgrading of ACP levels in the current study because of the real-time exchanges of residents' information between families and nurses, which gave families the opportunity to see the resident's big picture on an ongoing basis.

Healthcare Provider Level. The barriers identified at the healthcare provider level in the current study that were supported by the ACP literature included nurses' lack of knowledge about the resident/family; discomfort with death and dying (Ke et al., 2017; Rietze & Stajduhar, 2015; Rietze et al., 2018; Stone et al., 2013); ACP knowledge deficit (Ampe et al., 2017; Gilison et al., 2017; Ke et al., 2015); lack of education about ACP (Gilissen et al., 2017; Ke et al., 2015); reluctance to initiate ACP discussions with family (Gutierrez et al., 2012; Ke et al., 2015; Robinson et al., 2013; Stewart et al., 2011); and cultural background (Baughman et al., 2012; Ke et al., 2015) as well as physicians' lack of interest in ACP discussions, lack of relationships with family, and lack of availability (Banerjee et al., 2018; Kastbom et al., 2020; Sheild et al., 2005; Wetle et al., 2005). On-call physicians' lack of knowledge about the residents was also identified as a barrier to ACP in this study as well as in the literature (Giger et al., 2020; Heckman et al., 2021). Barriers identified in the current study that have limited supporting evidence in the LTC ACP literature included: new/causal nurses, internationally educated nurses, English as an additional language, lack of standardized practices regarding the provision of comfort care for LTC residents by physicians, and limited knowledge about LTC among paramedics and hospital staff.

There was limited LTC literature that reported on new/casual nurses' experiences of death and dying or that suggested they were unable to communicate effectively with families regarding ACP/EOL, answer specific questions about the dying process, or cope with overwhelming family dynamics (Croxon et el., 2018; Deravin-Malone et al., 2016). Deravin-Malone et al.'s (2016) literature review found that nursing students who had inadequate exposure to death and dying during their training felt ill-equipped to deal with EOL care in their nursing practice. A qualitative study (Croxon et al., 2018) examined the experiences of newly graduated nurses working in hospital and community settings and found that the graduates lacked a sense of readiness to communicate with patients/family members about EOL. Nurses have also expressed that, while the university curriculum prepared them to provide physical care to palliative patients, there was insufficient education in the curriculum regarding communication in palliative care (Croxon et al., 2018).

Participants from the current study indicated that casual nurses struggled to initiate the downgrading process due to unfamiliarity with the residents. According to the literature, casual nurses have less opportunities to build rapport and familiarity with patients and other team members (Batch et al., 2009) when compared to full/part-time nurses. This lack of familiarity has been associated with direct adverse effects on the quality of patient care, including increased patient dissatisfaction, higher incidences of falls, and higher rates of pressure ulceration (Batch et al., 2009). A critical ethnographic study identified that casual nurses lacked continuity, connection, and familiarity in the workplace, meaning that they could not engage in teamwork and communication as effectively as their full-time counterparts (Batch & Windsor, 2015).

Internationally educated nurses experienced language challenges and an incongruence between their current professional expectations and the professional norms of their home country. These challenges significantly affected IENs’ engagement in and ability to conduct ACP conversations. In this study, both foreign- and Canadian-born nurses unequivocally believed that foreign nurses struggled to find the appropriate words for conducting ACP discussions. The nurses believed that communication between families and nurses was essential to effective ACP in LTC. They noted that language challenges arose when the nurse and family did not share the same native language. According to Hearnden (2007), the nursing profession in English-speaking countries has developed a complex practice culture and language system, consisting of phraseology, medical terminology, acronyms, and abbreviations, which may be unclear to those who were not educated in the local community or country.

In this study, IENs believed that families were more easily persuaded to choose comfort care when Canadian-trained nurses conducted the ACP conversations. According to Holmes and Major (2003), the socio-pragmatic or interactional aspects of professional conversations require a different set of communication skills. The majority of nurses' conversations (approximately 60%) involve informal, non-medical communication, which includes the use of "strategically positioned small talk and amusing anecdotes … balanced skillfully alongside medical talk to establish rapport and help patients feel comfortable in the medical environment and with medical procedures" (Holmes & Major, 2003, p. 5). Since different words are used in other languages to describe specific conditions, direct translation does not always communicate exact meanings. In general, IENs tended to have inadequate vocabulary to understand the names of equipment and specific patient conditions, the local idioms and slang, and other culturally-specific words (Hearnden, 2007). In order to develop language-proficiency, IENs needed to learn the socio-pragmatic conventions of the nursing profession in the local employment context (Hearnden, 2007; Holmes & Major, 2003). Eyre (2010) noted that "native" speakers were able to draw on their innate or intuitive knowledge of socio-pragmatic conventions and adjust their speech to suit a specific purpose or context by making it more linguistically complex. Internationally educated nurses may be lacking in some pragmatic skills, which may lead employers to "feel that workers seem unfriendly or uncomfortable at work and that they do not fit in smoothly" (Eyre, 2010, p. 14).

A literature review reported that language barriers can negatively impact patient satisfaction and the delivery of healthcare services (Al Shamsi et al., 2020). In addition, a qualitative study from Saudi-Arabia reported that Arabic-speaking patients had difficulty understanding non-Arabic-speaking nurses' instructions (Al-Khathami et al., 2010). The patients felt that nurses did not understand their concerns most of the time and questioned the reliability of nurses' information. More than half of the patients (n=116) in the study believed that non-Arabic-speaking nurses were more susceptible to making errors, while two-thirds of the patients felt uncomfortable dealing with a nurse who could not speak their native language (Al-Khathami et al., 2010). This finding is consistent with the findings from the current study, whereby the nurses noticed that English-speaking families were more comfortable choosing ACP-C for their loved ones when ACP discussions were conducted by nurses who spoke English as a first language.

The IEN interviewed in the current study expressed having difficulty persuading families to choose a realistic ACP level. It has been argued that, in order to develop language competency, individuals must have a proficient grasp of the rules of English but also develop pragmatic communication skills (Bachman, 1990, as cited in Lum et al., 2016). Lum et al. (2016) has advocated for the integration of the Bachman English learning model into bridge programs for IENs to increase their pragmatic language competency. Pragmatic competency is concerned with how language is used to achieve a particular goal, such as explaining, persuading, or requesting within particular contexts. Therefore, higher pragmatic competency among IENs could enable them to effectively engage in ACP conversations in LTC.

Bridging programs have been established for IENs to address the various barriers to their recertification in Canada (Canadian Association of Schools of Nursing [CASN], 2012). In 2012, there were approximately 35 bridging programs in Canada, but only some of them included clinical placements (CASN, 2012). The existing literature offers various recommendations for the content of bridging programs, including curricula that orient IENs to the Canadian healthcare system (Baumann et al.,2006); assess language skills and provide appropriate instruction; and address theory and practice gaps specific to the Canadian context, such as LTC and psychiatry (McGuire & Murphy, 2005).

Lum et al. (2016) examined the conflicting professional norms between Canada and other countries and the struggles faced by IENs who had to reconcile these differing norms. The norms of the healthcare system in IENs' home countries required that a nurse behave one way, while the Canadian healthcare system often expected something different. For example, the norm of professional nursing care within Canadian LTC settings is to emphasize the importance of ACP and honour residents' wishes; this norm posed a major challenge for IENs. According to IENs in the current study, the concepts of ACP and LTC did not exist in their home countries. For instance, IENs from India reported that the concept of DNR and orders for DNR did not exist because the Indian norm was that everyone should be resuscitated. Since Indian law does not recognize advance directives of any type, advance directives are virtually non-existent in that country (Blank, 2011). In another example of differing healthcare norms, the Canadian healthcare system places a high degree of value on the therapeutic relationship for effective nursing communication, whereas other countries (e.g., India) place less value on therapeutic communication (Lum et al., 2016).

As reported by IENs in the current study, the norms they encountered in the Canadian healthcare system were incompatible with their prior experiences. They found it difficult to accept the differing practice expectations and expressed confusion about how to address these challenges (Lum et al., 2016). O'Neill (201l) argued that IENs have to negotiate between three or four different worlds: the world of "learning the rules of the English language"; the world of "learning the nursing specific terminology"; the world of "learning the discourse of the nursing profession and the culture of the Canadian health care system"; and the world of "learning the

Canadian language culture" (p. 1127). Moreover, IENs in the current study also had to negotiate the world of "learning the conversations of ACP." Due to the limited ACP education provided by the LTC facilities included in this study, IENs independently sought out ACP learning opportunities and taught themselves how to complete ACP. Surprisingly, none of the nurses from this study had completed any formal ACP education or been offered any education by their current employer. Many of the nurses expressed the desire to have mandatory annual ACP education. The nurses in this study reported that the gap in ACP education left them feeling unprepared to navigate ACP conversations.

Study participants readily identified approaches to help support their competence and proficiency in ACP, including mandatory online ACP education on LMS; ACP mentors for new nurses; ACP drills; ACP case studies with role playing; ACP competency assessments; and integration of ACP education in the curricula of nursing programs and bridging programs for IENs. The merit of these approaches has been supported in the literature (Billings et al., 2010; Chan et al., 2018; Coogan et al., 2022). The Letter Project Pilot (LPP) is a scalable, cost effective, multidisciplinary faculty mentorship program developed by Coogan et al. (2022). The LPP was found to increase medical and NP students' abilities and confidence in leading ACP conversations. The LPP was a faculty-supervised ACP orientation, which included an overview of ACP and a conversational role play, followed by weekly faculty-supervised inpatient ACP discussions with the students (Coogan et al., 2022). Other research has shown that clinical and mentored experiences were most impactful in preparing students to lead ACP discussions (Billings et al., 2010). Chan et al. (2018) conducted a systematic review of the effects of training programs for ACP facilitators. Their research validated that ACP education and training for healthcare professionals had positive effects on participants' knowledge, attitude, skills, and comfort in discussing issues related to EOL decision making.

Even though the culture of the healthcare provider was mentioned in the existing literature as a hindrance to ACP engagement, the struggle of Asian-born nurses to conduct ACP was not clearly reported in the LTC literature. In this study, Asian-born nurses had difficulty identifying appropriate ACP levels for older residents because of their high level of cultural respect for elders. Asian culture has been widely described as collectivist-oriented, where members of these communities tend to be more focused on the feelings and thoughts of others (Lui et al., 2019). People from Asian cultures seek to maintain intergroup harmony within families and the broader society (Lui et al., 2019). For many Asian people, filial piety significantly impacts their attitudes, decisions, and preferences regarding EOL care. The concept of filial piety is generally understood to be a cultural obligation of family members to care for and respect one another (Chew, 2012). In this study, nurses from Asian cultures believed it was their personal duty to save older residents by staving off death. As a result, these nurses felt that recommending comfort care and attempting to persuade family members not to pursue life-prolonging treatment were in direct violation of filial piety (Bowman & Singer, 2001; Lou et al., 2021).

Physicians' limited relationships with families and lack of availability at the bedside has been mentioned previously in the literature. More specifically, concerns about physicians' infrequent presence in NHs and family members' frustrations regarding the lack of communication with physicians were noted in the empirical literature almost two decades ago (Sheild et al., 2005; Wetle et al., 2005). Similar findings surfaced in this study as well as from several other recent studies (Banerjee et al., 2018; Kastbom et al., 2020). The nurses in this study reported that physicians were not key players in ACP discussions and were unknown to many residents/families due to their limited presence at NHs. An exploratory study of physicians from Canada and the US noted that physicians' familiarity with residents and their families was essential for quality of care, but found that physicians infrequently engaged with family members (Banerjee et al., 2018). Nurses from the current study reported that physicians rarely participated in care conferences. The nurses arranged family meetings with physicians when they had difficulty persuading family members to accept ACP-C for their loved ones. These meetings were usually scheduled during the physicians' weekly rounds at the NH. Similarly, this lack of physician involvement was captured in a study that compared the provision of medical care in NHs across Canada, Germany, Norway, and the US (Agotnes et al., 2019). In that study, a medical director from Manitoba reported that LTC physicians generally did not participate in care conferences, but that family members could arrange to meet with physicians on-site while conducting their rounds (Agotnes et al., 2019). Families' dissatisfaction and limited contact with physicians were captured in the LTC literature as "missing in action" (Shield et al., 2005, p. 1652) and "the missing doctor" (Fosse et al., 2014, p. 8).

The current study generated findings about physicians' ACP practices that were similar to the findings of other studies (Kaasalainen et al., 2017; Keijzer-Van Laarhoven et al., 2020). Physician factors, such as taking the path of least resistance and communication style, were identified as barriers to ACP in this study but were not mentioned in the LTC literature. In this study, nurses reported that physicians tended to 'take the easy path' and send residents to the hospital, rather than downgrading their ACP level, when families pressured or challenged them to implement more aggressive, non-beneficial interventions. This finding reinforced the notion that LTC physicians could play an important role in EOL care if they were committed to keeping residents at the LTC facility for EOL care and actively avoiding terminal hospital transfers (Kaasalainen et al., 2017). Studies have demonstrated correlations between increased physician involvement in DNR discussions in NHs, a reduction in EOL hospitalizations and emergency room visits, and greater physician attention to residents' needs (Lamb et al., 2011; Young et al., 2010). A recent meta-analysis of systematic reviews and primary studies (Keijzer-Van Laarhoven et al., 2020) reported that physicians refused to engage in ACP when they had fears of blame, litigation, and/or conflict with family members.

In this study, physicians' style of communication with families was not effective in facilitating the downgrading of ACP levels because they provided insufficient information about the residents' conditions, used clinically-focused and formal language, and displayed little compassion/empathy. The importance of physicians' communication style has been previously noted in the literature. The optimal physician communication style for ACP discussions would be rooted in kindness, politeness, and openness (Abdual-Razzak et al., 2014; Vanderhaeghen et al., 2019). Vanderhaeghen et al.'s (2019) qualitative study emphasized that productive ACP discussions occurred when patients/family members saw the physician as a trustworthy partner, who was loyal to their personal wishes about treatment and medical care, and who shared information in a steady, sincere, emotionally supportive, and understanding manner. Moreover, Abdual-Razzak et al. (2014) identified that patients had two major preferences regarding physicians' behaviours during EOL communication: 'knowing me' and 'conditional candour.' Patients wanted physicians to be familiar with them and their family. Patients also expressed their desire to receive candid, sensitive communication from physicians about their health status as well as the expected trajectory of their illness and prognosis; patients wanted this information titrated according to their own level of readiness (Abdual-Razzak et al., 2014).

The current study identified a lack of standardized practices among physicians for the provision of comfort care in LTC residents. In addition, the study participants noted that paramedics and hospital staff had limited knowledge about LTC settings and residents' needs. These issues presented a variety of challenges for LTC nurses who wanted to optimize residents' comfort during acute events. In this study, it was noted that older physicians generally interpreted ACP-C as being synonymous with EOL care. These physicians were reluctant to treat residents' acute issues, such as urinary tract infection, but would provide comprehensive EOL orders for the management of symptoms like dyspnea or pain. Haapasalmi et al. (2021) also reported that the more senior the physician the more likely they were to offer palliative care and the less likely they were to provide active treatments to residents with dementia. Nurses in the current study believed that a universal understanding and practice among physicians regarding ACP-C would improve physicians' indifferent attitudes about simultaneously treating infection while providing comfort care.

Nurses in the current study experienced disrespectful pushback and questioning from paramedics during acute events, specifically with regard to transferring residents who were ACP-C to the hospital. The nurses reported these interactions were reflective of the paramedics' poor understanding of residents' needs and the function of LTC. A study by Pulst (2019) reported that paramedics often believed that nursing staff were unable to handle residents' changing status due to staffing shortages, increased workloads, and lack of physician presence in LTC facilities. Paramedics viewed transfers of NH residents to the hospital as unwanted and inappropriate. At the time of this study, there was no clear consensus or universal definition regarding 'unwanted transfers' among NH residents in the Canadian healthcare system (Lemoyne et al., 2019).

Ideologies held by paramedics were understood to be absolute and produced “premature cognitive commitments” (Langer, 1989, as cited in McCloskey, 2010, p. 56). Premature cognitive commitments were problematic for improving residents’ comfort during hospital transfers for acute illness, as paramedics became committed to these ideologies without engaging in critical thinking. Paramedics opposed residents’ hospital transfers without considering the ‘big picture’ or the context of LTC. Premature cognitive commitments caused conflict between LTC nurses and paramedics who had differing interpretations of the severity and acuity of residents’ physical problems and best interests. As a result, paramedics and nurses were unable to share or respect each other’s perspectives, which caused conflict and mindlessness and, ultimately, negatively impacted the residents’ level of comfort.

All of the ACP facilitators identified at the healthcare provider level in this study were supported by the ACP literature, and included: nurse knowledge (Gilissen et al., 2017; Ke et al., 2017); seasoned/experienced nurse (Ampe et al., 2017; Rietze & Stajduhar, 2015); personal comfort with death and dying (Lenherr et al., 2012; Moore, 2005); making ACP a priority (Gilissen et al., 2017); and building relationships and effectively communicating with families (Gilissen et al., 2017; Ke et al., 2017).

Institutional/Organizational Level. Barriers at the institutional/organizational level that were identified in this study and also mentioned in the ACP literature included: insufficient physician presence (Kastborn et al., 2020; Sheild et al., 2005; Wetle et al., 2005); lack of time (Ampe et al., 2017; Gilissen et al., 2017; Giger et al., 2020; McGlade et al., 2017); the team not being on the same page (Ampe et al., 2017; Black, 2006; Beck et al., 2017; Ke et al., 2017); and impoverished space (Hagen et al., 2015; Peck et al., 2018). Barriers to ACP engagement that were not identified in the ACP literature were: the inhibiting nature of the ACP forms provided by WRHA, faith-based LTC facilities, ageism, and the devaluing of the LTC sector. Although the ACP literature mentioned ill-defined ACP policies, unclear ACP documentation requirements (Beck et al., 2017; Flo et al., 2016; Gilisen et al., 2017) and unfriendly ACP programs (Wickson-Griffiths et al., 2014), no research specifically examined the limitations of ACP forms as a barrier to the ACP process. The ACP form used by the WRHA at the time of this study was described by nurses as being 'whishy-washy,' 'false advertising,' and 'unclear.' Nurses in this study believed that having a specific set of treatment interventions on the ACP form would make it easier to facilitate individualized ACP levels, which would most closely honour residents' EOL wishes. Nurses noted that the existing ACP form did not address clinical situations and treatments beyond cardiac arrest and cardiopulmonary resuscitation. In addition, the binary choices regarding hospital transfers were insufficient; for residents who wished to receive comfort care without transfers for burdensome interventions, the form provided no flexibility for transfers that might be necessary to maintain comfort (e.g., in the event of fracture repair, for reinsertion of urinary catheters, etc.). In addition, antibiotic treatment for uncomfortable infections was not readily available for those who chose ACP-C, and there was no space on the form to add such requests.

The three ACP levels on the WRHA form were vague and did not translate into specific medical treatments and interventions, like those offered by the POLST (The POLST California, 2016) or MOST (Fraser Health Service, 2012), and did not help nurses persuade residents/families to choose comfort care. While the WRHA's ACP-GOC form was useful for documenting residents' resuscitation preferences, it was not helpful for specifying other desired interventions, such as artificial nutrition and hydration, antibiotic treatments, and hospital transfers for comfort measures. In contrast, research has indicated that the POLST (Hickman et al., 2011) and MOST (Lum, et al., 2017) forms capture specific therapeutic approaches and increase concordance between residents/families' preferences and the actual care received.

Hill et al. (2019) indicated there is a lack of LTC-specific documents to guide palliative care in Manitoba. The researchers urged the province to develop LTC-specific guidelines that would aid healthcare providers in delivering high quality EOL care in these settings (Hill et al., 2019). The nurses in this study identified inefficiencies in the WRHA ACP form and advocated for its re-evaluation to facilitate comfort care, especially among frail, older LTC residents. Interestingly, nurses from this study pushed for a medically-specific ACP form rather than a goal-based form, while Sussman et al. (2020) encouraged the use of an ACP form with psychosocial content rather than one with a strictly medical focus. In contract to the current study, Sussman et al. (2020) believed that an ACP form with psychosocial content would be more acceptable and useful in improving ACP engagement and uptake in LTC.

Moreover, the nurses believed the option for ACP-R on the WRHA's form was 'false advertising' because most LTC facilities were equipped with a policy that precluded nurses from offering on-site CPR. One of the NHs from which participants were recruited in this study had a policy of refusing to admit residents if they chose ACP-R. Facilities where nurses could not offer on-site CPR were required to alert emergency medical services by calling 911 and waiting for them to start CPR upon arrival. A retrospective study by Shibahashi et al. (2021) reported that survival outcomes of CPR in NHs are mainly dependent on the timing of the emergency call, whether the event was witnessed, and the bystander's ability to provide CPR. A delay in initiating CPR compromised survival outcomes of NH residents who wished to be resuscitated (Shibahashi et al., 2021).

Institutional policies that prohibited or delayed the initiation of on-site CPR caused an ethical dilemma for nurses in this study. Ethical dilemmas often arise in clinical practice when there is a real or perceived conflict between two ethical principles (Marco, 2005). The most common ethical principles in clinical practice are beneficence (doing good), non-maleficence (doing no harm), respect for patient autonomy, and justice (Marco, 2005). The ethical dilemma experienced by the nurses with regard to CPR policies arose from the conflict between respect for resident autonomy (honouring residents' wishes) and beneficence (preserving life). These institutional policies caused an ethical dilemma because they forced nurses to withhold care, failed to respect residents' autonomy, and dishonoured residents' wishes.

The WRHA's ACP-GOC form and institutional on-site CPR policies created challenges for resident autonomy and organizational paternalism. Moreover, studies have shown poor survival outcomes with CPR in NH residents who have advanced age, functional dependency, and comorbidities (Applebaum et al., 1990; Günther et al., 2020). In general, CPR survival rates among LTC residents are low, with estimates ranging from 1.5 to 2% (Pape et al., 2018). Furthermore, CPR necessitates mechanical ventilation in the hospital and may be associated with neurological impairment (Girotra et al., 2016) and traumatic injuries from chest compression (Kaldirim et al., 2016). Offering this type of futile intervention would violate the basic nursing ethics principle of 'non-maleficence,' because the CPR attempt is disproportionate to the residents' expected prognosis in terms of survival or quality of life and obliges nurses to provide futile care. It is evident that the WRHA ACP form in use at the time of this study did not address older adults' palliative care needs or the clinical and communication complexities of LTC settings.

The ACP literature reported an inverse association between ACP uptake and individual religiosity (Carr, 2012; Garrido et al., 2013). In addition, the literature has identified a direct association between ACP uptake and the desire to receive life-sustaining measures from primary care clinics (Assaf et al., 2021), dialysis clinics (Scherer et al., 2021), cancer care facilities (Balboni et al., 2007; True et al., 2005), and critical care settings (Romain & Sprung, 2014). The relationship between faith-based LTC facilities and ACP engagement has been seldom addressed in the literature. The nurses in this study reported that the religious affiliation of the facility deeply influenced the choice of medical interventions for the residents, especially when their health was declining. Families whose loved ones resided at faith-based facilities tended to choose life-prolonging aggressive interventions and were more reluctant to downgrade ACP levels when compared to those at non-faith-based facilities. Similar to individual religiosity, this study reported that faith-based facilities had a lower number of residents with ACP-C, likely due to the high value placed on life and life-sustaining measures that superseded any potential harm, when compared to non-faith-based facilities.

Ageism and the devaluing of the LTC sector were not referenced in the ACP literature as barriers to improving comfort for LTC residents. In the current study, negative stereotypes of older LTC residents prevailed in the healthcare system and formed the basis of every interaction between residents and acute care staff. Residents who were transferred back and forth between LTC and acute care often experienced evidence of discrimination, which stemmed from the stereotype that the residents were old and lived in LTC so were, therefore, dying and at EOL. Widespread systemic ageism was also noted in this study, whereby acute care staff and paramedics seemed to believe that LTC residents required a disproportionate amount of resources. The nurses reported that paramedics and acute care staff perceived that LTC residents were depleting limited acute care resources and using services that could have been directed toward younger/healthier patients. This finding is concerning, given Kilaru and Gee's (2020) assertion that years of systemic ageism and undervaluing of LTC in the Canadian healthcare system contributed to the needless deaths of thousands of LTC residents. Kilaru and Gee indicated that these deaths occurred as a result of healthcare providers denying LTC residents access to hospitalization, in order to preserve hospital and ICU beds for younger people.

Moreover, nurses in this study indicated that acute care staff perceived that residents' health issues were irreversible and that any acute care interventions would offer limited benefits only. Acute care staff protected resources and refrained from providing services to LTC residents, to prevent the filling of acute care beds by LTC residents. Systemic ageism also arose from the CIHI's (2009) creation of an 'alternate level of care' (ALC). The designation of ALC applied to patients who occupied a hospital bed and who could be cared for elsewhere (CIHI, 2009), yet remained in the hospital for one reason or another. It was shown that, on average, one ALC patient occupying a bed in the ED denied access to four other patients per hour (Canadian Association of Emergency Physicians, 2005). The practice of trying to identify patients as ALC has led acute care staff to the mindless construction of LTC residents as inappropriate and problematic to the hospital system. The current study found that such perceptions among acute care staff created challenges for LTC nurses who were trying to provide comfort care and seek out appropriate acute care interventions for residents experiencing painful acute events.

Several ACP facilitators were identified at the institutional/organization level in this study. The following facilitators were supported by the ACP literature: building clinically strong nurses (Batchelor et al., 2019; Gilissen et al., 2017; Heckman et al., 2021); availability of on-site NP and supportive management (Gilissen et al., 2017); provision of ACP education (Gilissen et al, 2017); having the team on the same page (Ampe et al., 2017; Beck et al., 2017; Black, 2006; Ke et al., 2017); integrating ACP discussions into routine practice (Batchelor et al., 2019; Gilissen et al., 2017); and introducing ACP prior to LTC admission (Heckman et al., 2021). Facilitators of ACP uptake that were not cited in previous LTC studies included designating ACP responsibility to the nursing profession and the availability of a 24/7 house medical officer (HMO). Nurses in this study reported that the HMO's timely assessment of the resident's status and their prompt communication with family members facilitated ACP. Interestingly, the presence of a 24/7 in-house internist in the ICU was associated with increased quality of overnight assessments and treatments, improved family commitment to ACP on admission, and streamlined transfers of ICU patients (Sisk et al., 2014). This finding lends some support for 24-hour physician presence in LTC settings.

In the current study, nurses believed that ACP discussions should be designated to the nursing profession so that nurses would be accountable for initiating and leading these discussions in LTC. They believed that this would increase the uptake of realistic ACP levels among residents. The nurses in this study did not have any ambiguity about their role in ACP because they believed they were the best professionals for this task in LTC. Nurses were the most well respected and trusted professionals in LTC and had the most constant contact with residents, families, and other healthcare members when compared to other professionals in the LTC setting. This perspective was supported in the literature. Bennett and colleagues (2021) reported that LTC nurses were a critical nexus for ACP conversations due to their unique professional role and the length and breadth of their relationships with residents and families. As noted in a scoping review, dedicated resources and a clearer differentiation of nurses' roles and responsibilities in the ACP process could place nurses in the ideal position to commence proactive and decisive ACP conversations with residents and families (Fliedner et al., 2021). Although the nurses in this study were clear about their role in ACP, the responsibility for completing ACP had not been designated to a particular profession in the WRHA at the time of this study.

The ACP literature remains ambiguous about which healthcare professionals should engage in ACP and in which settings (Izumi, 2017). This ambiguity in ACP roles has contributed to low uptake of ACP in various settings. Izumi (2017) postulated that physicians working in acute care settings typically believed that ACP was the responsibility of the primary care provider, while primary care providers often believed that ACP conversations were the responsibility of the specialist provider. In addition, some specialists thought that ACP was the responsibility of the primary care provider or other clinicians (Izumi, 2017).

The integration of ACP discussions into routine practice was identified as a facilitator of comfort care in this study, but was not referenced in the LTC ACP literature. In spite of this, the study's findings complemented existing literature from primary and chronic care. A cross-sectional research survey of 181 primary care providers from Alberta, Canada reported that integrating ACP conversations into routine practice, as had been done with cancer screening for preventive health, could increase ACP engagement in primary care (Howard et al., 2018). Similar findings were noted in an e-Delphi study, in which 81% of the participants provided consensus to incorporate ACP conversations into the routine care of chronic obstructive pulmonary disease (COPD) patients, because of the unpredictable nature of COPD and the associated difficulties in accurately predicting patients' disease trajectories (Kelleher et al., 2020). One of the pre-conditions for the successful implementation of ACP into LTC was to embed ACP in routine care (Gilissen et al., 2017). The integration of ACP into everyday practice and routine procedures was highly encouraged in NHs (Ampe et al., 2015; Sharp et al., 2013). Wendrich-Van Dael et al. (2021) developed the ACP+ intervention, a multicomponent ACP integration tool, to support the integration of ACP into routine NH practice in Flanders, Belgium.

In the current study, the ACP process and provision of comfort care measures were positively impacted by the availability of full-time NP and the NP's general approach to care. According to research by Liu et al. (2012) and Klaasen et al. (2009), NPs' styles of communication and relationship-building with families/residents ensured that families were kept informed of changes in the residents' status, enhanced the quality of EOL care, and increased families' satisfaction with NHs. Likewise, a Canadian study about the LTC setting highlighted NPs' caring relationships with residents/families, intimate knowledge of residents, and facilitation of families' EOL decision making through active listening and education (Ploeg et al., 2013). Similar to the findings of this study, Ploeg et al. (2013) reported that NPs were more accessible to residents/families when compared to physicians. In addition, NPs provided more timely communication with families and higher quality resident-/family-centered care when compared to their physician counterparts (Ploeg et al., 2013). The NPs' communication style of "laying everything out in a caring manner" was complemented by their mutuality of relationship, which allowed them to be "fully present and real with resident and family members" (Ploeg et al., 2013, p. 9). The notion of improved EOL care with the availability of an on-site NP observed in this study was endorsed by Mileski et al. (2020). Mileski et al.'s (2020) systematic review confirmed that NPs working in the LTC setting provided more timely responses to families, spent more time with residents, built stronger relationships with families, and conducted more comprehensive and timely assessments of residents than their physician counterparts. Furthermore, the review reported that NPs improved family satisfaction with care received and facilitated high quality ACP discussions with families (Mileski et al., 2020). These findings were congruent with those of the current study.

Nurses in the current study recommended that NPs be implemented into every NH. This recommendation was also encouraged by Mileski et al. (2020). Overall, NPs practicing in the LTC sector were portrayed more positively than physicians in the literature, and it was stated that “the best nursing homes use geriatrics NPs” (Shield et al., 2014, p. 91). Nurse practitioners were found to be more skilled than physicians with regard to communicating with families, since NPs could lead less stressful conversations and were more accessible to families (Shield et al., 2014). Finally, the positive impact of NPs on ACP engagement was highlighted in a recent study conducted in Manitoba, which further stressed the importance of integrating NPs into Canadian LTC facilities (Dangwa et al., 2022).

The need to educate healthcare providers about ACP has been noted in the literature (Gilissen et al, 2017). The current study identified a unique educational strategy to help meet this goal. The nurses in this study believed that medical and paramedic students should have clinical placements at LTC facilities as part of their training. The nurses believed these placements and experiences could mitigate the negative attitudes that many acute care staff and paramedics had toward LTC residents. The nurses felt this strategy could build healthier relationships between acute care staff, paramedics, and LTC providers by enhancing overall respect and clarifying the roles, responsibilities, and complexities of the LTC context.

According to the Revere Report on Ageism in Canada (2016), older Canadians hoped for raised awareness about ageism that would make it a socially unacceptable phenomenon. It was evident from this study that systemic ageism was a threat to NH residents’ dignity, autonomy, health, and wellbeing. Many healthcare-related education programs lack a consistent curriculum regarding the care of older adults. As a result, there is a need to create foundational healthcare education to reduce the prevalence of ageism and promote high quality whole-person care (Nemiroff, 2022).

The Consequences of Orchestrating Comfort: Getting Everyone on the Same Page

The following section situates the positive and negative consequences of orchestrating comfort at the resident, family, and nurse levels within the existing literature. Successful downgrading of residents' ACP levels was associated with positive consequences in the current study. Positive outcomes at the resident and family levels included a smooth transition to EOL care, a dignified death, decreased family stress, and increased family satisfaction. The nurses described the process of downgrading residents to comfort care as the most rewarding part of their job.

Negative consequences of the downgrading process at the resident level included increased suffering due to disagreements about realistic ACP and/or dishonoring of residents' living wills by their family members. The negative consequences of the downgrading process at the nurse level included: taking an emotional toll, conflict between personal and professional values, witnessing suffering while feeling a moral obligation to reduce suffering, and the feeling of being resented by physicians.

The consequences of the upgrading process were noted to be positive when nurses were able to optimize residents' comfort. Conversely, negative consequences arose when residents were sent to the hospital without having their ACP level upgraded. A positive consequence of the upgrading process at the family level was their satisfaction with the care provided in the LTC facility. A positive consequence for the nurses was their feeling of being competent and self-confident about their care decisions. The negative consequence of the upgrading process at the resident level was discriminatory treatment from hospital staff. Negative outcomes for nurses included feelings of frustration, feelings of impotence, feeling judged on clinical competence, and being treated disrespectfully by acute care staff and paramedics.

Nurses who engaged in the downgrading and upgrading processes of the model *orchestrating comfort: getting everyone on the same page* had the overarching goal of ensuring realistic ACP levels and optimal comfort for frail NH residents, both at EOL and during acute events. When nurses were able to deliver comfort care to residents, they expressed feeling competent and confident about their decisions to downgrade or upgrade ACP levels and tended to receive positive recognition from families for their nursing care. Nurses' efforts to downgrade residents' ACP levels were more likely to be successful when they built consensus with other members of the team and family to transition residents' care from curative, aggressive, life-prolonging interventions to comfort-oriented care without hospital transfers. As such, nurses were able to help residents die with dignity at the LTC facility. In these instances, families expressed satisfaction with the quality of their loved ones' deaths and experienced lower levels of stress throughout the process.

Similar findings were identified in a systematic review in which ACP improved the quality of EOL care, prepared families for EOL, and reduced incidents of overtreatment (Fleuren et al., 2020). Staff from 52 Indiana NHs reported feeling gratified with the EOL care they had provided when their actions had positive impacts on the quality of residents' death (Cagle et al., 2017). Staff also felt that providing comfort care was personally rewarding (Cagle et al., 2017). In contrast to the current study, the findings from a sequential mixed methods study examined 87 bereaved family members whose loved ones resided in LTC facilities (Thompson, 2007), indicated that having an advance care plan had no impact on family members' feelings of satisfaction, but having an HCD increased their satisfaction.

In the current study, nurses reported that ACP helped them make appropriate treatment decisions and prioritize residents' wishes in order to decrease inappropriate hospital transfers, unwanted resuscitations, and hospital transfers at EOL. Several studies, including the current study, have demonstrated the effectiveness of ACP in avoiding hospital transfers for frail LTC residents (Girio-Fragkoulakis et., 2011; Jensen et al., 2009; Lemoyne et al., 2019; Quinn et al., 2017; Shanley et al., 2011). A systematic literature review showed that the engagement in ACP, and use of palliative care services and on-site NPs significantly reduced burdensome hospital transfers within NHs (Graverholt et al., 2014). The literature has shown that rates of terminal hospitalizations vary among countries, with Germany and Japan having the highest rates of EOL hospitalizations among NH residents (Allers et al, 2019; Hoffmann et al., 2019). Countries with comprehensive and high frequency ACP (Australia, Belgium, and Netherland) had lower rates of EOL hospital transfers when compared to countries with low frequency ACP implementation (Germany and Japan) (Allers et al., 2019; Hoffmann et al., 2019).

When nurses were unable to orchestrate comfort, negative consequences often ensued. For example, nurses' ability to provide comfort care was hindered in situations where they felt that residents should be transitioned to comfort care yet family members still wanted life-sustaining measures, physicians continued to prescribe curative treatments such as antibiotics, or the PGTs delayed comfort care until death. In these situations, nurses' efforts to provide comfort care were unsuccessful and the residents suffered in silence. The nurses then experienced moral distress, feeling powerless to do the right thing and were obligated to do what others wanted. Studies of critical care nurses have shown that providing interventions that the nurses perceived as inappropriate, overly aggressive, or even futile, especially near EOL, were a universally common source of intense and frequent moral distress (de Villers & DeVon, 2012; O'Connell, 2015; Oh & Gastmans, 2015).

Similar to the results of this study, Broom et al. (2015) and Nikbakht Nasrabadi et al. (2021) noted that nurses had experiences of being caught in the middle of conflicting situations and felt powerless to change or influence the care provided. The professional cost of emotional suffering associated with ACP conversations was echoed in a study of 20 Australian hospital nurses who were regularly involved in negotiating futility and transitioning patients to palliative care (Broom et al., 2015). In the current study, it was noted that novice nurses were leaving the profession due to the emotional impacts of engaging in ACP discussions. Although this finding was not confirmed in the ACP literature, research has shown professional attrition among oncology nurses (Ghasemi et al., 2019) and hospital nurses (Laurs et al., 2020) due to the moral distress of EOL care.

In the current study, the negative consequences of the downgrading process at the nurse level included: taking an emotional toll, conflict between personal and professional values, witnessing suffering while feeling a moral obligation to reduce suffering, and the feeling of being resented by physicians. Similarly, qualitative studies of nurses working in hospitals, outpatient clinics (Susanne et al., 2022), and NHs (Young, Froggatt, & Brearley, 2017) have reported that nurses felt powerless to confront families about the outcomes of life-prolonging treatments and hospital transfers, felt that they could not express their concerns about these interventions to acute care staff, and felt frustrated that their own values were not being reflected in treatment decisions. Nurses also reported feelings of frustration and betrayal when they perceived that communication between physicians and families was unfair, particularly when the physician created unrealistic expectations for comfort care (Susanne et al., 2022).

In the current study, Asian nurses who had to advocate for comfort care for older residents experienced conflict between their personal values and professional responsibilities. Because of their cultural background, these nurses wanted to strongly advocate for more aggressive medical interventions for residents. However, their professional nursing responsibilities required that they recommend the most realistic options (comfort care) to residents and their families. For these nurses, the recommendation to forgo life-prolonging treatment conflicted with their cultural virtue of filial piety, in which individuals must uphold strong obligations to their families, and the hierarchical structure of their culture, in which elders deserve the utmost respect (Lee et al.,2017).

Utility of the Theoretical Perspectives

The following section explains the utility of the theoretical perspectives used in the current study, and is followed by a discussion of the strengths and limitations of the study. The theoretical underpinnings of this study were SI and the SEM by Simons-Morton el al. (2012). The sensitizing concepts from these two theoretical perspectives guided the research questions and data analysis of this study. The research questions, “what are the experiences of nurses regarding the process of ACP in the LTC setting?” and “what are the consequences/outcomes of this process?” were examined through the lens of SI. The research questions, “what are the factors that facilitate the process of ACP?” and “what are the factors that inhibit the process of ACP?” were examined through the lens of the SEM.

Symbolic interactionism facilitated the construction of the interview guide questions, which invited the nurses to explain the process of undertaking ACP. Symbolic interactionism also enabled the construction of subsidiary questions within the study, which were related to the why, how, where, when, under what conditions, and with what consequences the process of ACP unfolded. During their interactions with residents and other healthcare providers, the nurses created meaning and developed their own perspectives about residents' most appropriate ACP levels. The meanings nurses ascribed to a given situation affected the type of medical interventions they tried to pursue or avoid by either downgrading or upgrading residents' ACP levels. Consistent with the tenets of SI, nurses' actions were guided by their interpretations of the residents' overall situation.

The use of SI in this study illustrated the impacts that social interactions between nurses, families, and healthcare providers can have on the selection of ACP levels and the orchestration of comfort for frail LTC residents. Nurses' actions were based on symbolic meaning found within the complex context of LTC and were influenced by the cultures, social processes, and social norms of LTC and acute care. During their social interactions with residents and families, nurses created and modified meaning from the symbols and language they attached to people, objects, and events, such as signs and symptoms of declining health status/acute illness.

The SEM was suitable for this study's purposes and helped identify the barriers and facilitators that affected nurses' ability to orchestrate comfort at three levels: resident level (intrapersonal); family/healthcare provider level (interpersonal); and institutional/organizational level. The SEM allowed the focus to remain on factors that affected nurses' efforts on the broader contextual level, such as the socio-cultural and environmental contexts of both LTC and acute care. For example, the lack of a universal understanding of ACP-C, both at the LTC physician level and the acute care staff level, was problematic when nurses were trying to promote residents' comfort during acute events. The SEM model provided an understanding of the interconnected influences of the three levels on nurses' engagement in ACP conversations.

For example, new nurses often felt anxious when undertaking ACP discussions with complex families due to their limited exposure to death/dying and ACP in the nursing curriculum as well as the lack of ACP education in their workplace.

In this study, the SEM was used to identify a range of factors that either posed barriers to or facilitated the uptake of ACP in LTC. These barriers and facilitators were characteristics identified at the resident/family, health provider, and organizational levels. At the local level, the SEM helped identify the need to include universal ACP education across the healthcare system, language support for IENs, work considerations for causal nurses, and re-evaluation of the WRHA ACP-GOC form. Within the broader Canadian LTC context, the model identified that ageism and undervaluing of the LTC population were critical factors that need to be addressed. As a result, use of the SEM generated a comprehensive understanding of the numerous barriers and facilitators at the three levels, all of which required specific, well-considered interventions in order to enhance ACP uptake and provide high quality EOL care in LTC facilities.

Strengths and Limitations of the Study

This section outlines the strengths and limitations of the study, followed by recommendations for teaching, practice, research, and policy. Approaches to knowledge translation are also presented.

Findings must be viewed in light of the strengths and limitations of the study. The strength of this study lies in the fact that methodological rigor was maintained by using a GT approach to answer the study's aims and questions. Approaches to rigor, such as member checking, were previously described in chapter four. There is ongoing debate within the literature regarding the limitations of member checking in the GT approach (Motulsky, 2021). For the purposes of the current study, the researcher viewed this as a strength rather than a limitation. The current researcher's philosophical positioning was aligned with that of Charmaz (2014), who asserted that member checking is a useful way to co-create subjective meaning with and empower participants. Member checking in the current study was completed with the nurses as a way of giving them ownership over their own stories/responses. Involving the nurses in this way enriched the co-construction of the model that was generated from this study. Furthermore, the use of researcher reflexivity (p. 121) helped manage the researchers' assumptions, biases, and previous experiences to ensure they did not unduly influence the co-constructed meanings.

Limitations of the study included: self-selection bias of the participants, under representation of casual/male nurses, lack of natural observation of nurses undertaking ACP in their work settings, and the researcher's limited skills in conducting GT research. There may have been self-selection bias in this study. Self-selection bias occurs when only people who are very interested and positive about the research topic volunteer to participate. Therefore, the study sample may not have reflected the voices of LTC nurses who were wary about ACP conversations or did not view ACP as part of their professional responsibility. The sample did not contain any casual nurses. While the more experienced nurses reported that casual nurses encountered challenges with ACP discussions, there is no data from the casual nurse demographic to affirm this assertion. There were no direct observations of nurses' engagement in ACP in their work settings. Participant observation in the LTC setting would have enabled the researcher to witness nurses' actual behaviours and responses regarding ACP, and compare these observations with the nurses' verbal accounts.

There was an over-representation of female nurses in this study (n = 23 out of 25 nurses). Traditionally, male nurses are perceived as physically powerful and expected to vehemently defend their patients, which subsequently promotes a stereotypical image of male nurses as neither gentle nor caring (Evans, 2004). In addition, studies have shown that men were generally less engaged with ACP and EOL discussions when compared to women (Smets et al., 2012). Therefore, male nurses' perspectives and experiences of ACP engagement could be different from those of female nurses. The model generated from this study could be enriched through the integration of male nurses' perspectives.

Finally, the current study was completed by a novice GT researcher. While undertaking this study, the researcher was systematically learning GT research skills by attending various learning activities. The researcher reflexively considered this development while recording memos and discussing the research with her advisors. Peer support and other online learning activities strengthened the researcher's skills. Networking and collaborating with other PhD students who were using GT methodology for their research provided opportunities to understand the challenges of the GT approach and learn from the problems encountered by others. While it was challenging to undertake this GT research without previous experience, it did not impede the researcher from conducting a rigorous study.

The theoretical model explained in Chapter five offered a theoretical understanding of LTC nurses' experiences with undertaking ACP, the barriers and facilitators that affected ACP engagement, and ways to further develop the model. While many of the findings from this study were previously reported in the literature, new findings did emerge. However, the model that emerged is limited to the contexts and conditions of the data generated from this study.

Recommendations Arising from the Study

This section outlines suggestions for future research as well as recommendations for education, practice, and policy. Proposed knowledge translation approaches are also described.

Recommendations for Future Research

This study generated a preliminary theoretical model from which to understand the experiences of nurses working in LTC facilities and undertaking the ACP process. Further research is needed to validate the main processes and strategies identified, and determine the usefulness of the model. This research could include: (a) qualitative studies to understand the role of the nurse-family relationship in ACP, from the perspectives of both the nurses and families; (b) knowledge to action studies to develop ACP communication models for the interprofessional team; (c) knowledge to action studies to improve ACP conversations for residents under the PGT; (d) stakeholder engaged participation research to understand the clarity and effectiveness of the WRHA ACP form in LTC, from the perspectives of the public/PGTs/healthcare providers/residents/families; (e) qualitative research to examine the lack of physician engagement in ACP within LTC facilities; (f) environmental scanning methodology to identify gaps and develop educational programs to support ACP stakeholders across various cultural, religious, and lingual contexts; (g) cross-sectional descriptive studies to explore NPs' knowledge and attitudes of ACP across all practice settings; (h) qualitative studies to explore the perspectives of casual nurses/new nurses/IENs with regard to ACP engagement; (i) qualitative research to understand the impacts of public health orders on ACP engagement during the COVID-19 pandemic; (j) explorations of the usefulness of the current theory in other healthcare practice settings, outside the context of LTC.

One of the priorities of the 2019 Pan-Canadian Framework for ACP was to improve ACP communication practices across Canada (CHPCA, 2020). Moreover, the CHPCA asserted that, "for ACP research to have an impact, the questions, process, results, and recommendations must be developed in partnership with relevant stakeholders" (2020, p. 29). Taking the above statement into consideration, the findings from this study identified the following recommendations for future research.

Study participants reported several facilitators and barriers to conducting ACP conversations with residents/families in the LTC setting. A quantitative online survey, built from the findings of this qualitative study, could recruit a large sample of participants through the nursing regulatory bodies in Manitoba. This type of survey could further investigate the education and support required by LTC nurses to effectively engage in ACP. The survey results could inform actions that healthcare providers, researchers, educators, and policy makers could undertake to improve ACP communication and the quality of EOL care in Manitoba’s LTC sector.

It was evident in this study that nurse-family relationships played an important role in improving the ACP process. Relationship building and trust levels between families and nurses were identified as facilitators to implementing appropriate ACP levels and optimizing residents’ comfort. Much has been written about the dyadic relationship between these two groups. However, very little research has examined how these relationships develop and the practices, education, and policies that contribute to positive dyadic relationships and effective ACP communication in the Canadian LTC context. It is critical to gain an understanding of the nurse-family relationship, from the perspectives of both nurses and families, in order to improve the quality of the ACP process. Therefore, further research is warranted to explore these dyadic relationships in LTC.

This research study revealed that interprofessional team communication and collaboration facilitated effective resident-centered ACP during care conferences. In general, there were no universal standards to specify which members of the interprofessional team were to engage in ACP conversations in LTC. In most LTC facilities, ACP conversations were being initiated by members of the nursing team. At some facilities, initial ACP discussions were carried out by social workers. In facilities attached to health centres, the physician and/or CRN engaged in ACP conversations with residents/family members. Little is known about family/staff experiences of interprofessional team communication during ACP conversations and the potential family/resident/staff outcomes of using interprofessional team communication models. Future research using the knowledge to action (KTA) framework and various qualitative studies, such as GT/ethnographic fieldwork, could examine interprofessional team encounters and develop tools to improve ACP communication and collaborative action. The KTA framework is an approach for the development, implementation, and evaluation of a practice change intervention that consists of multi-phased knowledge creation and action cycles (Field et al., 2014). The KTA framework (Graham et al., 2006) stipulates that in order to achieve the translation of knowledge into practice, knowledge must be adapted to the local context and barriers to the use of that knowledge must be assessed. A stakeholder workshop, consisting of physicians, nurses, social workers, HCAs, and other members of the healthcare team along with family members/residents, could help assess the barriers, facilitators, solutions, knowledge resources, and types of support/interventions required by the different stakeholders. This information could then be used to develop interprofessional team communication models for ACP.

In this study, nurses identified the difficulties associated with conducting timely ACP for residents under the PGT. As of January 2021, there were 589 LTC residents under the committeeship of the PGT in Winnipeg (K. Ranson, personal communication, January 22/2021). Qualitative research from the Canadian context reported significant issues identifying GOC for unbefriended residents under PGTs; more specifically, research showed that PGTs were more likely than family members to request hospital transfers for residents (Chamberlain et al., 2020). Nurses from this study reported that the PGTs rarely visited and, thus, lacked familiarity with the residents. Trust building and person-centered knowledge are necessary components of optimal ACP engagement. This study showed the importance of understanding PGTs' experiences with ACP and their decision making processes, specifically from their own perspectives. A KTA framework could be used to engage stakeholders from healthcare and law, alongside LTC residents, to improve ACP conversations for residents under the PGT. According to the CHPCA (2020), ACP is more effective when different sectors, including law and healthcare, work together to uphold the guiding principle of *collaboration across sectors*, which was part of the 2019 Pan-Canadian Framework for ACP (CHPCA, 2020).

Residents of LTC facilities often experience a progressive burden of severe symptoms leading up to death. Aggressive medical interventions do not provide comfort to the residents and result in poor quality of life. The ACP forms used by the nurses in this study only provided three GOC options, which the nurses described as vague and open to multiple interpretations. Nurses suggested that having a list of medical interventions under each GOC category could serve to clarify the three levels and simplify ACP conversations for decision makers. No research has been conducted to understand the usability and effectiveness of the current WRHA ACP form, since its last revision in 2011. In accordance with the guiding principle of *quality improvement and accountability* from the 2019 Pan-Canadian Framework for ACP (CHPCA, 2020), future research is essential to understand the clarity and effectiveness of the WRHA ACP-GOC form. Future research should include a stakeholder engagement workshop that focuses on the perspectives of PGT/healthcare providers/residents/families in LTC as well as members of the public. There is an urgent need for an analysis and evaluation of the current WRHA ACP-GOC form and ACP policy, especially with the lessons learned during the COVID-19 pandemic in LTC facilities across Canada and the US.

Lack of physician involvement in ACP discussions was identified an ongoing issue in LTC settings. According to the nurses in this study, many residents and families were not familiar with the LTC physicians who provided care in the facility. Physicians mostly relied on the nurses' assessments, and discussions about the residents' medical care occurred through telephone conversations between the nurses and physicians. Empirical research has indicated that physicians' lack of familiarity with residents can lead to unsafe medical care, increased inappropriate hospitalizations, and suboptimal EOL care (Abdul-Razzak et al., 2014; Biola et al., 2007; Gjerberg et al., 2015). Nurses reported that physicians played an important role in providing information to families about residents' diagnoses, illness trajectories, and the impact of treatments. This study reported that families' lack of familiarity with physicians led to insufficient trust that hindered the physicians' engagement in ACP conversations. Moreover, the participants reported that physicians' styles of communication along with their lack of interest in ACP conversations further compromised their ability to engage in effective ACP. Little research has examined physicians/nurses/family/residents' perspectives of physicians' lack of presence in LTC facilities, and the potential reasons for their absence. In addition, there has been insufficient research to examine physicians' lack of interest in ACP communications and the potential impacts this may have on family/resident/staff outcomes. In accordance with the guiding principle of *evidence-informed* from the 2019 Pan-Canadian Framework for ACP (CHPCA, 2020), the researcher of this thesis recommends that future research focus on building new evidence about physicians' lack of engagement in LTC practice settings.

Nurses reported that they had to put significantly more effort into downgrading residents' ACP levels to maximize comfort when they were working at faith-based facilities, in comparison to non-faith-based facilities. Nurses noticed that family members from faith-based facilities had strong religious beliefs and were not easily swayed into making ACP decisions. Residents from faith-based facilities were frequently sent to hospital for aggressive life-prolonging interventions. The researcher strongly believed that nurses who work in faith-based facilities are in an ideal position to identify information needs for nurses/families and appropriate strategies, and use that information to engage in ACP conversations with families and develop EOL care plans for residents. In alignment with the 2019 Pan-Canadian Framework for ACP (CHPCA, 2020), it is essential that research studies focus on the needs, preferences, and practices of diverse communities to ensure that approaches to ACP remain respectful of cultural diversity. A thorough understanding of cultural diversity in death and dying may assist in identifying gaps for future ACP project planning and policy objectives. Advance care planning processes grounded in cultural and religious diversity could benefit health professionals, consumers, healthcare organizations, and government policy makers.

This study highlighted the lack of available ACP educational resources for healthcare providers and families/residents in LTC. It would be pertinent to conduct an environmental scan to examine the existing Manitoba-based educational resources pertaining to ACP and GOC. This type of research would provide direction regarding the types and breadth of educational resources that are still needed, while also guiding updates to existing resources. A robust inventory of ACP resources would support professional organizations, educational institutions, and community-based organizations in promoting awareness and education among different stakeholders. Considering Manitoba's multi-lingual, multi-cultural, and multi-faith population, results from an environmental scan could identify gaps for future ACP project planning and educational program objectives, and support ACP with stakeholders from various cultural, religious, and lingual contexts.

The results of this study also highlighted the positive impacts of NPs in LTC, specifically in terms of their active engagement in ACP conversations and their ability to enhance the quality of EOL care and overall family satisfaction. Knowledge of the extent and nature of NPs' involvement in ACP is limited, both provincially and nationally. This study reported that NPs in Winnipeg LTC facilities were actively engaged in ACP conversations. However, no other studies have explored NPs' knowledge, beliefs, and attitudes about or implementation of ACP in LTC, acute care, or primary care settings in Manitoba. It is important to understand the extent to which NPs engage in ACP conversations in their practice settings as well as their perspectives of ACP engagement. Replicating this GT study with NPs across healthcare settings would provide valuable information about the transferability of the model to other practice settings. One option would be to conduct a cross-sectional descriptive design, using an online survey, to explore NPs' knowledge, attitudes, and practices related to ACP engagement across all practice settings. This type of research could shed light on NPs' perspectives of the perceived barriers and facilitators to ACP engagement in their practice.

Further research should explore whether the current theory maintains credibility, resonance, and usefulness in substantive areas of healthcare practice, beyond the context of LTC settings. For example, the current theory could be tested in hospital, primary care, chronic care, and palliative care settings as well as with different patient populations. If the theory can be extended or adapted into a range of other areas while offering further abstraction of concepts, it could evolve into a formal theory about ACP in healthcare practice. Building a formal theory was beyond the scope of this researcher's doctoral program, but is a possibility to consider for the future, especially in collaboration with other researchers and organizations.

The data collection for this study was completed during the first wave of the COVID-19 pandemic in Winnipeg. During this time, Winnipeg was under the yellow tier of the "RestartMB" colour-coded response system, with few COVID-19 outbreaks in LTC. The response to COVID-19 in LTC facilities at that time involved the introduction of the single-site staffing model for nursing and support staff, restrictions of family members/visitors, limited on-site medical rounds (to one clinician visit per week for the entire facility), and triage of residents by the physician/NP prior to any hospital transfers. These responses were implemented during the data collection period of this study. More research is required to understand the effects of COVID-19 public health orders/guidelines on the health and well-being of the LTC population from the perspectives of healthcare providers, residents, and families. An online survey coupled with in-depth qualitative interviews could generate information about the practicalities and challenges of ACP conversations between healthcare providers and families in the midst of the public health orders, especially the visitor restrictions. This type of research could provide valuable insights into the potential impacts of public health orders on ACP engagement and the experiences of death and dying in LTC settings.

Recommendations for Education

This study identified gaps in ACP education for nursing students, healthcare providers, and healthcare consumers.

Recommendations for Nursing Education. Nurses in this study contended that new graduates did not receive any ACP education in their training programs. The degree of accuracy of this assertion is not known and requires further scrutiny. Where education is lacking, it may be appropriate to develop and implement a teaching strategy, such as a high-fidelity simulation for ACP. Simulation-based ACP education was found to be a valuable and feasible educational tool that increased participants' overall understanding and confidence. In a pilot study on simulation-based education within an oncology department, 90% of participants expressed confidence to participate in ACP discussions (Katz et al., 2020). Thus, such an educational approach may enhance undergraduate nursing students' satisfaction, self-confidence, and knowledge about ACP conversations across various healthcare settings. High-fidelity simulation could offer new avenues for teaching different ACP scenarios, allow students to engage in critical thinking and reflection based on their lived experiences and practices, and may be more beneficial when compared to conventional simulation with static manikins or role playing (Sanford, 2010). Opportunities for students to observe and practice ACP discussions should be sought out during their clinical placements. In addition, the integration of storytelling lectures from expert palliative/hospice care providers could reduce students' anxiety about real-world practice experiences. Treloar et al. (2017) described that storytelling can be used as "simulations outside of the laboratory" (p. 294) and believed that real-world practice stories could provide students with a "window on the world of clinical practice" (p. 299), which is particularly important considering that students have very limited practice experience.

Recommendations for Healthcare Provider Education. Lack of standardized ACP education across the healthcare system was reported as a major barrier in this study. Nurses believed this lack of education contributed to the inconsistent interpretations of ACP levels within the healthcare team. The nurses recommended that ACP education be included in annual mandatory education programs, along with fire safety. Due to time constraints at work, nurses suggested that instructor-led online ACP learning modules be offered through Shared Health's

LMS. The LMS is a software application used for the administration, documentation, tracking, and reporting of instructor-led and online courses. It is currently available to any healthcare staff in Manitoba who have a work email address. Several education topics are available for healthcare providers through the LMS, including wound care, respectful workplace, personal health information act, and hand hygiene. The flexibility of this learning system may offer LTC nurses a convenient way to learn about ACP. The nurses in this study also recommended ACP mentorship for new nurses to help them develop confidence with ACP engagement.

Recommendations for IEN Education. The concept of ACP was new to all of the IENs in this study. Recruitment of nurses from other countries has become a universal practice in Canada to address the nursing shortages across the country. In 2019, IENs represented 8.9% of practicing nurses in Canada (CIHI, 2020), with their numbers expected to grow. Most IENs are recruited from India and the Philippines (CIHI, 2020). The IENs in this study reported that their exposure to ACP/EOL conversations was limited and that care expectations in their home countries differed from those in Canada. Therefore, it is important that IENs receive education about Canadian healthcare practices/expectations that may differ from those of their home country, especially with regard to patient autonomy and DNR orders and how these factors influence the ACP process. This education could be incorporated into bridging education programs that are tailored to IENs.

Recommendations for Practicing Nurses. Nursing regulatory bodies and professional associations can organize ACP workshops/webinars as part of their continuing education programs. The College of Registered Nurses of Manitoba could introduce an ACP learning module to their annual jurisprudence program, a cloud-based self-learning system that can target all practicing RNs in Manitoba. There is evidence to support that multimodality education programs can effectively teach ACP and successfully target both newly hired and currently practicing healthcare professionals (Blomberg et al., 2020; Pearse et al., 2021). A combination of didactic teaching of ACP concepts along with role play simulations and case-based ACP discussions could enhance person-centered ACP and healthcare providers' engagement in ACP across practice settings.

The findings of this study indicated the importance of culturally-competent ACP educational resources to meet the needs of culturally diverse populations. Cultural humility promotes respect, empathy, and critical self-reflection at the intra- and inter-personal levels, and facilitates introspection and critical thinking among nurses (Hughes et al., 2020). Enhancing nurses' understandings of cross-cultural beliefs and values could promote culturally informed, resident-focused, individualized ACP conversations, which would increase the likelihood of improving EOL care and downgrading ACP levels in LTC. It would be important to develop cultural humility training strategies in order to achieve these goals.

Unresolved personal issues with death and dying inhibited the study participants from having ACP conversations, which could be emotionally charged. In order to be more comfortable with ACP conversations, nurses need to increase their self-awareness by reflecting on their personal factors and their own feelings about death and dying. Self-refection has been found to improve one's situational awareness, change one's own perspectives, promote higher levels of understanding, and increase overall confidence (Mann et al., 2009). Reflective practice helps to bridge the gap between professional knowledge and the demands of real-world practice (Dubé & Ducharme, 2015). Self-reflection can help LTC nurses confront their feelings, deal with any unease or anxiety regarding death and dying, and ultimately increase their involvement in ACP conversations. Self-reflection also gives nurses the opportunity to think about the positive outcomes of their ACP conversations (e.g., making residents comfortable, helping residents die peacefully, and being an advocate for the family/resident/physician). Reflecting on these positive outcomes can motivate nurses to become involved in future ACP conversations (Black, 2006). Reflective practice is seen as a vital component of nursing education and practice. As such, self-reflection should be a habitual practice for all nurses working in clinical areas. Employers and educators need to give nurses opportunities to reflect on their own practice and teach them to engage in self-reflection by offering reflective learning activities in nursing academia and the workplace (Matshaka, 2021).

Recommendations for Education of Paramedics and Acute Care Staff. Nurses from this study reported that acute care staff and paramedics displayed negative attitudes toward LTC settings and residents. Geriatric LTC rotations are not a requirement of the undergraduate medicine/nursing or paramedic education programs in Manitoba (McCleary et al., 2014). Medical students often struggle with the philosophical shift from curing to caring for patients (Hall et al., 2009). Populations in LTC facilities are medically complex, have extensive social influences, and live under unique circumstances, all of which are vital considerations in geriatric care. Studies have indicated that LTC settings provide a broader understanding of and approach to death and dying, which challenges the dialogue about EOL care and multidisciplinary teamwork for nursing and medical students (Fosse et al., 2017; Deravin et al., 2016). The inclusion of clinical rotations in LTC facilities for medical/nursing/paramedic students could impact their awareness of the complexities that exist within the LTC sector.

Recommendations for Family Education. The results of this study highlighted a strong need for dementia and ACP-related education for the families of LTC residents. Participants of this study stated that more education campaigns, such as ACP/dementia information pamphlets in the LTC admission/welcome packages and informational sessions on ACP/dementia, could help sensitize families to these topics. Such information could improve families' awareness of the complications of dementia (e.g., swallowing problems/aspiration pneumonia/dehydration and poor tolerance of hospital transfers/aggressive interventions), which may increase their receptivity to ACP conversations. Long term care admission packages and care conferences could include the *Comfort care at the end-of-life for persons with Alzheimer's disease or other degenerative diseases of the brain* booklet (Arcand & Caron, 2005) to help educate families about dementia and its complications. This booklet has been made available in several languages and is associated with a high degree of acceptability and perceived usefulness among LTC nurses in Canada (Arcand et al., 2013).

Recommendations for Practice

The findings of this study noted the importance of interprofessional teams in facilitating families' acceptance of a more accurate version of the residents' big picture and, thus, a more realistic ACP level for the resident. Team persuasion was used during family care conferences when members of the interdisciplinary team provided their assessment of the resident's status to family members. Effective teamwork has been recognized as an essential tool for constructing high quality person-centered care in NHs (Havig, 2013). Therefore, ACP educational packages should be developed with an interdisciplinary focus, so team members can participate in case-based ACP discussions. This type of interprofessional ACP education can assist team members to understand each other's roles in ACP and learn how to engage in ACP discussions with families as a unified team. Interprofessional ACP education could be offered in the form of "lunch-and-learn" in-services in the workplace.

Participants held the view that ACP is a clinical skill that should require novice nurses to demonstrate their competency, prior to independently engaging in ACP conversations in clinical practice. In order to assess ACP competency, nurses suggested the implementation of ACP mentors and champions. Evidence has suggested that clinically-based ACP mentorship programs in LTC settings may increase nurses' engagement in ACP conversations with families (Ampe et al., 2017; Ke et al., 2015). Experienced nurses, nurse managers, and CRNs are ideally situated to act as mentors to their fellow nurses and newly hired nurses. Given that the wound care champion program is well-known across LTC settings (McDonald, 2018), it is worth considering a similar ACP champion program for LTC facilities/units. The educational focus of the ACP champion program should be directed at increasing LTC nurses' comfort with ACP (Sudore & Fried, 2010).

The participants mentioned that many nurses in the LTC sector were unaware of and did not utilize the MDS-CHESS score. As part of the ACP Canada initiative, the CHPCA (2021) recently announced a toolkit called *Essential Conversations: A Guide to Advance Care Planning in Long-Term Care Settings.* This toolkit encouraged the routine use of CHESS to assess LTC residents for any significant decline in health or new symptoms of advanced chronic illness, with the goal of initiating proactive ACP conversations. The development of evidence-based practice initiatives to integrate MDS assessments into routine clinical practice is essential to improve the quality of care in LTC settings.

Prognostic uncertainty discouraged nurses from engaging in ACP conversation with families. While no tool can predict prognosis with absolute certainty, the failure to consider prognosis and the tendency to shy away from ACP conversations can lead to poor EOL outcomes. The validated prognostic indices available on the ePrognosis website (www.eprognosis.org) might improve the accuracy of nurses' prognostic assumptions, which ultimately influence GOC and ACP conversations in LTC settings. The ePrognosis website is a repository of published geriatric prognostic indices, where nurses can obtain evidence-based information on NH residents' prognoses. These indices can be used for NH residents without a dominant terminal illness and provide nurses with information about possible mortality outcomes. Ensuring that LTC nurses are aware of this resource and encouraging them to use it in their routine practice could increase their confidence and engagement in ACP conversations.

A small number of participants reported the benefits of incorporating a description of the illness trajectory, such as what to expect in specific illnesses like kidney/lung disease and dementia, into their ACP conversations with families. In general, illness-specific trajectories were not included in routine ACP conversations. Nursing practice initiatives might focus on ways to support the uptake and use of resources developed by the Strengthening a Palliative Approach in Long Term Care (SPA-LTC) program, which specifically focuses on routine ACP conversations for chronic, progressive, life-limiting illnesses such as dementia, heart failure, frailty, advanced lung disease, and advanced kidney disease (SPA-LTC, 2020). These communication tools can assist healthcare providers to engage in ACP conversations with residents/families and initiate a palliative approach to care.

Finally, innovation of an online ACP discussion forum for the LTC community is recommended to provide a safe space where nurses could share their ideas, opinions, and concerns about ACP engagement in their practice. This community forum would allow nurses to interact with and learn from each other by discussing their real-world ACP experiences. Nurses could work together in this type of community to create solutions for their ACP challenges and foster a culture of confidence and accountability to engage in routine ACP discussions.

Recommendations for Policy

In this study, nurses were unclear about their role in facilitating ACP. They were concerned about the lack of guidelines and policies regarding the process of ACP and how it should be conducted in their practice. The current WRHA ACP-GOC form and WRHA ACP policy have been in use since 2011. It is recommended that the WRHA's ACP policy be revised to provide more direction and clarity regarding the role of the nurse and the roles of other professional groups in ACP conversations.

It was evident in this study that ACP conversations mainly focused on the residents' overall health and functional status. Families and healthcare providers often found it easier to talk about the specifics of a condition and its treatments, rather than about the residents' wishes and preferences. When compared to the POLST and the MOST, the WRHA's ACP-GOC form does not clearly specify healthcare treatments and includes three broad categories, labeled C, M, and R. A simple modification of the WRHA ACP-GOC form would be to include a list of healthcare treatments from which family members could pick and choose; this strategy would help delineate the different ACP levels. Furthermore, a treatment-based ACP document like the POLST/MOST would facilitate ACP uptake, especially with the rationing of healthcare resources that occurred during the COVID-19 pandemic (Mason, 2020).

Although the WRHA ACP workbook (WRHA, 2011) provides different healthcare treatments, the workbook was rarely used in ACP conversations at LTC facilities. The workbook provides definitions of the three ACP levels and offers various suggestions as to how patients/families can engage in ACP. The workbook does not include any information or recommendations about cultural or ethnic background and does not account for the values/beliefs influenced by culture or how this might influence a person's perspectives of healthcare decisions.

Even though the workbook included a few pictures of people from different cultural backgrounds, its information did not reflect cultural sensitivity or support culturally safe ACP practices. A concerted effort must be made by WRHA to ensure that educational resources and policies respect the cultural values and beliefs surrounding ACP in order to meet the needs of individuals from diverse cultural backgrounds. The insights gained from this study warrant an urgent revision of the WRHA's ACP policy, ACP-GOC form, and ACP workbook to ensure that healthcare consumers and healthcare professionals can evoke and engage in effective ACP conversations.

This study identified the need for a policy to clarify the procedure for establishing ACP for residents under the PGT. At the time of this study, there was no policy or guideline outlining the steps for completing an ACP form between LTC staff and the PGT. Implementation of a policy/guideline that provides a clear and timely pathway for communication with the PGT, along with a set timeline for completion of the ACP form, would decrease unnecessary hospital transfers and suffering among residents under the PGT.

Availability of an on-site NP positively impacted the downgrading of ACP levels in this study. Participants reported that NPs had more frequent communication with family members, had more consistent attendance at care conferences, and engaged in more timely assessments of residents when compared to their physician counterparts, who visited the facility only briefly and infrequently. Studies have indicated that the introduction of NPs to LTC facilities was associated with a decrease in unnecessary hospital transfers and improvements in ACP (Craswell et al., 2020; Klaasen et al., 2009; Krishnan et al., 2015). The knowledge generated from this study could be used to inform the design and development of an NP-led medical model of care, which could support the provision of high quality EOL care in LTC facilities.

Study participants believed that introduction to the concept of ACP prior to LTC admission would improve ACP engagement in these facilities. Reviewing the different ACP levels with families/residents during the LTC paneling process could make future ACP discussions more efficient. The paneling process is usually initiated by the home care coordinator and/or the community primary care provider. The current WRHA ACP policy states that the timing of ACP should be dictated by the clinical situation (WRHA, 2011), and the transition to LTC is almost always precipitated by clinical situations. In practice, there is no initiation or revision of ACP during the LTC paneling process. In order to prepare families for inevitable ACP conversations in LTC, there is a need to implement policies that incorporate ACP conversations into the LTC paneling process.

As reported by the participants in this study, the involvement of physicians/NPs in hospital transfers helped reduce unnecessary transfers during the COVID-19 pandemic. Nurses expressed their desire that physicians/NPs be involved in all future hospital transfers of residents, well beyond the pandemic. The usual practice in LTC facilities was to send all residents with ACP-R or ACP-M to the hospital when they experienced a change in status. The results of this study suggested that hospital transfer policies/procedures need to be reviewed and updated to decrease unnecessary transfers and undue suffering among LTC residents.

Overall, this study demonstrated that there is a necessity for universally understandable ACP levels that outline specific strategies for emergency situations and acute complications. In addition, there is a need to enhance interdisciplinary and interprofessional collaboration to promote high quality EOL care in NHs. Optimizing the interprofessional and interdisciplinary collaboration between LTC staff, acute care staff, paramedics, physicians/NPs, and families could improve the management of LTC residents' complex care needs.

Knowledge Translation

Knowledge translation, or turning knowledge into action (Graham et al., 2006), is critical to effectively implement the recommendations that emanated from this study. The researcher will attempt to use the processes of dissemination and diffusion of information to share the findings of this study with various stakeholders (Estabrooks et al., 2006; Graham et al., 2006). The findings from this study that need to be communicated to stakeholders include: (a) a description of nurses' attitudes and experiences in ACP conversations; (b) a description of the processes and strategies nurses used to achieve realistic ACP levels and optimize residents' comfort; (c) an explanation of why these process and practices should be encouraged in ACP conversations; (d) a description of the major facilitators and barriers to these processes; and (e) the need for enhanced training and education about ACP across the healthcare system and the need for urgent revision of the WRHA ACP policy/form.

In an effort to disseminate the information and recommendations from this study, the researcher will refer to the KTA Framework proposed by Graham et al. (2006). This model stipulates that, in order to achieve the translation of knowledge into practice, one must select and adapt the message to the local context and assess any barriers to the use of this knowledge (Graham et al., 2006). The researcher recognizes that the transference of knowledge from this study into action will depend on the support of a number of stakeholders. Presentations about the study's findings will be modified according to the audience. The findings will not only be disseminated, but the researcher will attempt to stimulate conversations with and between these groups. Such interactions will hopefully lead to a common understanding of the importance of the findings and the need to implement suggested recommendations for the benefit of LTC residents, families, nurses, and other members of the healthcare team. Dissemination of this information will be achieved through meetings with key stakeholders, such as senior management of the WRHA LTC program, senior management of LTC facilities, and directors of organizations such as the Alzheimer Society of Manitoba and the Long Term and Continuing Care Association of Manitoba. As well, the researcher will attempt to meet with faculty members of the bridging program for IENs (Red River College Polytechnic), licensed practical nursing program (Red River College Polytechnic and Assiniboine Community College), primary care paramedic program (Red River College Polytechnic), and undergraduate nursing and medicine programs (University of Manitoba) to stimulate discussions about incorporating ACP education into their curricula. Dissemination to clinicians will occur via webinar presentations through the Association of Regulated Nurses of Manitoba [ARNM]. The diffusion of study findings will also be accomplished through publications in various journals focusing on primary care, geriatric care, LTC, and palliative care. The researcher will also submit abstracts for conference presentations to organizations such as the Long Term and Continuing Care Association of Manitoba, provincial and national Alzheimer's societies, provincial and national palliative care associations, and the University of Manitoba Centre on Aging. Dissemination of the study findings will also be achieved by making a short You-tube video that can be linked through various websites, including the ARNM and Canadian Virtual Hospice.

Knowledge Translation to Study Participants

All participants in this study requested a report of the study findings. The researcher will develop a two-page report and email it to the participants. The accompanying covering letter will remind the participant of his/her participation in the study and thank him/her for their participation. The report of the study findings will include the following: (a) a brief description of the study participants; (b) the name of the methodology used in the study; (c) a visual of the theoretical model; (d) an explanation of the model; (e) a brief explanation of each component of the model; and (f) the key recommendations that arose from the findings.

Presentation of the Study Findings to the Study Sites

The researcher has agreed to make a presentation about the study findings for staff at each of the 18 LTC facilities that participated in the study. The presentation will include the methods of the study, a description of the sample, an explanation of the model, and an outline of the recommendations that arose from the findings. The researcher will be available to present the study findings to staff at the participating sites upon the managers' request. This presentation would presumably be for the nurses working in the LTC facility. Such a presentation would allow the researcher to have direct contact with the nurses and address any questions about the findings. It might also serve as an opportunity to affirm to the nurses the significance of their role in ACP and the provision of high quality EOL care.

Conclusion

Even though studies from Canada explored the LTC nurses' perceptions and experiences of engaging in ACP conversations, the process through which the nurses engaged in ACP was lacking in these settings. This constructivist grounded theory study addressed this gap in the literature by developing an inductively derived empirical model aimed at understanding the experiences of nurses working in LTC facilities in regard to their engagement with the process of ACP. This study fills an important gap in the literature by explicating the ways in which LTC nurses engaged with ACP and the factors that facilitated or constrained their ability to optimize resident comfort. The theoretical perspectives, SI and SEM provided sensitizing framework that guided the development of the interview guide and throughout the analysis process and were useful in answering the research questions and purpose of the study. Although the findings from this study validated results reported in prior research, several new discoveries and conceptualization did emerge. It is the first Canadian study which illustrates the micro and macro perspectives of ACP through the dual lens of SI and SEM. The study findings could make an important contribution to the field of geriatrics, especially with end of life care for the most vulnerable members of our population, those who live in LTC. The inductively derived empirical model would benefit healthcare providers who wish to incorporate meaningful resident-centered, goal-consistent, evidence-based care for older Canadians, as they near end of life. The findings of this study have important implications for future research, nursing practice, education, and policy development. Knowledge dissemination and knowledge diffusion are the two methods that would be used to achieve knowledge translation of the study. Knowledge dissemination will be achieved by presenting the study findings at conferences and also sharing with LTC nurses, educational institutions, and decision makers of various organizations, whereas knowledge diffusion of the study will be attained by publishing in various journals and making the study findings available on the Internet.

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Appendix A: Experiences/perspectives of ACP from Patients/Families and Healthcare Providers

Quantitative/Mixed Methods Studies					
Author (s) **Year** **Location**	**Aim**	**Methodology** **Methods**	**Population** **Settings**	**Findings**	**Limitations/Gaps**
De Gendt et al. 2013 Belgium	To investigate the prevalence and characteristics of documented advance directives and physicians' orders for EOL care in nursing homes	Descriptive Retrospective cross-sectional study Structured mail questionnaire completed by the nurse most involved in the residents' care or the head nurse using the patient's medical record	1240 high level nursing home resident deaths between September and October 2006	Having advance directives or physician's orders was associated with receiving palliative care Nursing home residents who were not transferred to hospital during the last three months of life, who died in the nursing home, and who had longer lengths of stay were more likely to have ACP documentation	The study did not investigate the quality of the process preceding the documentation of ACPs; the quality of palliative care delivered; whether ACP's were actually followed and whether or not the absence of ACP led to automatic continuation of treatment Possible response bias as no direct comparison with a cohort of dying residents in this setting was available Potential overestimation of actual ACP completion due to selection bias, since nursing homes providing good EOL care may have been more

					likely to complete the questionnaire
Froggatt et al 2009 UK	To describe current ACP practice in English care homes for older people	Mixed methods Postal questionnaire survey In-depth telephone interviews with care home managers	Survey of 213 nursing home managers Interviews with 15 nursing home managers	The number of residents that completed any ACP processes varies Managers face intrinsic and extrinsic challenges related to the ascertaining of, and the implementing of wishes as they address ACP in the care home context	The survey technique limited the manager's ability to present the complexity of their engagement with ACP Managers were purposefully selected from nursing homes where ACP was actively undertaken and where at least 50% of residents had completed an advance care plan. Response rate was less than half (45%), n=213.
Reynolds et al. 2008 USA	To examine palliative care quality in nursing homes whether racial and/or age-based differences in EOL care exist in these institutional settings	Quantitative Chart review (from 2001-2004)	12 nursing homes 113 charts	White residents were more likely than minorities to have DNR orders, living wills, and health care proxies Advance directives were highly and positively correlated with age	There were no controls for individual organization factors All 12 nursing homes were in one south-eastern state, which may limit generalizability Univariate analysis only Any confounding variables influence the outcomes?
Wagner et al. 2010	To understand medical decision making in the	Quantitative analysis of baseline survey data from a	400 inpatient veterans admitted with a physician-	ACP facilitators: greater functional impairment, patient	Potential recall bias since patients self-reported on provider communication

USA	context of serious illness	RCT of a palliative care intervention	estimated risk of one-year mortality more than 25%	understanding of prognosis, better quality of life, and not being African American and higher education, ACP barriers: patients with poor understanding of prognosis	Causal inferences were not possible due to the cross-sectional nature of the analysis, and the lack of measures of variables The analysis did not assess patient preferences for receiving prognostic information or for communicating preferences Population was 97% male
Ampe et al. 2015 Belgium	To evaluate the actual policy of ACP vs. practice	Observational cross-sectional study Audit (questionnaire) Recorded ACP conversations (19 admission & 12 crisis) Pre-set ACP audit criteria	Managers & staff nurses (n= 153) 20 nursing homes	ACP barriers: lack of time, staff reluctance to talk about ACP, dementia. ACP facilitators: education on ACP & communication skills. Actual policy and practice of ACP varies significantly	Mostly ACP done by head nurses. (15 conversations) Actual conversation vary than intended recording (not blinded) Small sample size, Recording done by staff as it occurred (not pre-determined). ACP audit criteria not validated, developed by the authors. ACP was not discussed in all conversations (only 24) In half of the conversations were residents with patients with dementia, but no information about their cognitive status.

Hockley et al. 2010 UK	Evaluation of the impact of two EOL protocol (Gold Standards Framework for Care Homes & Liverpool Care Pathway for Care Homes)	Pre-& post implementation Survey research (50 questions) Staff audit pre and post implementation	7 NHs (private) Bed size: 35-70. 68 Staff	ACP facilitators: staff education, management support, palliative care culture ACP barriers: staff retention & recruitment issues, poor attitude and knowledge in palliative care, staff workload	Staff turnover; 16%-35% Not mentioned about the validity of the survey Staff audit done by the managers of the unit Training was not implemented in all nursing home at the same way.
Hagen et al. 2015 Canada (Alberta)	To characterize system specific barriers and facilitators to uptake of ACP	Survey research based on the TTM	51 participants: administrative staff (27) Public (2) Nursing (? 3) Physicians (17) Others (7) Participants from ambulatory services (Cancer, senior health, cardiovascular and stroke).	ACP barriers: lack of electronic health records, lack of organizational support, lack of time, lack of knowledge of ACP in public and HCPs, misunderstanding about ACP in patient and families, emotional discomfort, inadequate staff	Low involvement from nursing, convenience sample, not done in NHs. Not mentioned about the validity and reliability of the survey questionnaire. Not represented the whole province of Alberta.
Burgess et al. 2011	The primary aim was to identify key barriers to ACP completion among	optional 14-item electronic survey.	27 physicians & 12 mid-level providers	ACP barriers: dementia, lack of family involvement. lack	No definition provided about the mid-level practitioners.

USA	skilled nursing facility (SNF) providers. Secondary aim was to identify ACP practice-based differences between SNF physicians and midlevel providers			of a centralized location for ACP documentation, inconsistent documentation habits, limited time to counsel residents and their families, dispersion of responsibility, and under-recognition of team members' efforts ACP facilitators: education, standardized location and documentation of ACP, electronic records, reimbursement, improved training of ACP for nurses and social workers Low rate of ACP in NHs., need for a responsible person to initiate ACP in NHs	Social desirability bias may impact providers' responses. The survey questionnaire was not available Only half of the participants reviewed ACP with family/patient More involvement of midlevel practitioner on ACP than MDs. No definition given for the SNFs.

				Both said ACP is MDs' or midlevel practitioners' responsibility. Majority said it is the MDs'.	
Caplan et al. 2006 Australia	To evaluate a system of educating residents, their families, staff and GPs about dementia, ACP and hospital in the home.	Intervention vs control Implementation of the Let Me Decide' Advance Care Directive by a nurse consultant to the intervention group.	2 hospital and 19 NHs (intervention group); 1 hospital and 13 NHs (comparison group)	ACP facilitators: education of staff, resident & family, palliative care culture, routine use of ACP ACP decreased hospital transfers Increase ACP resulted in decreased hospital admission and mortality of residents,	Not randomized, unable to know results were related to the intervention Time period of the intervention and data collection was not clearly mentioned. Not mentioned about who collected the data. What is hospital in home means? No cost analysis done (what is cost of the intervention?) How feasible is the intervention?
Livingston et al. 2013 UK	To improve end-of-lifecare for people with dementia in a care home by increasing the number and implementation of advanced care	Mixed method study Review of chart Interview with relatives & staff	20 relatives (12 pre-intervention & 8 post-intervention) 98 chart review (56 pre-	ACP facilitators: low staff turnover, increase knowledge & awareness of ACP, support from management.	No data about staff demographics or information about the number of interviews with staff (says presented somewhere).

	wishes after an intervention	pre-& post intervention	intervention & 42 post intervention) A 120 bed NH	ACP barriers: legal implications, culture	Jewish nursing home, so the culture/belief about death and dying may be different. Generalizability of results to other nursing home is questionable related cultural difference.
Frahm et al. 2015 USA	Examine the relationship between race and advance directives, hospice services and hospitalization at EOL among deceased NH residents	Secondary data analysis of MDS data (2007)	All US nursing home certified for Medicare 183, 841 long stay NH residents	Black, Hispanic and Asian residents less likely to have ACP, surrogate decision makers or DNR orders. Black and Asian residents were less likely to be enrolled in hospice White residents were less likely to be hospitalized at end-of-life.	Questionable reliability of the MDS data and collection methods Racial information may be not captured accurately because MDS categories Hispanics as a separate category ACP policy may vary from nursing home to nursing home. Secondary data may not adequately capture the influence of ACP, hospice use or hospitalization Due to universal healthcare in Canada results may vary with hospice use and hospitalization. POLST is implemented in all most all states in US, no such initiatives in Canada

					No federal law like Patient Self Determination Act (PSDA) in Canada which mandates all nursing to discuss living/surrogate information with family/resident at admission to the facility.
Ampe et al. 2017 Belgium	To pilot 'we DECide' in terms of influence on advance care planning policy and practice in nursing home dementia care units. (2) To investigate barriers and facilitators for implementing 'we DECide'.	Quasi-experimental pre-test–post-test study with an intervention and a control group Mixed methods ACP audit of recorded ACP conversation (21 recorded conversations; 11 from intervention group and 10 from control group)	Nursing home staff from both management and clinical level 25 staff from management (5 nursing home managers & 20 department managers) 65 staff from clinical level (30 head nursed & 12 nursing auxiliaries) 18 dementia unit from 18 nursing homes (9 intervention group & 9 control group)	ACP barriers: lack of time, work pressure, unclear responsibilities, organizational hierarchy, lack of confidence, lack of knowledge and education, lack of vision of ACP ACP facilitators: involvement of staff all levels and disciplines, implementation of ACP in a structured way, hiring more staff, systematic documentation.	Most of the ACP conversations were with head nurses, they had limited knowledge with the resident/family. No recordings of informal routine conversations made with the control group How long the conversation lasted? Small number of conversations were recorded (11) Only two floor nurses involved in the ACP conversation recording. All are dementia care unit, what services these unit provide? In Winnipeg dementia care unit are for residents with behavioral issues.

McGlade et al. 2017 Ireland	To identify challenges in implementing the Let Me Decide ACP in LTC	Feasibility study Chart audit Staff survey before and after an education program	LTC residents from two NHs and one community hospital (total 250 beds) 30 senior nurses	ACP barriers: cognitive impairment & communication difficulties of residents, lack of staff education, lack of time, lack of confidence in staff, lack of ACP knowledge in family, nurses & MDs perception of depriving hope and distress in patients with ACP discussions ACP facilitators: structured ACP program, comprehensive ACP education to staff, embedding ACP in routine practice	No limitations of the study provided. No detailed information about data collection. Only senior nurses involved in ACP discussions and no demographic information about the nurses or the settings of the study. Legislative differences between Ireland and Canada: Irish Medical council explicitly encourages clinicians to consult family of those with cognitive impairment for treatment and care and Canada has no such recommendations. No detailed information about the chart audit or the survey of the staff (no statistics presented)
Detering et al. 2010 Australia	To investigate the impact of ACP on EOL care in elderly patients	Prospective RCT Intervention: facilitated ACP (by ACP facilitator) plus usual care vs. usual care	309 competent inpatient patients over 80 years old One nursing home	ACP intervention increases ACP knowledge in all parties. ACP conversations improved with	Single center study, only included cognitively intact patients. Excluded non-complaint patients (what is the definition of non-compliance).

		125 patients to the intervention group and followed for six months or until death Chart audit Survey of family members		non-medical trained ACP facilitators Of the 56 patients who died by six months, EOL wishes were much more likely to be known and followed in the intervention group (25/29, 86%) compared with the control group (8/27, 30%). In the intervention group, family members of patients who died had significantly less stress, anxiety, and depression than those of the control patients. Patient and family satisfaction were higher in the intervention group.	Only followed up to six months, did they change ACP post discharge? ACP discussion lasted about 60 min in average and had three meeting (is it possible with the regular care in LTC with staff shortage?) No cost analysis provided for the intervention. Is this non-medical ACP facilitator able to answer medical questions? No background provided about the ACP facilitators.
Rietze et al.	To determine the extent to which RNs	Cross sectional descriptive study	125 RNs	ACP barriers: resident and family	Low response rate (12.8%).

2018 Canada (Ontario)	engaged in ACP and the factors associated with their practice in ACP in Canada	Mailed survey questionnaire (demographic questionnaire plus 35 questions (dichotomous, likert scale & multiple choice, short answer questions)	From the Ontario RN registry	factors (less awareness of prognosis & acceptance of ACP, discord with family); organizations factors (unclear policy/procedure related to ACP roles, limited privacy), nurses limited knowledge and confidence on ACP and fear of increasing family discomfort. Only 27.5% identified of having policy supporting ACP and 50% reported that there was no expectation them to engage in ACP in their practice. 93% reported to learn more about engaging patients in ACP.	Most of RNs worked in acute care hospitals (67%) the rest were reported as non-acute care, which represented LTC, community and family practice. No information available about the number LTC nurses involved in the survey.

Amjad et al. 2014 Location not available	To examine whether experiences with illness and EOL care are associated with readiness to participate in advance care planning (ACP).	Observational cohort study. Face to face survey research	304, adult over the age 60, recruited from two primary care center and a senior center Community	Personal experiences were not associated with greater readiness for most ACP behaviors. In contrast, having one or more experiences with others was associated with greater readiness to complete a living will and healthcare proxy, discuss life-sustaining treatment with loved ones, and discuss quantity versus quality of life with loved ones and with physicians.	A lack of more-in-depth or more open-ended questions limits the ability to conclude why certain experiences are associated with readiness to participate in ACP. Excluded people with dementia. The cohort recruited from the primary care practices and senior center may not represent the population at highest risk of decisional incapacity or significant health decline. The potential for nonresponse bias in the results because information was not available on individuals who did not agree to participate. The analysis did not adjust for potential confounding variables. No mention about ethics or geographical information about the study

Qualitative Studies					
Author(s) **Year** **Location**	**Aim** **Theoretical Framework**	**Methodology** **Methods** **Data analysis**	**Population** **Setting**	**Findings**	**Limitations/Gaps**
Stewart et al. 2011 UK	To explore the view on ACP from staff and families of NH residents None	Qualitative, exploratory study Semi-structured individual interviews Framework analysis	34 NH staff (care managers, nurses and care assistants), community nurses and resident's families	ACP barriers: reluctance to discuss ACP, reluctance of care assistants to be involved, residents having dementia, family involvement and unforeseen medical scenarios ACP facilitators: early initiation of discussions, family involvement, good relationships, staff training	Family members and friends may not have experienced the outcomes of ACP. It may have been more relevant to interview relatives of deceased residents Mostly ACP done by care mangers No definition of the ACP provided.
Robinson et al. 2013 UK	To explore professionals' experiences on the implementation of ACP in two areas of clinical care, dementia and palliative care None	Qualitative descriptive study Focus groups and individual interviews Thematic analysis	14 focus groups and 18 interviews with 95 participants Participants were from palliative care, primary care, dementia care	Professionals agreed that ACP was a good idea in theory, though challenging to implement The array of different ACP forms and documentation available caused confusion	Purposeful sampling, Sample may have been biased towards health professionals interested in ACP

			services, social services, the voluntary and legal sectors	In dementia care, knowing when to initiate ACP was challenging Confusion of roles and responsibilities, and legal aspects	The study was limited to one geographical area, which may influence the generalizability
Fried et al. 2010 USA	To explore whether models of health behavior change can help to inform interventions for ACP None	Qualitative cross-sectional study Focus groups Transcripts were analyzed using grounded theory	93 participants: 63 community-dwelling persons aged 65 and older with multiple chronic conditions 30 caregivers with experience as surrogate decision-makers	Experience with healthcare decision-making for loved ones was a strong influence on perceptions of susceptibility and engagement in ACP	Study population limited to Caucasians and African Americans, and therefore the attitudes of other ethnic and cultural groups towards ACP were not elicited. Only constant comparative analysis done; no other requirement of GT was followed such as theoretical sampling, or theoretical saturation, no theory or theoretical understanding

					noted in the findings. Findings can't be used in NHs. Older adults were cognitively intact.
Piers et al. 2013 Belgium	To gain insight into the views of the elderly on ACP None	Qualitative Semi-structured interviews Thematic analysis	38 elderly patients with limited prognosis (median age 81 years) Community dwelling	ACP barriers; non-acceptance of nearing death, and less interest in planning for inconceivable EOL situations ACP facilitators: motivations to plan related to personal experiences and fears. trust in family and/or physician and the need for control	Patients having difficulties in accepting their terminal disease may have more frequently refused from participating in the study No available data on prognosis criteria How is their cognition?
Seymour et al. 2010 UK	To examine how community palliative care nurses in England understand ACP and their roles within ACP	Qualitative action research framework 6 focus group discussions and 3 follow up workshops Content analysis	23 community palliative care nurses	Challenges to ACP included: timing, how to effect team working in ACP, the instructional directives which related poorly to patients' concerns; managing differences in patients' and families' views	Questionable generalizability as the study did not reach data saturation Potential bias due to nurses being self-selecting and more likely to be

				Perceived barriers included: lack of resources; lack of public awareness about ACP; difficulties in talking about death	interested in the topic Mainly focused on palliative care nurses who were usually comfortable with ACP and death
Rhee et al. 2012 Australia	To explore why there is low uptake and implementation of ACP None	Qualitative descriptive analysis Semi-structured telephone interviews Iterative thematic analysis	23 participants Expert clinicians, representatives of government organizations, professional societies, consumer groups and other organizations involved in aged care and EOL care	Participants perceived the reasons for low uptake were the result of inadequate awareness, societal reluctance to discuss EOL issues, and lack of health professionals' involvement in ACP. Problems in implementation were thought to be a result of problems in accessing ACP documents; interpreting written documents; making binding decisions for future unpredictable situations; and paternalistic attitudes of health professionals and families	Purposeful sampling No study limitations provided No patient/frontline HCPs opinions The participants represented or worked for organizations with a national agenda therefore opinions may have been biased

				Some participants believed in strict implementation of ACP, while others believed in a more flexible approach	
Shaw et al. 2017 Canada (Alberta)	To explore factors and readiness of ACP among residents, family members and healthcare providers None	An interpretive descriptive approach Semi-structured interviews Thematic analysis	Twenty-seven participants (10 residents, 8 family members, 9 health care practitioners) affiliated with four supportive living facilities (three physicians, one social worker, one nurse practitioner, two registered nurses, and two nurse aides	ACP Barriers: lack of knowledge of ACP in resident/family; lack clarity and understanding of ACP in all, difficult terminology of ACP ACP facilitators: prior experience with ACP, EOL decision-making, education on ACP, Uncertainty about who should initiate ACP	Potential bias in recruitment, Small sample size, only two nurses Different healthcare services, no 24/7 nursing service Usually residents are more stable health status and high functional status. Not provided the demographics of the supportive living residents. Finding may not be applicable to the LTC context
Stone et al. 2013	To explore the experiences of patient-family-staff	Qualitative descriptive study	11 older adults, 5 family members and 5 staff	Staff was uncomfortable in undertaking ACP and fear about the emerging emotions.	Small sample size, No description of older adults.

UK	in having ACP discussions in NHs None	Semi structured interviews	Three NHs in England	Education for staff was warranted through role modeling.	ACP a new concept to staff, Cognition of the residents not mentioned Data analysis not clear
Ramsbottom et al. 2014 Canada (Ontario)	To understand experiences & perspectives to guide quality improvement of ACP in LTC None	Qualitative descriptive study Open-ended questions, semi structured interviews Inductive analytic approach	31 family members and 3 staff members (one nurse practitioner, one RN and one healthcare aid) two LTC facilities (100 beds)	Lack of understanding of ACP on the part of staff & families. Staff discomfort with ACP discussions and inconsistent implementation of ACP in the organization	Purposeful sampling Small sample of nurses Only two facilities involved Findings can't be generalized to other NHs Not mention about the process of ACP
Jeong et al. 2010 Australia	To investigate the phenomenon of ACP and use of Advance Directives in residential aged care facilities Modified Axford's framework	Case study research Multiple data collection methods: participant observation (clinical nurse	2 teaching hospitals (710 beds) 20 nursing homes (1335 beds)	Four determinative requisites for successful implementation of ACP in NHs: the expert nurse, discussion, education and involvement of multidisciplinary team.	GPs involvement with ACP was higher compared to Canadian context. Limitations of the study were not provided.

	Nursing	consult engagement with ACP; resident/family and RN with ACP) filed notes (recording conversations r/t ACP Semi-structured interview (resident, family and nurses) an document analysis (ACP & demographics of residents) Data collection for six months Critical incident technique & thematic content analysis		Education is essential to correct myths and misunderstanding about ACP.	No information about selecting the observation or the participants for interview. No information about the number of interviews or observations. No information about the trustworthiness of the study, other than minimizing the researcher's subjectivity by codes & themes.
Livingston et al. 2011 UK	The aim of this study is to examine barriers and facilitators to care home staff delivering improved EOL care	qualitative descriptive study Individual interviews Content analysis	58 participants; 20 nurses; 38 care home workers One nursing home (120 beds)	ACP barriers: concerns about validity of advance care plans, lack of knowledge and belief in ACP, fear blame, lack of education and support about discussing and	Mean time of the interview was short: (12 minute) Demographic characteristics of nurses mixed with

	for people with dementia. None			implementing plans around care at EOL/ACP and cultural issues, avoided conversations to protect residents from upset, death as taboo, feelings of inappropriateness to talk with residents about dying, worries about accuracy of information relayed to relatives ACP Facilitators: education to all, collaborative relationship in all staff	other care home workers. Study done in only one nursing home No information about the trustworthiness of the study. Findings can't be generalized to other settings
Pauls et al. 2001 Canada (Toronto)	To describe an ideal model for the transfer of advance directive from LTC facilities to emergency department (ED) None	Qualitative study 7 Semi-structured focus group interviews Grounded theory methodology to identify significant themes"	35 healthcare providers ED nurses (7) ED physicians (7) LTC nurses (7) LTC physicians (4) Paramedics (10)	Education of ACP to all staff, residents and families at LTC Introduce ACP to LTC residents/families at the time admission Physicians should play an important role in ACP Simple standardized ACP form more focus on DNR ACP form should be easily available	Main focus was around the ACP form development, not the actual communication process of ACP Data analysis was thematic analysis, no GT principles were followed. No information about saturation of data/theoretical sampling

				Physician signature to attest to competency of decision maker Review annually and with changes in health status Have mechanism to hold providers accountable if form not followed	Sample size of nurses was too low (4 RNs, 1 LPN and 1 BscN). Not sure whether these nurses were from one nursing home or multiple NHs. Study done 18 years ago, the legislation around AD varies from province to province in Canada Findings may not be generalized to LTCs in Canada. Research was from the discipline of medicine. Not clear about the combination of the focus group? nurse only or mixture all participants

Ingravallo et al. 2017 Italy	To explored the attitudes of NH residents and family members toward ACP and their opinions as to the right time to broach the subject, the manner in which it should be approached, and the content of ACP None	Qualitative study Semi-structured face to face interviews conventional content analysis	30 NH residents & 10 family members 4 Nursing homes (beds vary from 60-106).	Need a facilitator outside the family, who can act as a primer and catalyst for ACP conversations. Residents reported lack of availability of physicians to discuss their health concerns. Lack of a structured ACP process to discuss future care preferences	No mention about the trustworthiness of the study. No information about the cognitive function of the residents. The organization of NHs and their provision of care and support services to residents and families varied across the study settings Sample size was independent from data saturation. Sample size determined by previous studies.
de Vleminck et al. 2014 Belgium	To identify the barriers, from GPs' perspective, to initiating ACP and to gain insight into any differences in barriers between	Qualitative exploratory Design Focus group interviews	36 GPs Five focus group interviews	ACP barriers: lack of communication skills, fear of creating anxiety and destroying hope in patient by initiating ACP, lack of knowledge and experience about ACP, lack of long-	75% male physicians, Majority were less than 39 years

	the trajectories of patients with cancer, heart failure and dementia None	Constant comparative analysis		standing relationship with patient, lack of patient initiation, difficulty to define the key moment to initiate ACP in dementia and COPD, lack of knowledge regarding illness trajectories of CHF and dementia, future decision-making capacity in CHF and dementia	All the physicians worked in the community

Reviews

Author (s) **Year**	**Aim** **Review type** **Search period**	**Theoretical lens**	**Characteristic of Studies**	**Findings**	**Limitations/gaps**
Lovell et al. 2014	To identify the contextual factors influencing the uptake of ACP in palliative care Systematic review 2008-2012	None	27 studies; 13: qualitative, 3: mixed method; 11 observational quantitative studies) United States (10), United Kingdom (8), Australia (4), Belgium (2), Netherlands (1), China (1) Taiwan (1)	Contextual factors influencing the uptake of ACP are complex and multifaceted	Only ACP from palliative care focus included No study from Canada Mainly from cancer, three studies from NHs Definition of ACP varies across the studies. A few studies view ACP as an iterative process

					Quality of studies varies. Various study settings and population (different health systems and cultures.) Findings can't be generalized to the Canadian healthcare system,
Myers et al. 2018	To provide evidence regarding tools/practice for HCPs to effectively facilitate ACP/GOC Systematic review 2010-2015	None	34 studies from adult; 4 studies from pediatrics (Adult studies: 29 quantitative studies, 1 systematic review & 4 qualitative studies)	ACP facilitators: professional education, community engagement, trained facilitators, policy, practices and technology supporting ACP, monitoring practices through QIs., improving communication skills in providers ACP is associated positive outcome in families and patients.	Only well-known ACPs like RC, POLST and an online ACP (making your wishes known) were included in the review. No programs from Canada included in the review. Limited qualitative studies
Gilissen et al. 2017	Identify pre-conditions for successful ACP	Theory of change	38 studies (13 qualitative studies; 1 mixed method, 6	17 pre-conditions at five levels (resident, family,	No studies from Canada and no studies used

	implementation in NHs Systematic review 2004-2015.		quantitative, 11 systematic review and 7 reviews). Most studies are from Europe, USA & Australia	HCPs, facility and community). ACP facilitators in five domains; skills and sufficient knowledge, willingness, good relationship, supportive administration and contextual factors: sufficient resources, ACP embedded in routine care, palliative care ideology, community approach.	grounded theory methodology. Most of the studies were low quality,
Mignani et al. 2017	Exploring the perspectives of residents and family living in LTC on ACP Systemic review (thematic analysis) 2000-2015 None	None	9 studies (all qualitative studies) 7 studies: semi-structured interviews 2studies: focus groups 5 studies from LTC Mostly UK & USA	ACP barriers: Lack of communication between staff and families, lack of HCPs drive to initiate ACP, Lack of ACP knowledge in staff, family and residents	No studies from Canada Seven studies came from countries that have legislation on ACP No limitations of the review provided
Flo et al. 2016	Investigates, methods, design, outcomes and implementation of ACP in NHs Scoping review	None	16 studies (3; qualitative studies; used interviews, 5 mixed method studies & 8 quantitative studies)	ACP barriers: Physician non-availability, reluctance to initiate ACP by HCPs, legal issues, unseen medical scenarios, staff shortage, workload, lack of time, lack of administrative support	Only two studies from Canada (done in 2001(Toronto) & 2000; Ontario; RCT); 2001 study; Small sample size (7 LTC nurses & 4

	1806-2014		Most studies are from UK & USA & Australia.	ACP facilitators: education, providing information about ACP to residents/families, standardization of ACP process and forms, administrative support and good relationship with families Physicians were identified an important agent to initiate ACP, families want physicians to imitate ACP.	LTC MDs, focus group interview). Mostly well know ACPs included; POLST, GSFCH, LMD. ACP was defined as only conversations about EOL
Lund et al. 2015	To investigate barriers and facilitators of ACP focusing on workability and integration into clinical practice Systematic review (Explanatory qualitative implementation studies)	Normalization process theory	13 studies (only implementation studies included) Mostly from UK, & Australia Two studies from Canada	ACP facilitators: systematic implementation, trained staff, ACP barriers: limited time, workload, emotional distress in initiating ACP, communication issues, prognostic uncertainty, reluctant to talk about death and dying.	No search period provided. Only two studies from LTC; none from Canadian LTC facilities. No limitations of the review provided.
Martin et al. 2016	To identify effects of ACP in NHs Systematic review	None	13 studies (all quantitative studies) 5 systematic reviews	Positive outcomes in residents: decreased hospital transfer, increase use of DNH &orders.	Canadian study was from 2000 & was a RCT and used LMD ACP

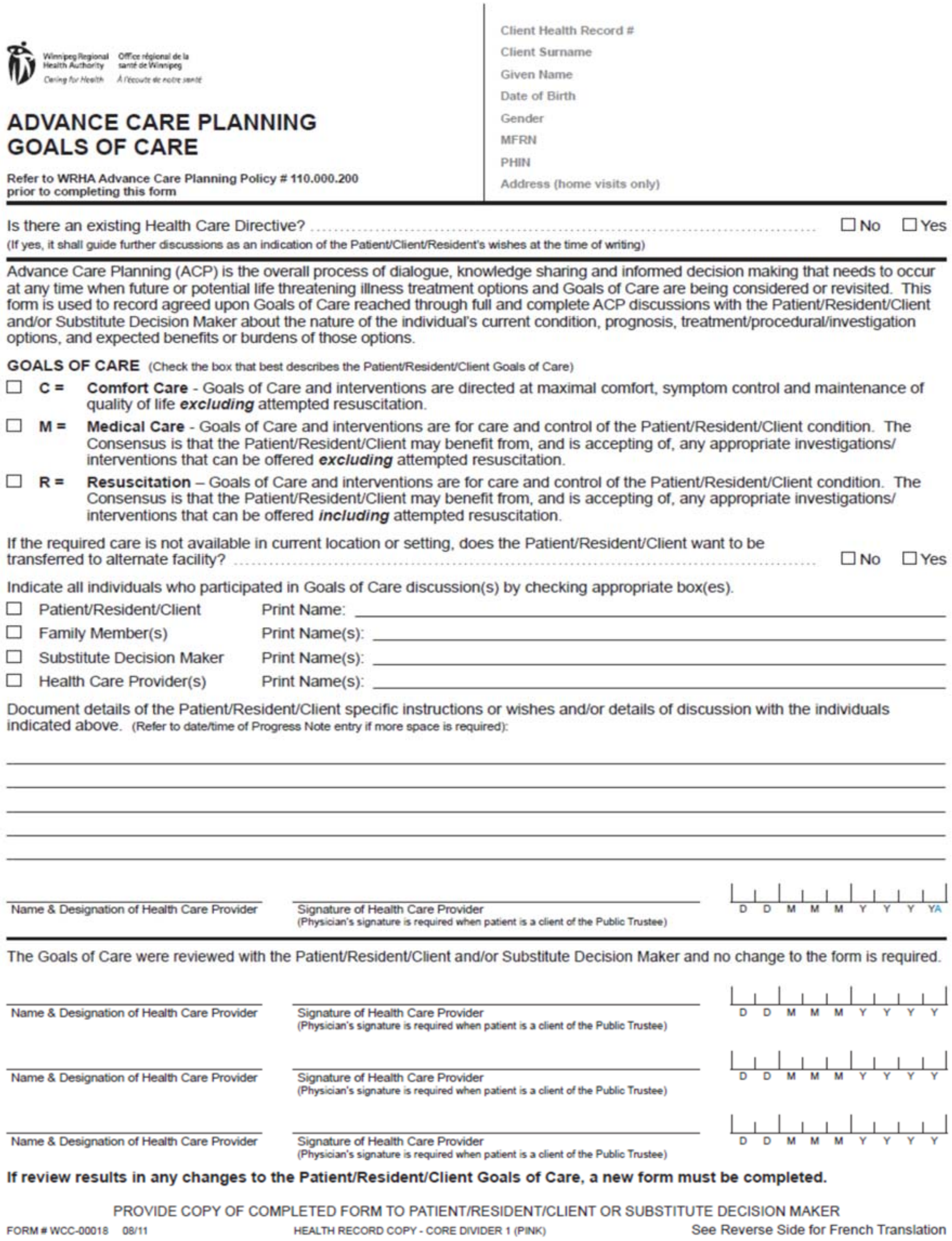
	Until April 2015 (no limitation on year)		Mostly from USA (7 studies); one from Canada		
Séchaud et al. 2013	To identify the best ACP strategies for older people living in nursing homes in relation to concepts & models Integrative review of literature (1992-2012)	None	23 published articles	ACP was superior to AD to achieve the objectives of residents & families in EOL care ACP constitutes a process of shared decision making. ACP implementation needs significant changes in professional practice & organizational policy. The best model of ACP would a consistent program focused on the promotion of palliative care.	No information available about the studies. Stated most research conducted in north American. How many from Canada? Unable to find out methodologies of the included studies.
Sharp et al. 2013	To investigate the attitudes of the public and healthcare professionals to advance care planning discussions with frail and older people	None	26 studies 13 qualitative studies; 10 studies quantitative (8, survey research, & 2 chart review); mixed methods (interview & survey)	ACP barriers: reluctance of family to talk about ACP, uncertainty about future, cognitive impairment, lack of close family, break down in family relationship, lack of HCPs willingness to talk about ACP, HCPs' emotional distress r/t ACP, lack of time and work load in HCPs.	Most were qualitative studies with small sample size whose primary focus was other than that of this review. The most studies rated as low to medium quality, no

	Systematic literature review and narrative synthesis. 1991-2012		Most studies from USA & UK One study from Canada		study rated as high quality. Risk of publication and selective reporting bias by parties with a policy agenda. Only one study reported from Canada (participants were primary care physicians at University of Nebraska Medical Centre, and used focused group and none practiced in LTC.
Rietze & Stajduhar 2015	To understand what factors, influence registered nurses involvement in ACP with their patients in acute care settings Integrative review	None	9 studies, mostly from US (7) Quantitative studies = 7; qualitative study =1 (exploratory descriptive design) and mixed method study =1	Low engagement of acute care nurses in ACP Only some nurses considered ACP as one of their nursing roles ACP barriers: lack of autonomy, lack of confidence and experience in ACP, lack of guidelines or tool to guide discussions, unclear roles,	Only studies conducted in acute care settings included in the review No studies from Canada Only one qualitative study.

	1990-2014			discomfort in initiating discussions. ACP facilitators: More education in ACP and initiatives to increase confidence in ACP discussions, integration of ACP into RN practice	Quality of the studies were not assessed Most of the included studies were cross-sectional surveys conducted in the US Limiting the generalizability of these findings to countries that have ACP medico-legalities and nursing scopes of practices that are different from that in the US No definition of ACP provided. The majority of the included studies did not have an explicit theoretical base, which may have limited the scope of the research or the

					researcher's understanding of the findings in clinical practice.
Ke et al. 2015	To explore nurses' experiences and perspectives regarding implementation of ACP for older adults. Qualitative meta synthesis 1993-2014 May	None	18 studies; most form UK (7) & US (4). Only two studies form Canada (done in 1993 & 2001).	Nurses act mediators between patients and families/HCPs. Doctors should take responsibility for implementing ACP. ACP barriers: time, culture, cost, language family, environment, cognitive impairment, family issues, lack of confidence and knowledge in discussing ACP. ACP facilitators: Good communication skills, knowledge about death and dying, good relationship with family, community involvement, public education, & leadership support.	Findings might not be represented nurses own view because the studies did not explore nurses' experiences deeply (only 4 studies focus on nurses' view). Questionable Inter –rater reliability. Studies vary from settings. Studies from Canada not represent the LTC context and were older studies.

Appendix B: Advance Care Planning -Goals of Care: Winnipeg Regional Health Authority



Winnipeg Regional Health Authority | Office régional de la santé de Winnipeg
Caring for Health | À l'écoute de notre santé

ADVANCE CARE PLANNING
GOALS OF CARE

Refer to WRHA Advance Care Planning Policy # 110.000.200 prior to completing this form

Client Health Record #
Client Surname
Given Name
Date of Birth
Gender
MFRN
PHIN
Address (home visits only)

Is there an existing Health Care Directive? ☐ No ☐ Yes
(If yes, it shall guide further discussions as an indication of the Patient/Client/Resident's wishes at the time of writing)

Advance Care Planning (ACP) is the overall process of dialogue, knowledge sharing and informed decision making that needs to occur at any time when future or potential life threatening illness treatment options and Goals of Care are being considered or revisited. This form is used to record agreed upon Goals of Care reached through full and complete ACP discussions with the Patient/Resident/Client and/or Substitute Decision Maker about the nature of the individual's current condition, prognosis, treatment/procedural/investigation options, and expected benefits or burdens of those options.

GOALS OF CARE (Check the box that best describes the Patient/Resident/Client Goals of Care)

☐ **C =** **Comfort Care** - Goals of Care and interventions are directed at maximal comfort, symptom control and maintenance of quality of life ***excluding*** attempted resuscitation.

☐ **M =** **Medical Care** - Goals of Care and interventions are for care and control of the Patient/Resident/Client condition. The Consensus is that the Patient/Resident/Client may benefit from, and is accepting of, any appropriate investigations/ interventions that can be offered ***excluding*** attempted resuscitation.

☐ **R =** **Resuscitation** – Goals of Care and interventions are for care and control of the Patient/Resident/Client condition. The Consensus is that the Patient/Resident/Client may benefit from, and is accepting of, any appropriate investigations/ interventions that can be offered ***including*** attempted resuscitation.

If the required care is not available in current location or setting, does the Patient/Resident/Client want to be transferred to alternate facility? ☐ No ☐ Yes

Indicate all individuals who participated in Goals of Care discussion(s) by checking appropriate box(es).

☐ Patient/Resident/Client Print Name: ____
☐ Family Member(s) Print Name(s): ____
☐ Substitute Decision Maker Print Name(s): ____
☐ Health Care Provider(s) Print Name(s): ____

Document details of the Patient/Resident/Client specific instructions or wishes and/or details of discussion with the individuals indicated above. (Refer to date/time of Progress Note entry if more space is required):

Name & Designation of Health Care Provider
Signature of Health Care Provider
(Physician's signature is required when patient is a client of the Public Trustee)
D D M M M Y Y Y YA

The Goals of Care were reviewed with the Patient/Resident/Client and/or Substitute Decision Maker and no change to the form is required.

Name & Designation of Health Care Provider
Signature of Health Care Provider
(Physician's signature is required when patient is a client of the Public Trustee)
D D M M M Y Y Y Y

Name & Designation of Health Care Provider
Signature of Health Care Provider
(Physician's signature is required when patient is a client of the Public Trustee)
D D M M M Y Y Y Y

Name & Designation of Health Care Provider
Signature of Health Care Provider
(Physician's signature is required when patient is a client of the Public Trustee)
D D M M M Y Y Y Y

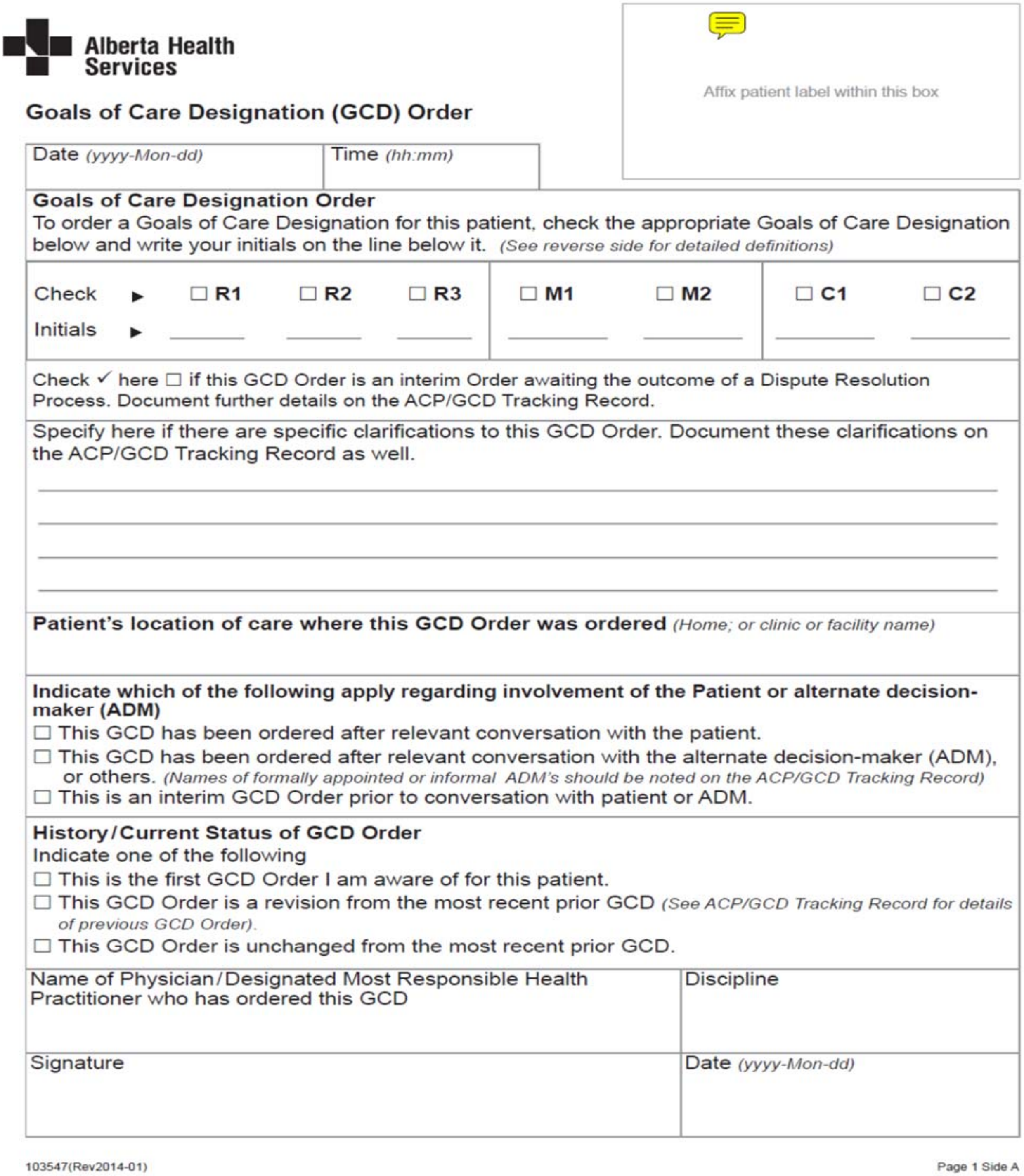
If review results in any changes to the Patient/Resident/Client Goals of Care, a new form must be completed.

PROVIDE COPY OF COMPLETED FORM TO PATIENT/RESIDENT/CLIENT OR SUBSTITUTE DECISION MAKER

FORM # WCC-00018 08/11
HEALTH RECORD COPY - CORE DIVIDER 1 (PINK)
See Reverse Side for French Translation

Source: http://www.wrha.mb.ca/staff/acp/files/goalsOfCareForm.pdf

Appendix C: Goals of Care Designation Order: Alberta Heath Services



Alberta Health Services

Affix patient label within this box

Goals of Care Designation (GCD) Order

Date *(yyyy-Mon-dd)*	Time *(hh:mm)*

Goals of Care Designation Order
To order a Goals of Care Designation for this patient, check the appropriate Goals of Care Designation below and write your initials on the line below it. *(See reverse side for detailed definitions)*

Check ▶	☐ **R1**	☐ **R2**	☐ **R3**	☐ **M1**	☐ **M2**	☐ **C1**	☐ **C2**
Initials ▶							

Check ✓ here ☐ if this GCD Order is an interim Order awaiting the outcome of a Dispute Resolution Process. Document further details on the ACP/GCD Tracking Record.

Specify here if there are specific clarifications to this GCD Order. Document these clarifications on the ACP/GCD Tracking Record as well.

Patient's location of care where this GCD Order was ordered *(Home; or clinic or facility name)*

Indicate which of the following apply regarding involvement of the Patient or alternate decision-maker (ADM)
- ☐ This GCD has been ordered after relevant conversation with the patient.
- ☐ This GCD has been ordered after relevant conversation with the alternate decision-maker (ADM), or others. *(Names of formally appointed or informal ADM's should be noted on the ACP/GCD Tracking Record)*
- ☐ This is an interim GCD Order prior to conversation with patient or ADM.

History/Current Status of GCD Order
Indicate one of the following
- ☐ This is the first GCD Order I am aware of for this patient.
- ☐ This GCD Order is a revision from the most recent prior GCD *(See ACP/GCD Tracking Record for details of previous GCD Order).*
- ☐ This GCD Order is unchanged from the most recent prior GCD.

Name of Physician/Designated Most Responsible Health Practitioner who has ordered this GCD	Discipline
Signature	Date *(yyyy-Mon-dd)*

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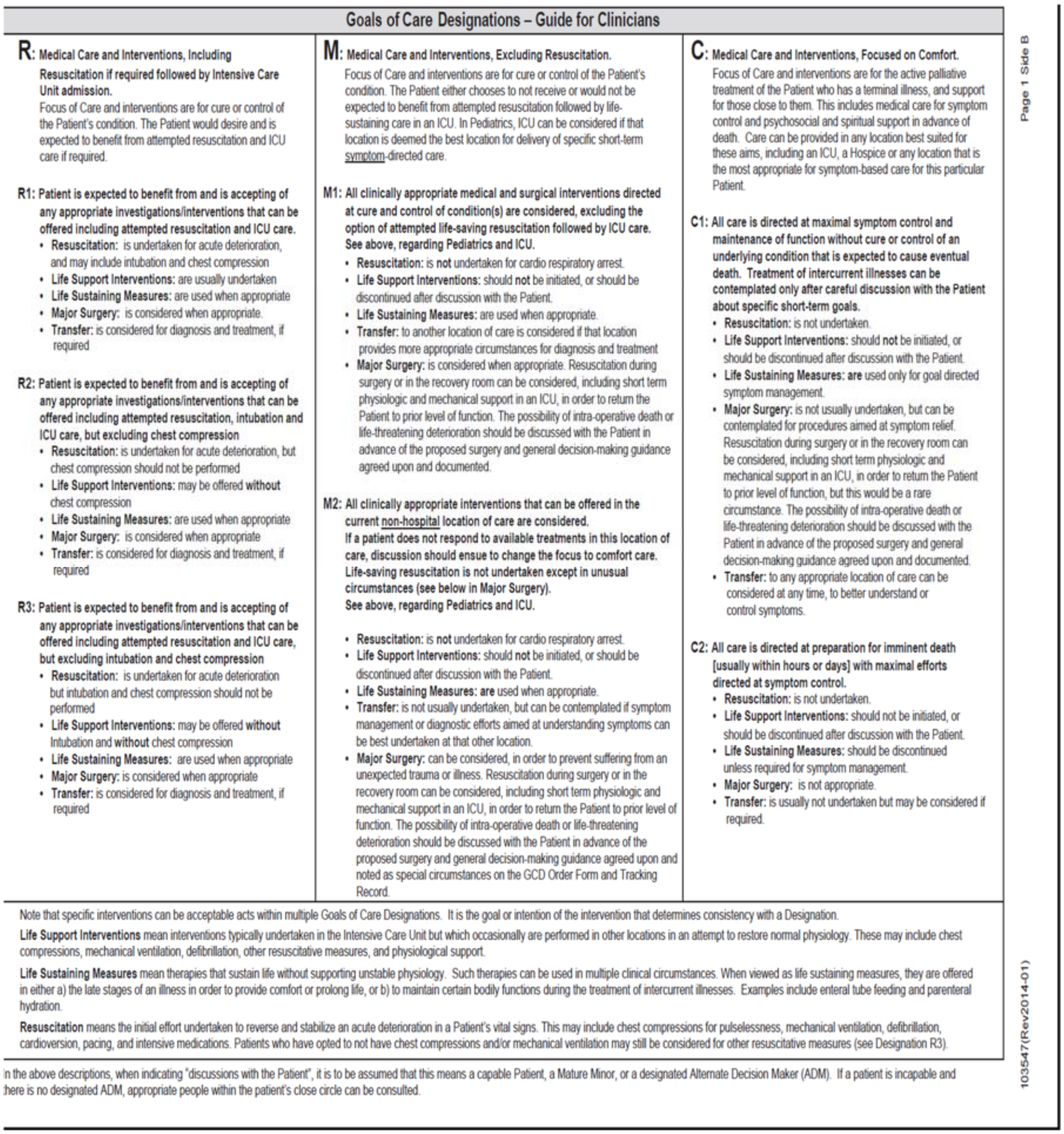
Source: https://www.albertahealthservices.ca/frm-103547.pdf



Goals of Care Designations – Guide for Clinicians

R: Medical Care and Interventions, Including Resuscitation if required followed by Intensive Care Unit admission.

Focus of Care and interventions are for cure or control of the Patient's condition. The Patient would desire and is expected to benefit from attempted resuscitation and ICU care if required.

R1: Patient is expected to benefit from and is accepting of any appropriate investigations/interventions that can be offered including attempted resuscitation and ICU care.

- **Resuscitation:** is undertaken for acute deterioration, and may include intubation and chest compression
- **Life Support Interventions:** are usually undertaken
- **Life Sustaining Measures:** are used when appropriate
- **Major Surgery:** is considered when appropriate.
- **Transfer:** is considered for diagnosis and treatment, if required

R2: Patient is expected to benefit from and is accepting of any appropriate investigations/interventions that can be offered including attempted resuscitation, intubation and ICU care, but excluding chest compression

- **Resuscitation:** is undertaken for acute deterioration, but chest compression should not be performed
- **Life Support Interventions:** may be offered **without** chest compression
- **Life Sustaining Measures:** are used when appropriate
- **Major Surgery:** is considered when appropriate
- **Transfer:** is considered for diagnosis and treatment, if required

R3: Patient is expected to benefit from and is accepting of any appropriate investigations/interventions that can be offered including attempted resuscitation and ICU care, but excluding intubation and chest compression

- **Resuscitation:** is undertaken for acute deterioration but intubation and chest compression should not be performed
- **Life Support Interventions:** may be offered **without** Intubation and **without** chest compression
- **Life Sustaining Measures:** are used when appropriate
- **Major Surgery:** is considered when appropriate
- **Transfer:** is considered for diagnosis and treatment, if required

M: Medical Care and Interventions, Excluding Resuscitation.

Focus of Care and interventions are for cure or control of the Patient's condition. The Patient either chooses to not receive or would not be expected to benefit from attempted resuscitation followed by life-sustaining care in an ICU. In Pediatrics, ICU can be considered if that location is deemed the best location for delivery of specific short-term symptom-directed care.

M1: All clinically appropriate medical and surgical interventions directed at cure and control of condition(s) are considered, excluding the option of attempted life-saving resuscitation followed by ICU care. See above, regarding Pediatrics and ICU.

- **Resuscitation:** is **not** undertaken for cardio respiratory arrest.
- **Life Support Interventions:** should **not** be initiated, or should be discontinued after discussion with the Patient.
- **Life Sustaining Measures:** are used when appropriate.
- **Transfer:** to another location of care is considered if that location provides more appropriate circumstances for diagnosis and treatment
- **Major Surgery:** is considered when appropriate. Resuscitation during surgery or in the recovery room can be considered, including short term physiologic and mechanical support in an ICU, in order to return the Patient to prior level of function. The possibility of intra-operative death or life-threatening deterioration should be discussed with the Patient in advance of the proposed surgery and general decision-making guidance agreed upon and documented.

M2: All clinically appropriate interventions that can be offered in the current non-hospital location of care are considered.
If a patient does not respond to available treatments in this location of care, discussion should ensue to change the focus to comfort care. Life-saving resuscitation is not undertaken except in unusual circumstances (see below in Major Surgery).
See above, regarding Pediatrics and ICU.

- **Resuscitation:** is **not** undertaken for cardio respiratory arrest.
- **Life Support Interventions:** should **not** be initiated, or should be discontinued after discussion with the Patient.
- **Life Sustaining Measures: are** used when appropriate.
- **Transfer:** is not usually undertaken, but can be contemplated if symptom management or diagnostic efforts aimed at understanding symptoms can be best undertaken at that other location.
- **Major Surgery:** can be considered, in order to prevent suffering from an unexpected trauma or illness. Resuscitation during surgery or in the recovery room can be considered, including short term physiologic and mechanical support in an ICU, in order to return the Patient to prior level of function. The possibility of intra-operative death or life-threatening deterioration should be discussed with the Patient in advance of the proposed surgery and general decision-making guidance agreed upon and noted as special circumstances on the GCD Order Form and Tracking Record.

C: Medical Care and Interventions, Focused on Comfort.

Focus of Care and interventions are for the active palliative treatment of the Patient who has a terminal illness, and support for those close to them. This includes medical care for symptom control and psychosocial and spiritual support in advance of death. Care can be provided in any location best suited for these aims, including an ICU, a Hospice or any location that is the most appropriate for symptom-based care for this particular Patient.

C1: All care is directed at maximal symptom control and maintenance of function without cure or control of an underlying condition that is expected to cause eventual death. Treatment of intercurrent illnesses can be contemplated only after careful discussion with the Patient about specific short-term goals.

- **Resuscitation:** is not undertaken.
- **Life Support Interventions:** should **not** be initiated, or should be discontinued after discussion with the Patient.
- **Life Sustaining Measures: are** used only for goal directed symptom management.
- **Major Surgery:** is not usually undertaken, but can be contemplated for procedures aimed at symptom relief. Resuscitation during surgery or in the recovery room can be considered, including short term physiologic and mechanical support in an ICU, in order to return the Patient to prior level of function, but this would be a rare circumstance. The possibility of intra-operative death or life-threatening deterioration should be discussed with the Patient in advance of the proposed surgery and general decision-making guidance agreed upon and documented.
- **Transfer:** to any appropriate location of care can be considered at any time, to better understand or control symptoms.

C2: All care is directed at preparation for imminent death [usually within hours or days] with maximal efforts directed at symptom control.

- **Resuscitation:** is not undertaken.
- **Life Support Interventions:** should not be initiated, or should be discontinued after discussion with the Patient.
- **Life Sustaining Measures:** should be discontinued unless required for symptom management.
- **Major Surgery:** is not appropriate.
- **Transfer:** is usually not undertaken but may be considered if required.

Note that specific interventions can be acceptable acts within multiple Goals of Care Designations. It is the goal or intention of the intervention that determines consistency with a Designation.

Life Support Interventions mean interventions typically undertaken in the Intensive Care Unit but which occasionally are performed in other locations in an attempt to restore normal physiology. These may include chest compressions, mechanical ventilation, defibrillation, other resuscitative measures, and physiological support.

Life Sustaining Measures mean therapies that sustain life without supporting unstable physiology. Such therapies can be used in multiple clinical circumstances. When viewed as life sustaining measures, they are offered in either a) the late stages of an illness in order to provide comfort or prolong life, or b) to maintain certain bodily functions during the treatment of intercurrent illnesses. Examples include enteral tube feeding and parenteral hydration.

Resuscitation means the initial effort undertaken to reverse and stabilize an acute deterioration in a Patient's vital signs. This may include chest compressions for pulselessness, mechanical ventilation, defibrillation, cardioversion, pacing, and intensive medications. Patients who have opted to not have chest compressions and/or mechanical ventilation may still be considered for other resuscitative measures (see Designation R3).

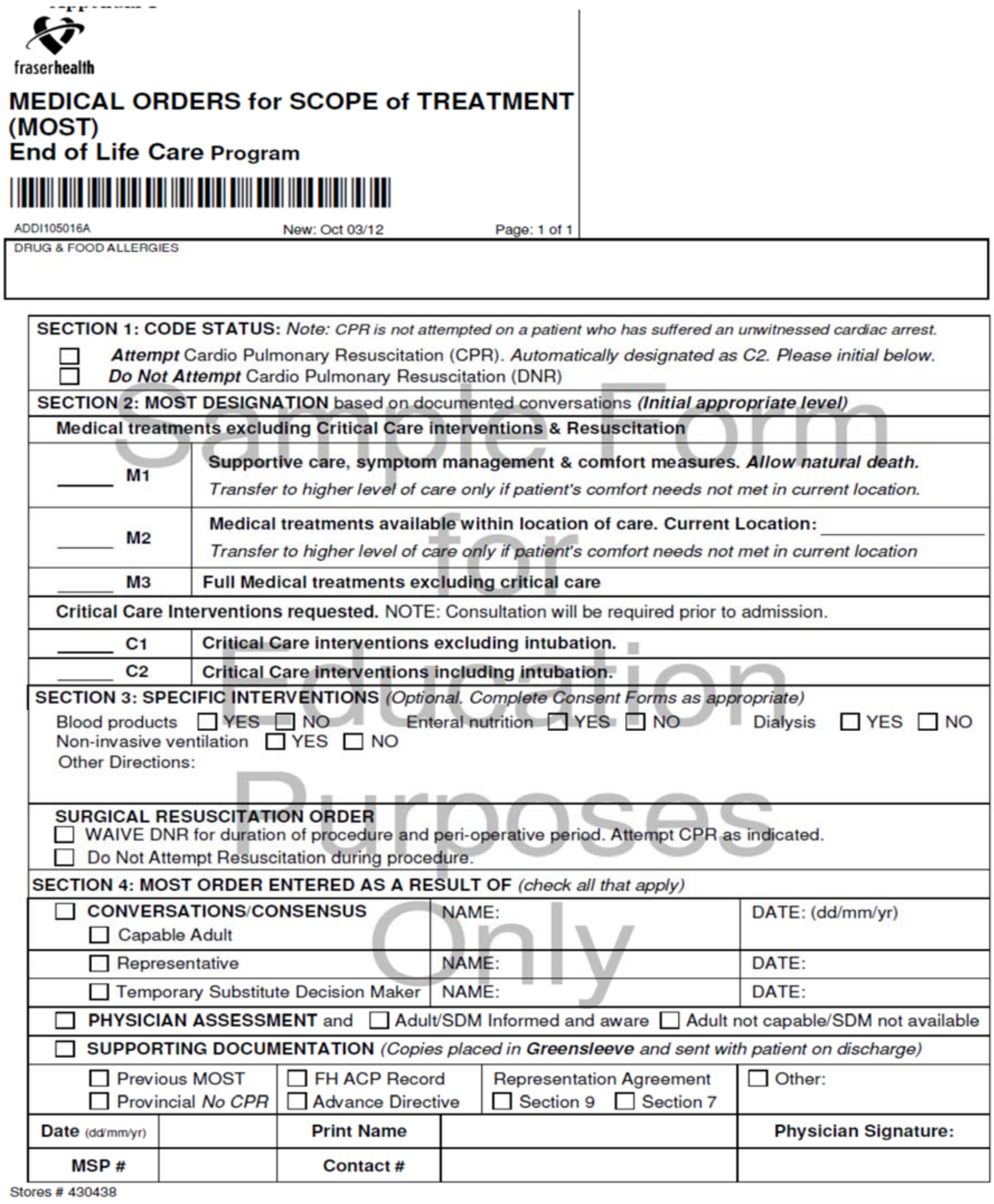
n the above descriptions, when indicating "discussions with the Patient", it is to be assumed that this means a capable Patient, a Mature Minor, or a designated Alternate Decision Maker (ADM). If a patient is incapable and here is no designated ADM, appropriate people within the patient's close circle can be consulted.

Page 1 Side B

103547(Rev2014-01)

Source: https://www.albertahealthservices.ca/frm-103547.pdf

Appendix D: Medical Orders for Scope of Treatment: Fraser Health Authority



fraserhealth

MEDICAL ORDERS for SCOPE of TREATMENT (MOST)
End of Life Care Program

ADDI105016A New: Oct 03/12 Page: 1 of 1

DRUG & FOOD ALLERGIES

SECTION 1: CODE STATUS: *Note: CPR is not attempted on a patient who has suffered an unwitnessed cardiac arrest.*

☐ ***Attempt*** Cardio Pulmonary Resuscitation (CPR). *Automatically designated as C2. Please initial below.*
☐ ***Do Not Attempt*** Cardio Pulmonary Resuscitation (DNR)

SECTION 2: MOST DESIGNATION based on documented conversations ***(Initial appropriate level)***

Medical treatments excluding Critical Care interventions & Resuscitation

______	**M1**	**Supportive care, symptom management & comfort measures. *Allow natural death.*** *Transfer to higher level of care only if patient's comfort needs not met in current location.*
______	**M2**	**Medical treatments available within location of care. Current Location:** ______________ *Transfer to higher level of care only if patient's comfort needs not met in current location*
______	**M3**	**Full Medical treatments excluding critical care**

Critical Care Interventions requested. NOTE: Consultation will be required prior to admission.

______	**C1**	**Critical Care interventions excluding intubation.**
______	**C2**	**Critical Care interventions including intubation.**

SECTION 3: SPECIFIC INTERVENTIONS *(Optional. Complete Consent Forms as appropriate)*

Blood products ☐ YES ☐ NO Enteral nutrition ☐ YES ☐ NO Dialysis ☐ YES ☐ NO
Non-invasive ventilation ☐ YES ☐ NO
Other Directions:

SURGICAL RESUSCITATION ORDER
☐ WAIVE DNR for duration of procedure and peri-operative period. Attempt CPR as indicated.
☐ Do Not Attempt Resuscitation during procedure.

SECTION 4: MOST ORDER ENTERED AS A RESULT OF *(check all that apply)*

☐ **CONVERSATIONS/CONSENSUS** ☐ Capable Adult	NAME:	DATE: (dd/mm/yr)
☐ Representative	NAME:	DATE:
☐ Temporary Substitute Decision Maker	NAME:	DATE:

☐ **PHYSICIAN ASSESSMENT** and ☐ Adult/SDM Informed and aware ☐ Adult not capable/SDM not available

☐ **SUPPORTING DOCUMENTATION** *(Copies placed in **Greensleeve** and sent with patient on discharge)*

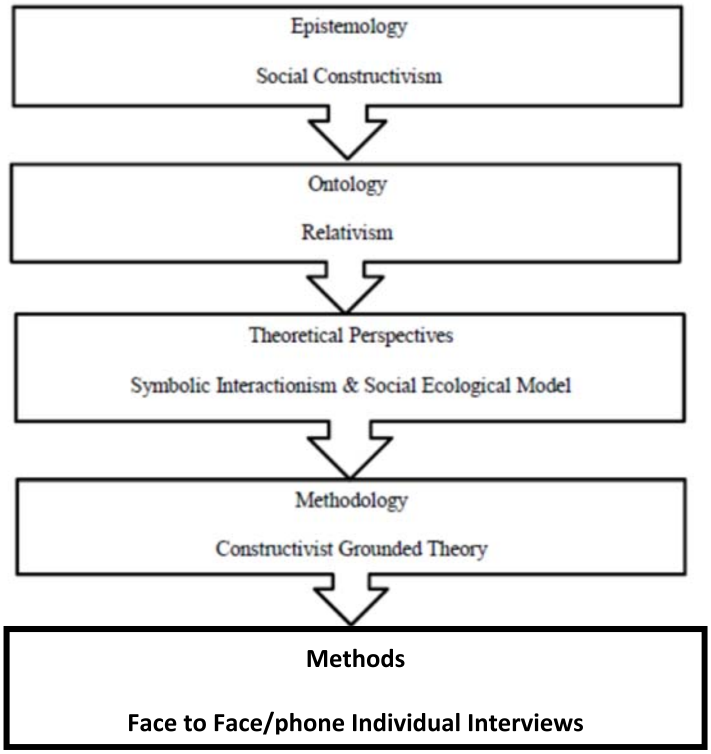
☐ Previous MOST ☐ Provincial *No CPR*	☐ FH ACP Record ☐ Advance Directive	Representation Agreement ☐ Section 9 ☐ Section 7	☐ Other:

Date (dd/mm/yr)		**Print Name**		**Physician Signature:**
MSP #		**Contact #**		

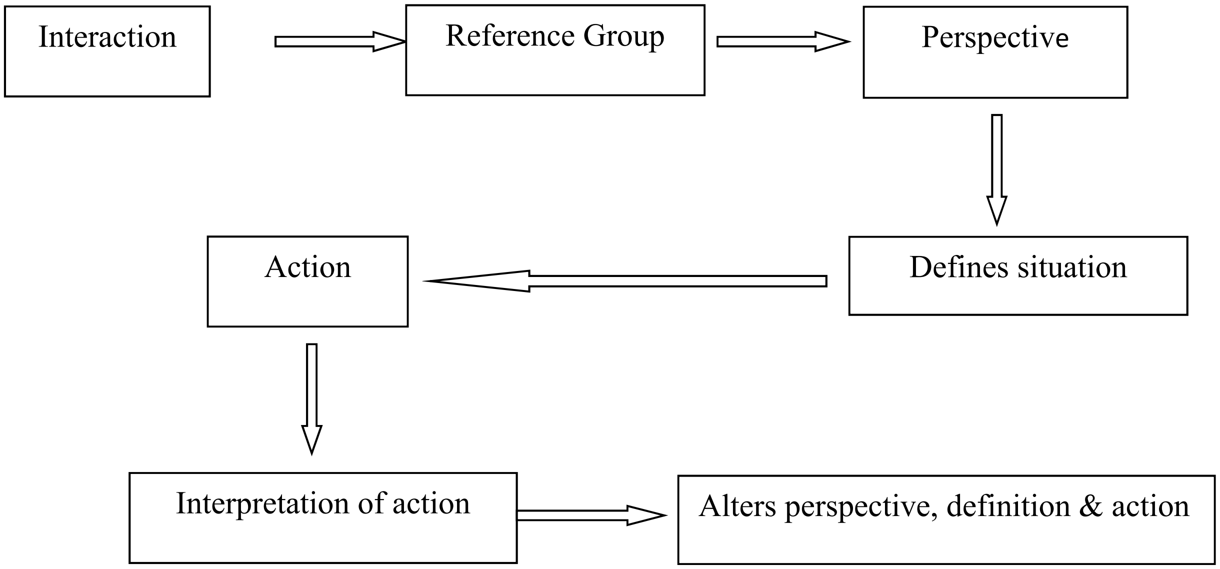
Stores # 430438

Source:
http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.699.3680&rep=rep1&type=pdf

Appendix: E Schematic Representation of the Research paradigm

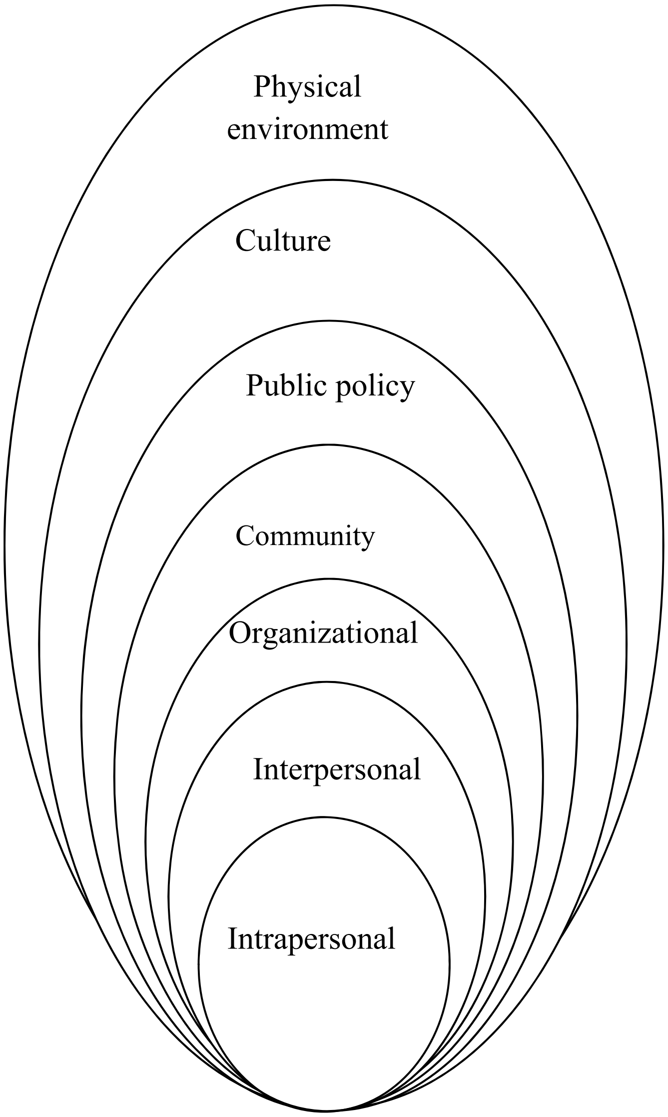


Appendix F: Symbolic Interaction Process



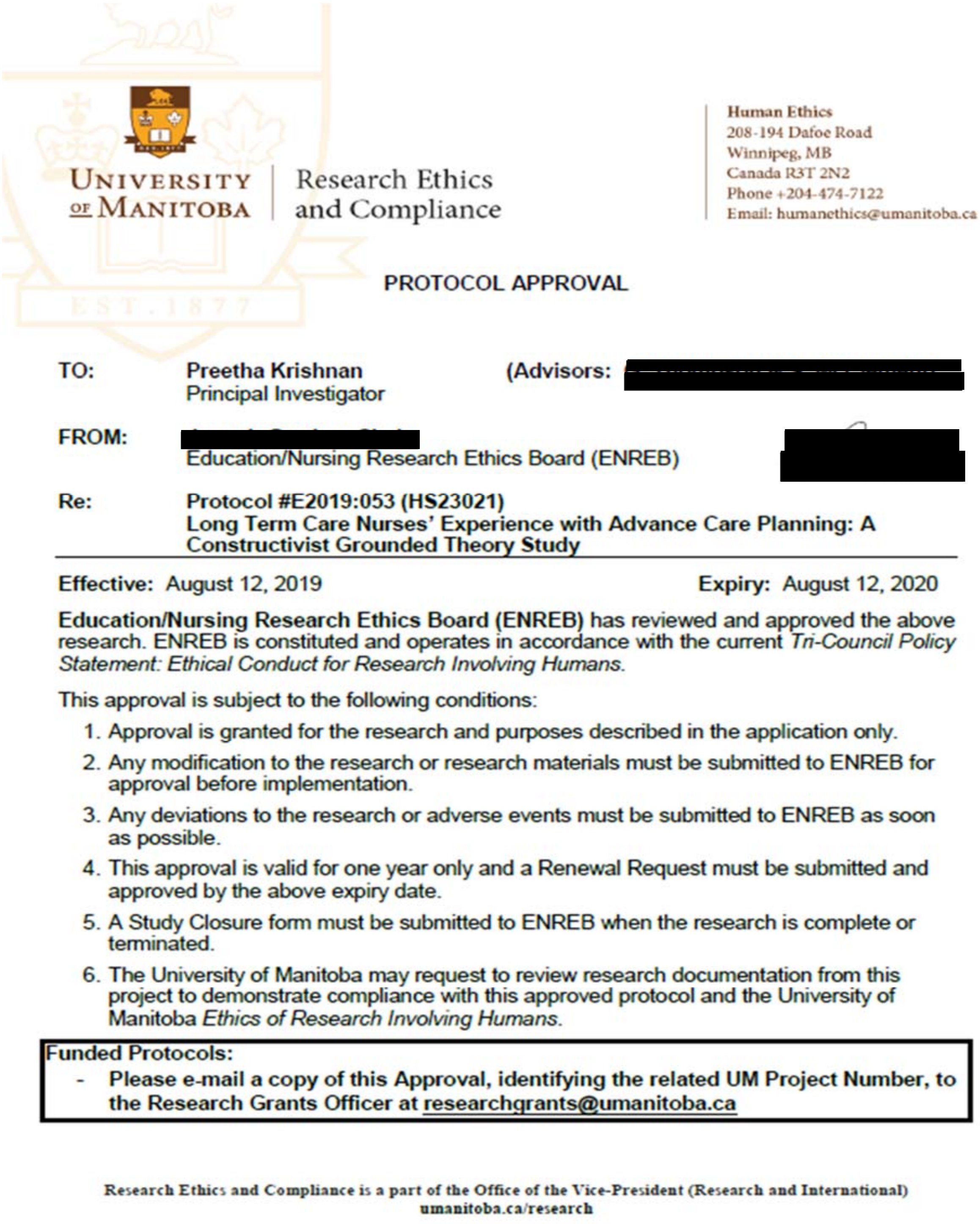
Source: Burbank & Martins, 2009; Charon, 2010

Appendix G: Socio-Ecological Model



Source: Simons-Morton et al. (2012)

Appendix H: University of Manitoba Ethics Research Board Approval



UNIVERSITY OF MANITOBA | Research Ethics and Compliance

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Email: humanethics@umanitoba.ca

PROTOCOL APPROVAL

TO: **Preetha Krishnan** **(Advisors:** [redacted]
Principal Investigator

FROM: [redacted]
Education/Nursing Research Ethics Board (ENREB) [redacted]

Re: **Protocol #E2019:053 (HS23021)**
Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study

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Effective: August 12, 2019 **Expiry:** August 12, 2020

Education/Nursing Research Ethics Board (ENREB) has reviewed and approved the above research. ENREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.*

This approval is subject to the following conditions:

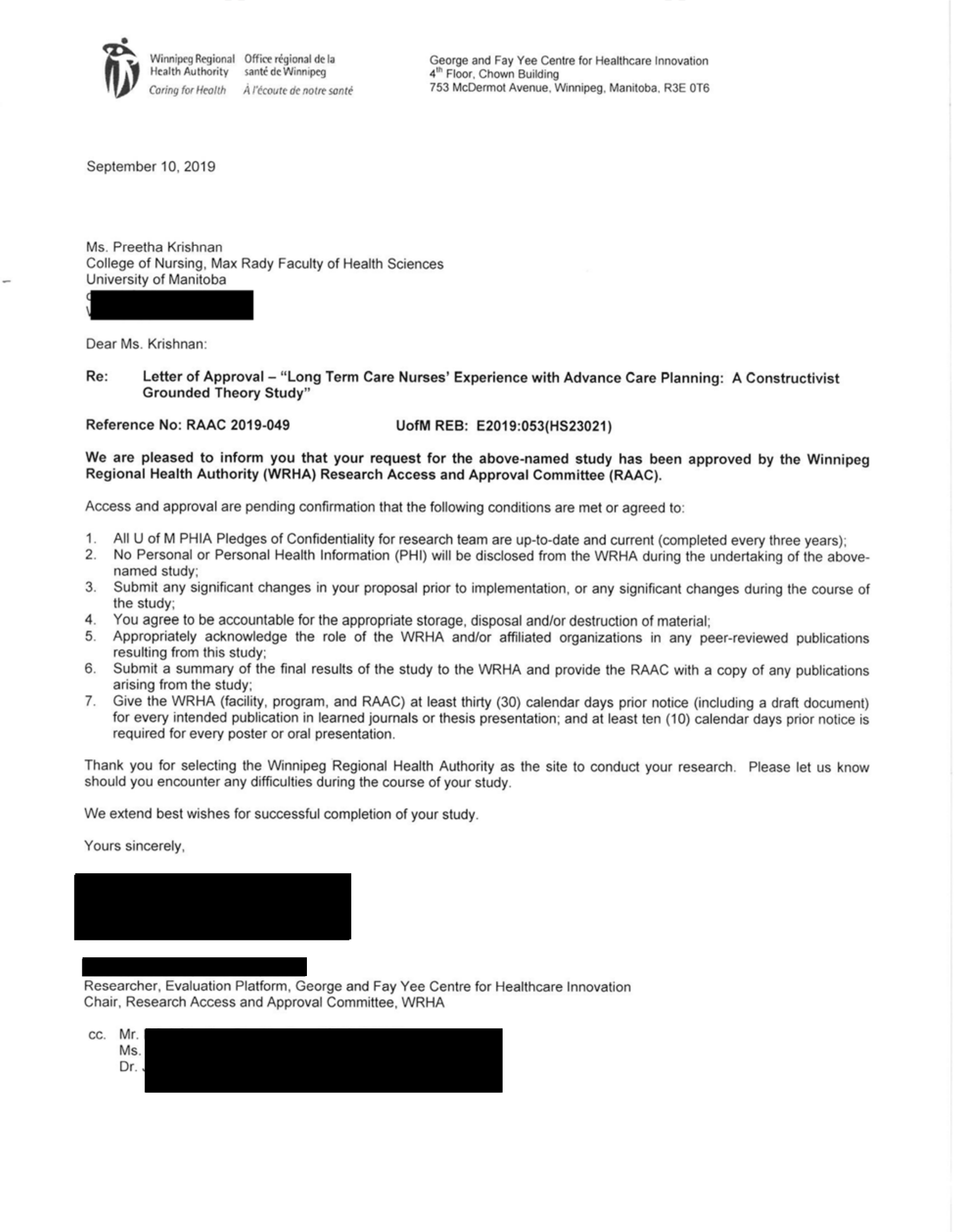
1. Approval is granted for the research and purposes described in the application only.
2. Any modification to the research or research materials must be submitted to ENREB for approval before implementation.
3. Any deviations to the research or adverse events must be submitted to ENREB as soon as possible.
4. This approval is valid for one year only and a Renewal Request must be submitted and approved by the above expiry date.
5. A Study Closure form must be submitted to ENREB when the research is complete or terminated.
6. The University of Manitoba may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans.*

Funded Protocols:

- **Please e-mail a copy of this Approval, identifying the related UM Project Number, to the Research Grants Officer at researchgrants@umanitoba.ca**

Research Ethics and Compliance is a part of the Office of the Vice-President (Research and International)
umanitoba.ca/research

Appendix I: WRHA Research Access and Approval



Winnipeg Regional Health Authority
Caring for Health
Office régional de la santé de Winnipeg
À l'écoute de notre santé

George and Fay Yee Centre for Healthcare Innovation
4th Floor, Chown Building
753 McDermot Avenue, Winnipeg, Manitoba, R3E 0T6

September 10, 2019

Ms. Preetha Krishnan
College of Nursing, Max Rady Faculty of Health Sciences
University of Manitoba
[redacted]

Dear Ms. Krishnan:

Re: Letter of Approval – "Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study"

Reference No: RAAC 2019-049 UofM REB: E2019:053(HS23021)

We are pleased to inform you that your request for the above-named study has been approved by the Winnipeg Regional Health Authority (WRHA) Research Access and Approval Committee (RAAC).

Access and approval are pending confirmation that the following conditions are met or agreed to:

1. All U of M PHIA Pledges of Confidentiality for research team are up-to-date and current (completed every three years);
2. No Personal or Personal Health Information (PHI) will be disclosed from the WRHA during the undertaking of the above-named study;
3. Submit any significant changes in your proposal prior to implementation, or any significant changes during the course of the study;
4. You agree to be accountable for the appropriate storage, disposal and/or destruction of material;
5. Appropriately acknowledge the role of the WRHA and/or affiliated organizations in any peer-reviewed publications resulting from this study;
6. Submit a summary of the final results of the study to the WRHA and provide the RAAC with a copy of any publications arising from the study;
7. Give the WRHA (facility, program, and RAAC) at least thirty (30) calendar days prior notice (including a draft document) for every intended publication in learned journals or thesis presentation; and at least ten (10) calendar days prior notice is required for every poster or oral presentation.

Thank you for selecting the Winnipeg Regional Health Authority as the site to conduct your research. Please let us know should you encounter any difficulties during the course of your study.

We extend best wishes for successful completion of your study.

Yours sincerely,

[redacted]

[redacted]
Researcher, Evaluation Platform, George and Fay Yee Centre for Healthcare Innovation
Chair, Research Access and Approval Committee, WRHA

cc. Mr. [redacted]
Ms.
Dr.

Appendix J: Script for Presenting the Study at the Monthly WRHA LTC Directors of Cares' Meeting

Research Title: Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study

Researcher: Preetha Krishnan PhD Candidate

My name is Preetha Krishnan and I am a PhD student in the College of Nursing at the University of Manitoba. I am also a nurse practitioner working at Misericordia Transitional care unit and Misericordia Place in Winnipeg. I have more than a decade of experience in working with long term care nurses.

As part of the requirements for the completion of my PhD degree, I am conducting a research project to understand the experience of long term care nurses with respect to advance care planning. The title of this study is: *Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study.* In this study, I will attempt to identify a linkage between the thoughts and understandings of these nurses and the way they undertake the advance planning with resident/family. The ultimate goal of my research is to develop a theoretical understanding of the ACP process from the perspectives of LTC nurses.

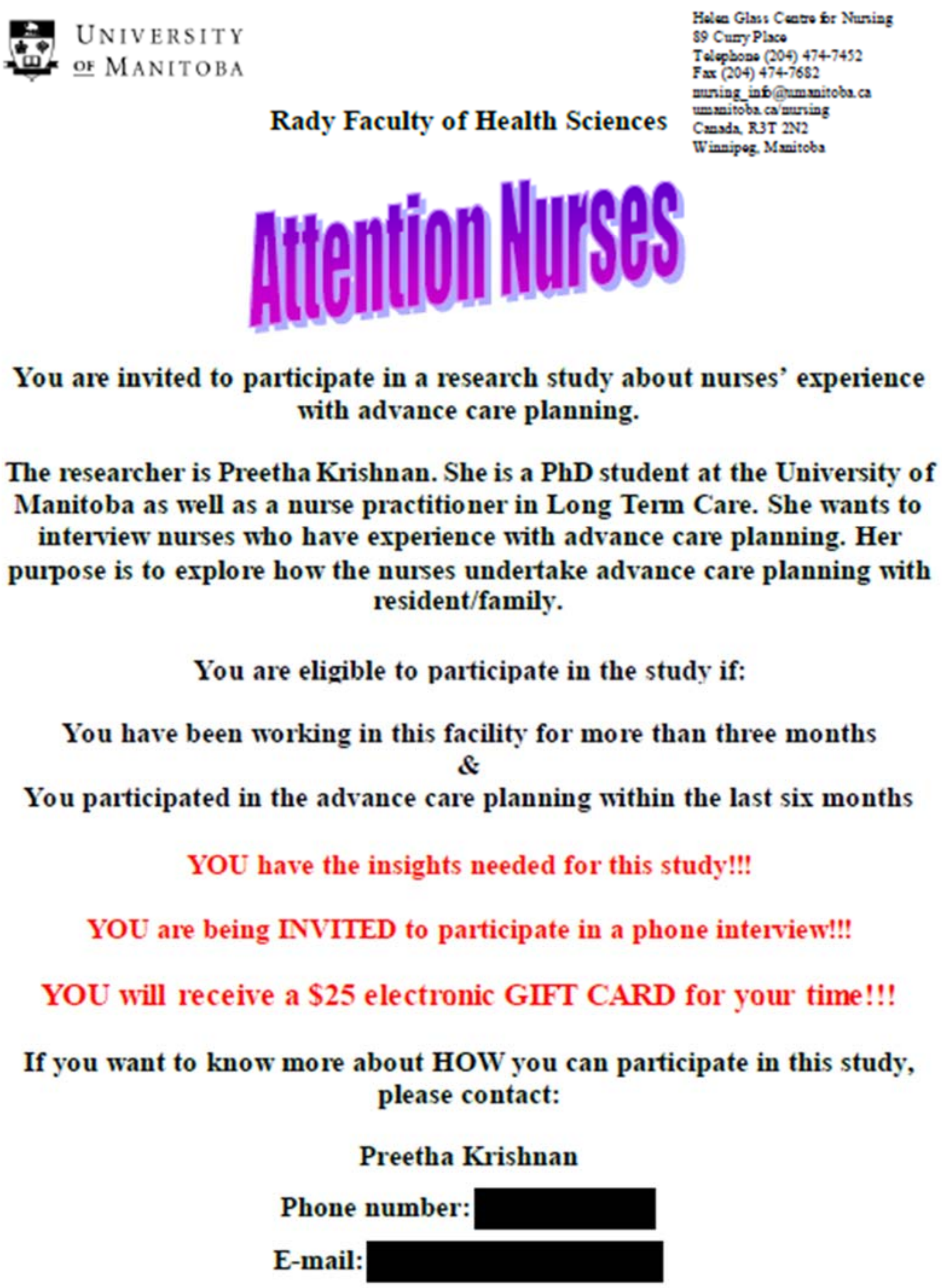
I would like to have the nurses from your facility participate in my study.
The participant will participate in an individual audio-taped face-face interview with me. Prior to the interview I will obtain written consent from the participant and each nurse will receive $25 gift card for the appreciation of his/her participation in the study. All interviews will occur outside of the nurses' regular working hours and will therefore take place on the participant's own time.

I am requesting the following assistance from you.

- Recruiting nurses to participate in this study. I would like to meet with nurses at a convenient time, such as a staff meeting or break time, to explain the study and invite these nurses to participate in this study. I would like to meet with nurses once. This meeting would take about fifteen minutes.
- Permission to put posters up on your unit advertising the study to nurses.
- Permission to leave information sheets and consent forms on the units. The consent forms would be left in a cardboard box identified with my name and the title of the study.

This study provides an important opportunity for nurses to participate in research that can have a direct impact on the care they provide to residents at end-of-life.
I hope that you will be able to provide the assistance that I am requesting.
At the request of your facility, I will be pleased to provide your facility with a copy of the findings. I will also be available to present the study findings to staff.

Appendix K: Recruitment Poster



UNIVERSITY OF MANITOBA

Helen Glass Centre for Nursing
89 Curry Place
Telephone (204) 474-7452
Fax (204) 474-7682
nursing_info@umanitoba.ca
umanitoba.ca/nursing
Canada, R3T 2N2
Winnipeg, Manitoba

Rady Faculty of Health Sciences

Attention Nurses

You are invited to participate in a research study about nurses' experience with advance care planning.

The researcher is Preetha Krishnan. She is a PhD student at the University of Manitoba as well as a nurse practitioner in Long Term Care. She wants to interview nurses who have experience with advance care planning. Her purpose is to explore how the nurses undertake advance care planning with resident/family.

You are eligible to participate in the study if:

You have been working in this facility for more than three months
&
You participated in the advance care planning within the last six months

YOU have the insights needed for this study!!!

YOU are being INVITED to participate in a phone interview!!!

YOU will receive a $25 electronic GIFT CARD for your time!!!

If you want to know more about HOW you can participate in this study, please contact:

Preetha Krishnan

Phone number: [redacted]

E-mail: [redacted]

Appendix L: Script to Recruit Nurses at the Nurses' Meeting

Research Title: Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study

Researcher: Preetha Krishnan, PhD Candidate

Thank you for agreeing to meet with me.

My name is Preetha Krishnan. I am a PhD student in the nursing at the University of Manitoba. I am conducting a research project about how nurses engage in advance care planning with the resident/family at LTC as part of the requirements for graduation from this program. The name of this study is Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study. Dr. Genevieve Thompson and Dr. Susan McClement are my advisors. This research has been approved by University of Manitoba Ethics Review Board and the and the Winnipeg Regional Health Authority Research Access and Approval Committee.

I am also a nurse practitioner working in Misericordia place & Misericordia TCU. I am working in LTC for more than ten years as a nurse practitioner. I work with many nurses like you. I understand the important contribution that you make to the care of your residents. Did you know that nurses are the eyes and ears of the physicians who work in these settings? You interact with the residents, families and the physicians on a daily basis. You play a major role in advance care planning and end-of-lifecare in these settings. You also make sure the residents receive the right care at the right time. Since you spend so much time with the residents and their families, you are the people who have the greatest amount of knowledge about these residents' health status and their wishes. This study is about how you undertake advance care planning with these residents and their families.

I am asking you to participate in this study. Your participation in this study is completely voluntary. There are no negative consequences if you decide not to participate.

Participation in this study includes an interview and filling out a socio-demographic form.

I would interview you alone. This interview will take about an hour and a half. All interviews will occur outside of your regular working hours on your own time. The interviews will be recorded using a digital recorder that will only record your voice. I will take notes during the interview also. You are free to withdraw from the study at any time during the interview or within 48 hours of the interview, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence.

You will receive a $ 25 gift card as an expression of appreciation for your participation in the interview and you may keep the gift card regardless of whether you decide to discontinue your participantion in the interview.

By participating in this study, you will have a unique opportunity to talk about your experiences with advance care planning.

For example, you will be able to tell me how you talk to the resident/family about advance care planning, what things help you to facilitate advance care planning, what things prevent you to engage in ACP.

The findings from this study

May help to improve end-of-lifecare and advance care planning in LTC
May be used by colleges and universities to train nurses on advance care planning.
May also be used by policy makers and administrators to develop/modify advance care planning

Therefore, by participating in this study, you can contribute to the improvement of end-of-lifecare in LTC by sharing your experiences and perceptions of ACP.

Risks associated with Participating in the Study

You might feel distressed about what you are telling me about your experiences with ACP.
If this happens, we can talk about this and you might decide to end the interview. You are free to withdraw from the study at any time during the interview or within 48 hours of the interview and you are able to keep your gift card.

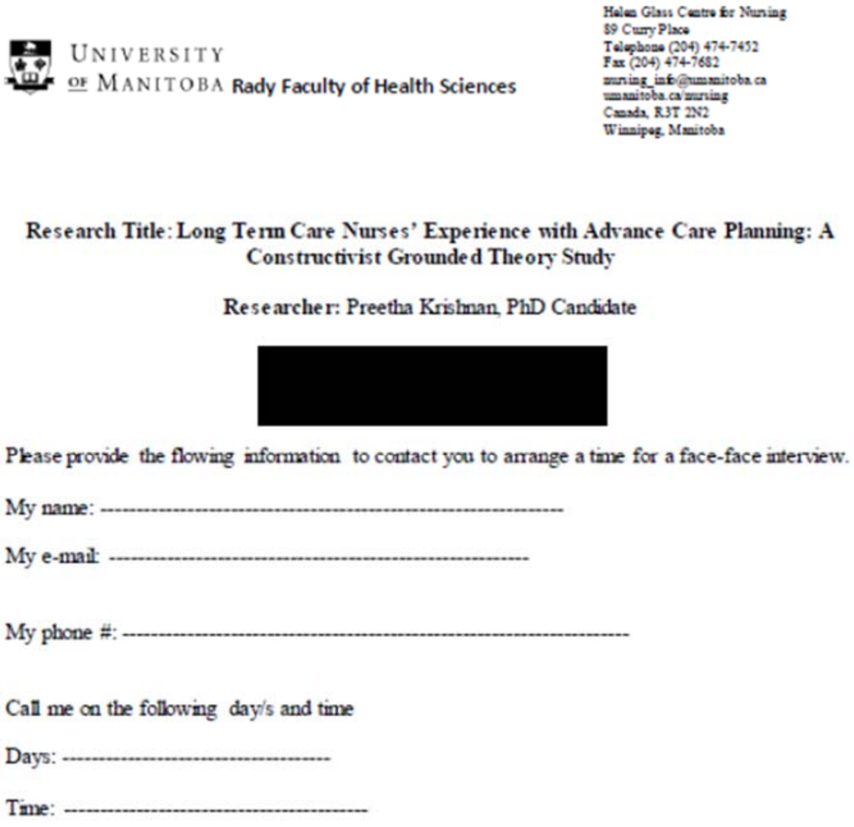
I hope that you will think seriously about taking part in this study. If you want more information, you can call me by telephone or email me. My telephone number and email address are on this information sheet and on a poster that I will leave on your unit.

If you agree to take part in the study, please write your name, phone number/e-mail address and your convenient days of week and time of the day on the sheet for me to call you to set up a time for the interview.

I am leaving a box at the front desk that has the title of the study and my name written on it . You can drop the sheet in the box. I will pick the sheets weekly for the next two weeks. You can also pick up a consent form which is placed near the box. You will need to read or may also want to go over the consent form with someone you know and trust to discuss what it means to you to take part in this study. You can always contact me to discuss with the consent form. I will be happy to discuss any information about the study and the consent form with you. Before the interview I will go over the consent form with you as well.

Thank you for agreeing to meet with me.

Appendix M: Form to Set up Face-to-Face Interview



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Canada, R3T 2N2
Winnipeg, Manitoba

Research Title: Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study

Researcher: Preetha Krishnan, PhD Candidate

[redacted]

Please provide the flowing information to contact you to arrange a time for a face-face interview.

My name: --

My e-mail: --

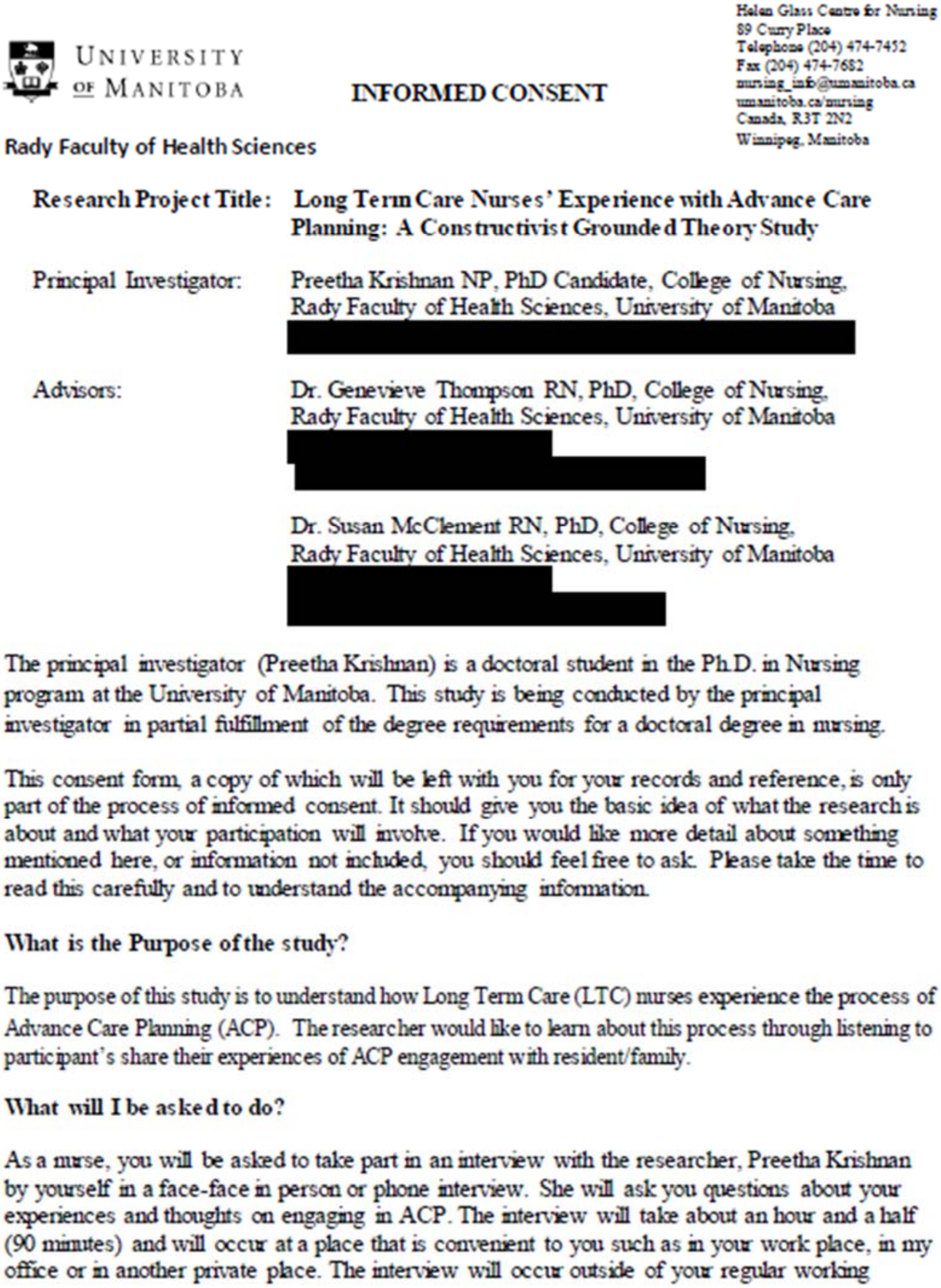
My phone #: --

Call me on the following day/s and time

Days: --------------------------------------

Time: ---

Appendix N: Informed Consent



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INFORMED CONSENT

Research Project Title: **Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study**

Principal Investigator: Preetha Krishnan NP, PhD Candidate, College of Nursing, Rady Faculty of Health Sciences, University of Manitoba
[redacted]

Advisors: Dr. Genevieve Thompson RN, PhD, College of Nursing, Rady Faculty of Health Sciences, University of Manitoba
[redacted]

Dr. Susan McClement RN, PhD, College of Nursing, Rady Faculty of Health Sciences, University of Manitoba
[redacted]

The principal investigator (Preetha Krishnan) is a doctoral student in the Ph.D. in Nursing program at the University of Manitoba. This study is being conducted by the principal investigator in partial fulfillment of the degree requirements for a doctoral degree in nursing.

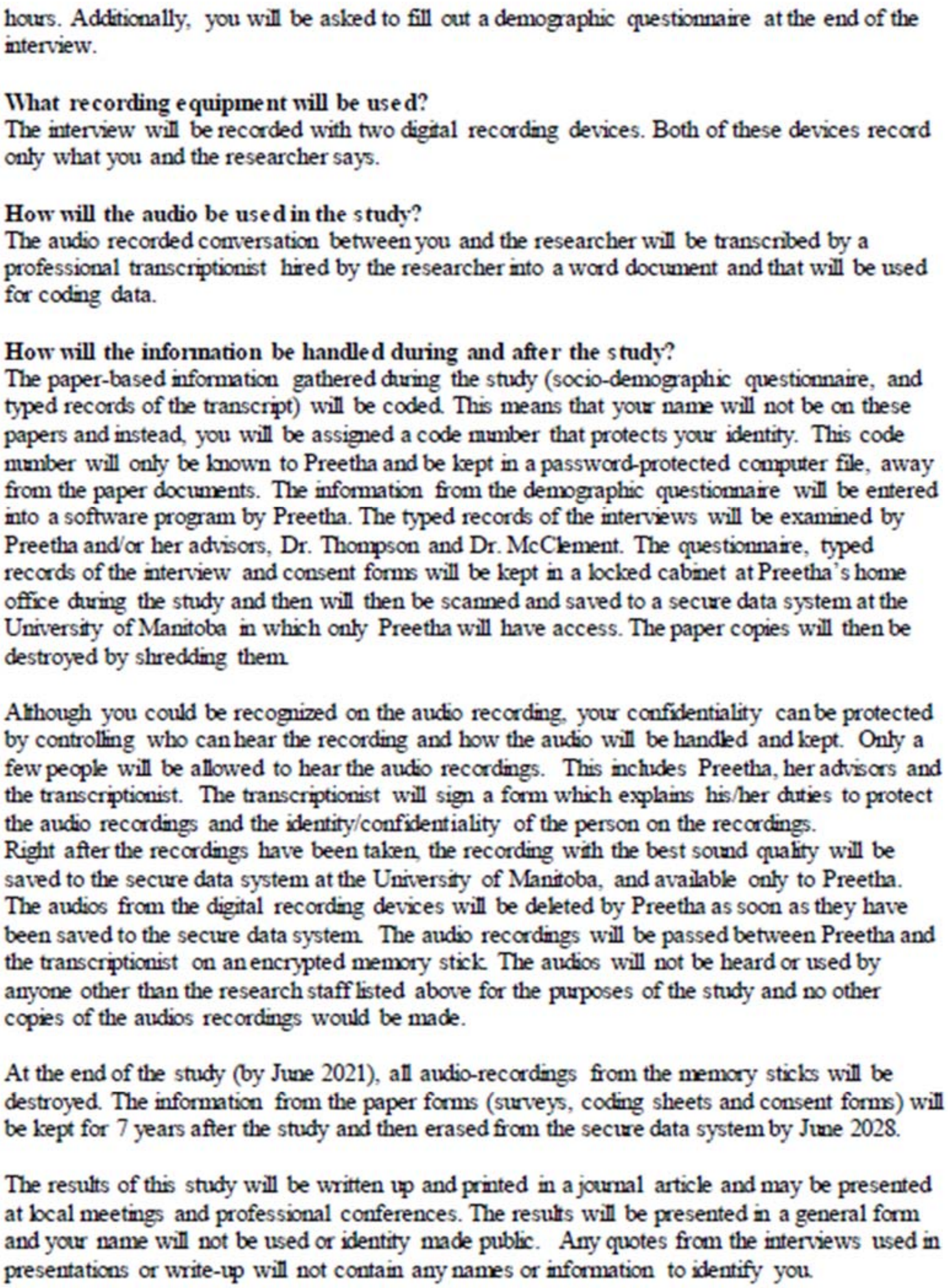
This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included, you should feel free to ask. Please take the time to read this carefully and to understand the accompanying information.

What is the Purpose of the study?

The purpose of this study is to understand how Long Term Care (LTC) nurses experience the process of Advance Care Planning (ACP). The researcher would like to learn about this process through listening to participant's share their experiences of ACP engagement with resident/family.

What will I be asked to do?

As a nurse, you will be asked to take part in an interview with the researcher, Preetha Krishnan by yourself in a face-face in person or phone interview. She will ask you questions about your experiences and thoughts on engaging in ACP. The interview will take about an hour and a half (90 minutes) and will occur at a place that is convenient to you such as in your work place, in my office or in another private place. The interview will occur outside of your regular working



hours. Additionally, you will be asked to fill out a demographic questionnaire at the end of the interview.

What recording equipment will be used?
The interview will be recorded with two digital recording devices. Both of these devices record only what you and the researcher says.

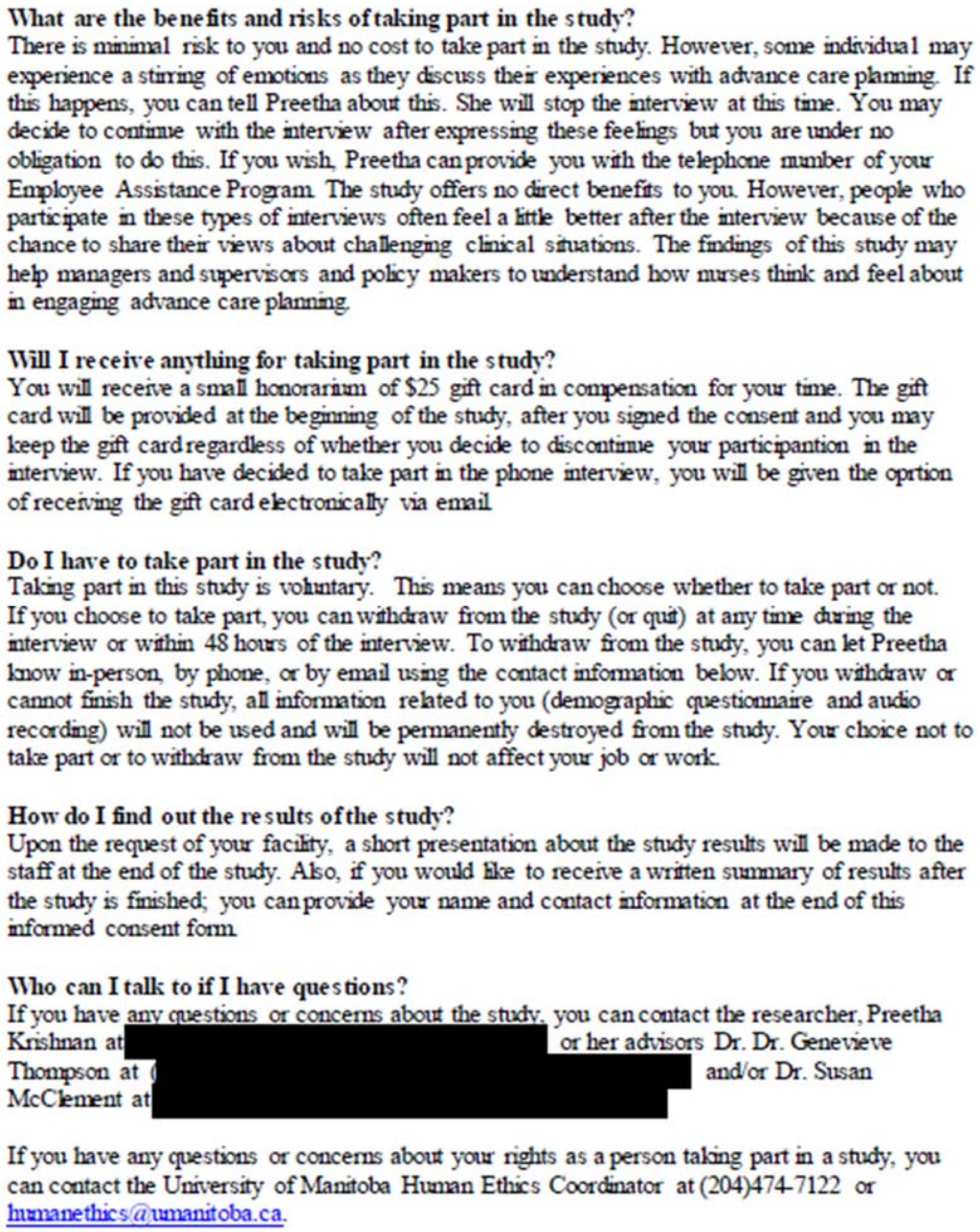
How will the audio be used in the study?
The audio recorded conversation between you and the researcher will be transcribed by a professional transcriptionist hired by the researcher into a word document and that will be used for coding data.

How will the information be handled during and after the study?
The paper-based information gathered during the study (socio-demographic questionnaire, and typed records of the transcript) will be coded. This means that your name will not be on these papers and instead, you will be assigned a code number that protects your identity. This code number will only be known to Preetha and be kept in a password-protected computer file, away from the paper documents. The information from the demographic questionnaire will be entered into a software program by Preetha. The typed records of the interviews will be examined by Preetha and/or her advisors, Dr. Thompson and Dr. McClement. The questionnaire, typed records of the interview and consent forms will be kept in a locked cabinet at Preetha's home office during the study and then will then be scanned and saved to a secure data system at the University of Manitoba in which only Preetha will have access. The paper copies will then be destroyed by shredding them.

Although you could be recognized on the audio recording, your confidentiality can be protected by controlling who can hear the recording and how the audio will be handled and kept. Only a few people will be allowed to hear the audio recordings. This includes Preetha, her advisors and the transcriptionist. The transcriptionist will sign a form which explains his/her duties to protect the audio recordings and the identity/confidentiality of the person on the recordings.
Right after the recordings have been taken, the recording with the best sound quality will be saved to the secure data system at the University of Manitoba, and available only to Preetha. The audios from the digital recording devices will be deleted by Preetha as soon as they have been saved to the secure data system. The audio recordings will be passed between Preetha and the transcriptionist on an encrypted memory stick. The audios will not be heard or used by anyone other than the research staff listed above for the purposes of the study and no other copies of the audios recordings would be made.

At the end of the study (by June 2021), all audio-recordings from the memory sticks will be destroyed. The information from the paper forms (surveys, coding sheets and consent forms) will be kept for 7 years after the study and then erased from the secure data system by June 2028.

The results of this study will be written up and printed in a journal article and may be presented at local meetings and professional conferences. The results will be presented in a general form and your name will not be used or identity made public. Any quotes from the interviews used in presentations or write-up will not contain any names or information to identify you.



What are the benefits and risks of taking part in the study?
There is minimal risk to you and no cost to take part in the study. However, some individual may experience a stirring of emotions as they discuss their experiences with advance care planning. If this happens, you can tell Preetha about this. She will stop the interview at this time. You may decide to continue with the interview after expressing these feelings but you are under no obligation to do this. If you wish, Preetha can provide you with the telephone number of your Employee Assistance Program. The study offers no direct benefits to you. However, people who participate in these types of interviews often feel a little better after the interview because of the chance to share their views about challenging clinical situations. The findings of this study may help managers and supervisors and policy makers to understand how nurses think and feel about in engaging advance care planning.

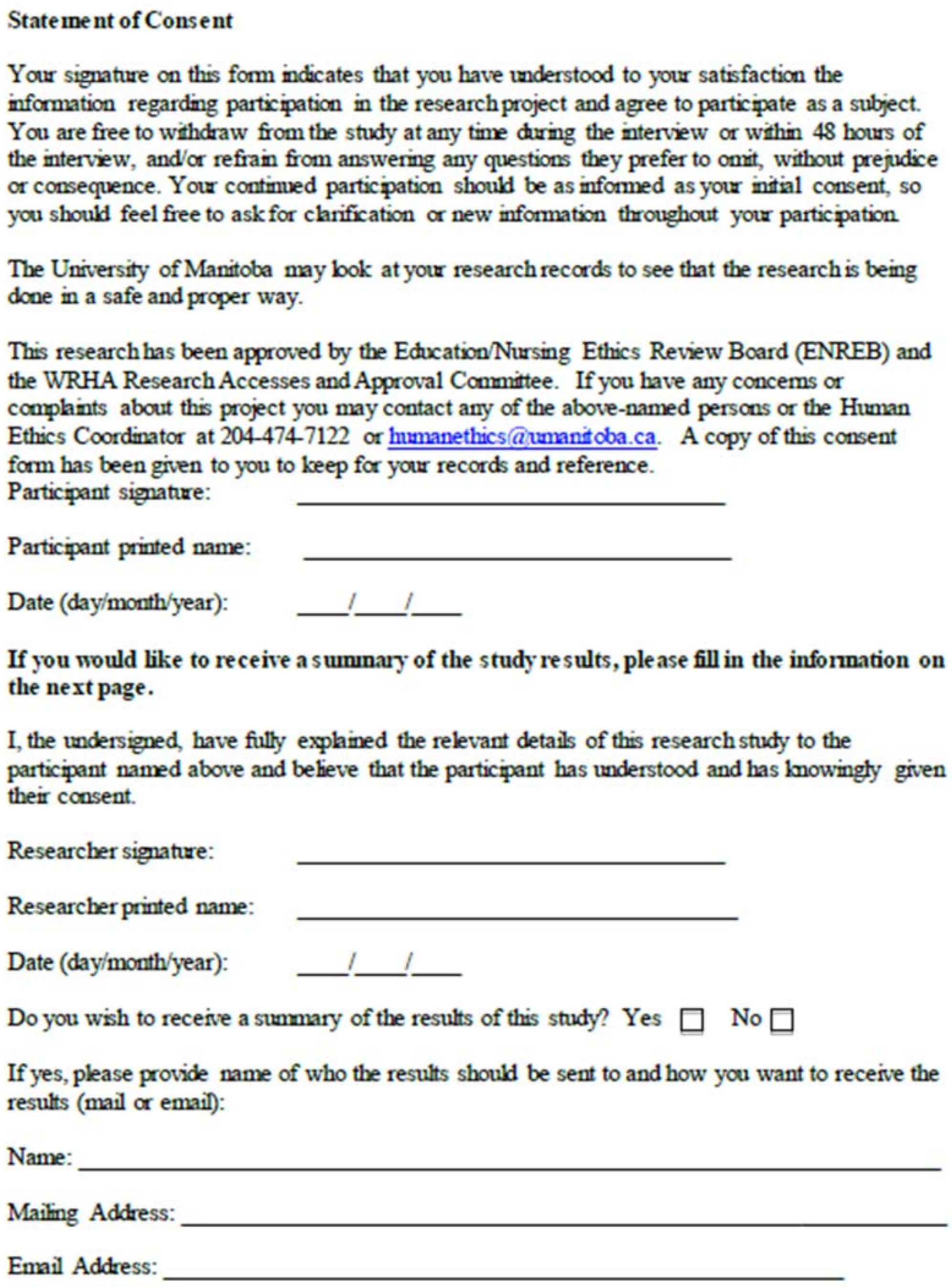
Will I receive anything for taking part in the study?
You will receive a small honorarium of $25 gift card in compensation for your time. The gift card will be provided at the beginning of the study, after you signed the consent and you may keep the gift card regardless of whether you decide to discontinue your participantion in the interview. If you have decided to take part in the phone interview, you will be given the oprtion of receiving the gift card electronically via email.

Do I have to take part in the study?
Taking part in this study is voluntary. This means you can choose whether to take part or not. If you choose to take part, you can withdraw from the study (or quit) at any time during the interview or within 48 hours of the interview. To withdraw from the study, you can let Preetha know in-person, by phone, or by email using the contact information below. If you withdraw or cannot finish the study, all information related to you (demographic questionnaire and audio recording) will not be used and will be permanently destroyed from the study. Your choice not to take part or to withdraw from the study will not affect your job or work.

How do I find out the results of the study?
Upon the request of your facility, a short presentation about the study results will be made to the staff at the end of the study. Also, if you would like to receive a written summary of results after the study is finished; you can provide your name and contact information at the end of this informed consent form.

Who can I talk to if I have questions?
If you have any questions or concerns about the study, you can contact the researcher, Preetha Krishnan at [redacted] or her advisors Dr. Dr. Genevieve Thompson at [redacted] and/or Dr. Susan McClement at [redacted]

If you have any questions or concerns about your rights as a person taking part in a study, you can contact the University of Manitoba Human Ethics Coordinator at (204)474-7122 or humanethics@umanitoba.ca.



Statement of Consent

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. You are free to withdraw from the study at any time during the interview or within 48 hours of the interview, and/or refrain from answering any questions they prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Education/Nursing Ethics Review Board (ENREB) and the WRHA Research Accesses and Approval Committee. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122 or humanethics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Participant signature: ____________________________

Participant printed name: ____________________________

Date (day/month/year): ____/____/____

If you would like to receive a summary of the study results, please fill in the information on the next page.

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

Researcher signature: ____________________________

Researcher printed name: ____________________________

Date (day/month/year): ____/____/____

Do you wish to receive a summary of the results of this study? Yes ☐ No ☐

If yes, please provide name of who the results should be sent to and how you want to receive the results (mail or email):

Name: ____

Mailing Address: ____

Email Address: ____

Appendix O: Socio-Demographic Questionnaire

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Canada, R3T 2N2
Winnipeg, Manitoba

LTC Facility Code:

Participant #:

Alpha numeric code:

Date: Time:
Place of interview:

Duration of interview:

Research Title: Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study

Researcher: Preetha Krishnan, PhD Candidate

1. Current position
    a. Unit nurse----------------------------
    b. Clinical Resource Nurse-------------
    c. Resident Care Manager --------------
    d. Director of Care ----------------------
    e. Other----------------------------- Specify--------------------------
2. Age
    a. 18- 30 years ----------
    b. 31-50 years------------
    c. 51-65 years------------
    d. Over 65 years-----------
3. Gender
    a. Male--------------
    b. Female -----------------
    c. Other ------------
4. Highest Education Attained
    a. Licensed practical nursing diploma-------------
    b. Registered nursing diploma---------------------
    c. Baccalaureate nursing degree -----------------------
    d. Registered psychiatric nursing degree--------------
    e. Master of Nursing ------------------------

5. Do you have any special education/certification in gerontology/long term care/palliative care?
    a. Yes--------------------- Specify ----------------------------
    b. No------------

6. Work status
    a. Full time-------------
    b. Part time---------------- EFT---------
    c. Casual--------------

7. How often have you engaged in advanced care planning (ACP) in the last six months?
    a. Never ---------
    b. Less than 5 times----------
    c. Between 5-10 times-------------
    d. More than 10 times--------------

8. Do you have any formal education on ACP?
    a. Yes------------------------------ Specify----------------------
    b. No--------------------------------

9. Years of experience working as a nurse -----------

10. Years of experience working in Long Term Care (LTC)------------------

11. Length of time worked on the current facility-------------

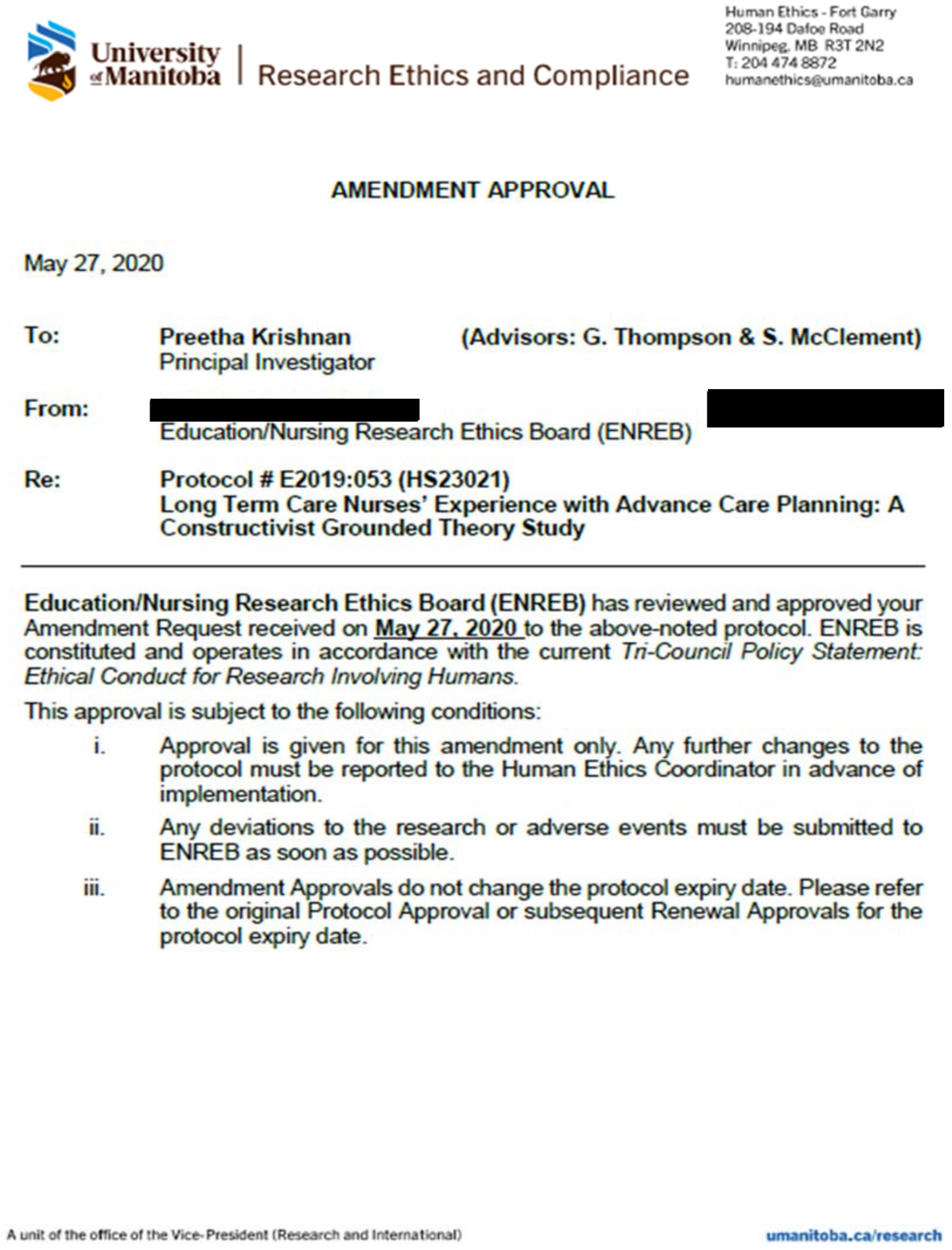
12. Are you working at more than one LTC facility? Yes------------ No--------

13. How would you describe your ethnic origin? -------------------------------------

14. Are you part of a religious or spiritual community?
    a. Yes------------------- Specify---------------------------------- b. No------------

Thank you for participating in this study.

Appendix P: Amendment Approval from Research Ethics Board



University of Manitoba | Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

AMENDMENT APPROVAL

May 27, 2020

To: **Preetha Krishnan** **(Advisors: G. Thompson & S. McClement)**
Principal Investigator

From: [redacted] [redacted]
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol # E2019:053 (HS23021)**
Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study

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Education/Nursing Research Ethics Board (ENREB) has reviewed and approved your Amendment Request received on **May 27, 2020** to the above-noted protocol. ENREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.*

This approval is subject to the following conditions:

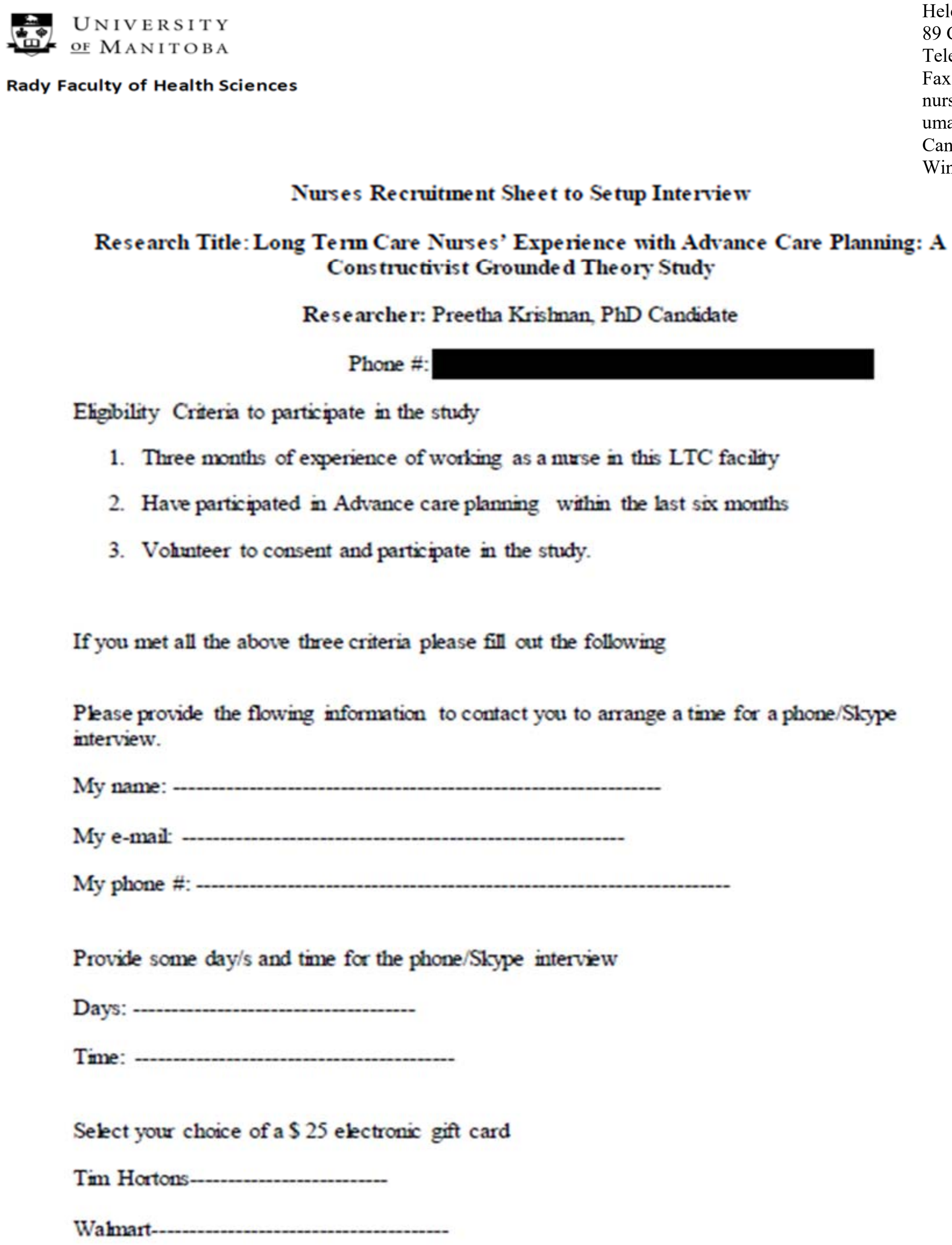
i. Approval is given for this amendment only. Any further changes to the protocol must be reported to the Human Ethics Coordinator in advance of implementation.

ii. Any deviations to the research or adverse events must be submitted to ENREB as soon as possible.

iii. Amendment Approvals do not change the protocol expiry date. Please refer to the original Protocol Approval or subsequent Renewal Approvals for the protocol expiry date.

A unit of the office of the Vice-President (Research and International) umanitoba.ca/research

Appendix Q: Modified Form to Set up Phone Interview



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Winnipeg, Manitoba

Nurses Recruitment Sheet to Setup Interview

Research Title: Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study

Researcher: Preetha Krishnan, PhD Candidate

Phone #: [redacted]

Eligibility Criteria to participate in the study

1. Three months of experience of working as a nurse in this LTC facility
2. Have participated in Advance care planning within the last six months
3. Volunteer to consent and participate in the study.

If you met all the above three criteria please fill out the following

Please provide the flowing information to contact you to arrange a time for a phone/Skype interview.

My name: ---

My e-mail: ---

My phone #: ---

Provide some day/s and time for the phone/Skype interview

Days: -----------------------------------

Time: --

Select your choice of a $ 25 electronic gift card

Tim Hortons-------------------------

Walmart--------------------------------------

Appendix R: Preliminary Interview Guide

Please remember that all information provided will be kept strictly confidential and the information you provide will not be publicly identified with you.

Researcher: Preetha Krishnan, PhD Candidate

1. Tell me what does Advance Care Planning (ACP) mean to you?

    Probe: When you think ACP, what comes into your mind?
    Is it the same for EOL care? Explain.

2. Tell me about your most recent experience with an ACP?
    Probe: Walk me though the steps you have had used?

        Who else was involved? (Physician, family/resident, other team members)

        What were the circumstances for you to engage in this ACP?

        Was it a formal/informal meeting/over the phone?

        Do you like to engage in ACP? Why/why not? Explain

3. From your experience in engaging ACP, what kinds of things make it easier?

    Probe: How important is your relationship with family/resident?
        How important is the communication between: nurse-physician; physician-family/resident; nurse-other team members of the LTC
        How do your co-workers and the managers view ACP?
        Do you get enough time to do ACP? Is there a private room to talk about ACP?

    Probe: What is the facilities view of ACP discussion?

        Have you noticed any difference in the process of doing the ACP in this facility compare to the other facilities that you work? Explain.

4. Describe for me a time you felt it was difficult to engage ACP

    Probe: What kinds of things made it harder? How did it feel for you?

        What are some of the barriers for ACP?

        What elements are needed for you to engage in ACP?

Does this facility have a policy on ACP? How often is ACP reviewed with resident/family?

5. What does a good ACP mean to you?

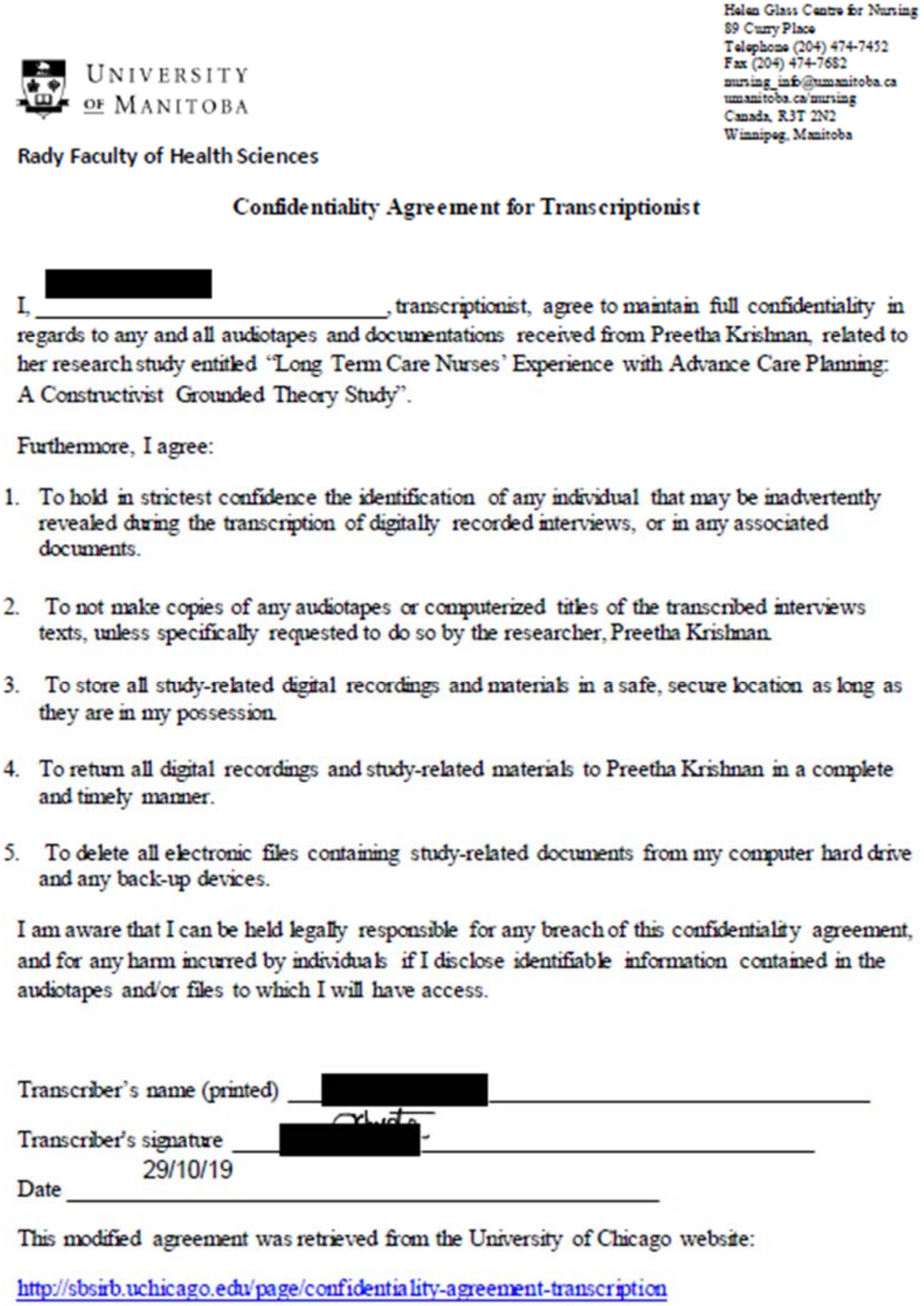
   Probe: Does ACP help with a good death? Why or why not?

   What you would like to see in an ACP discussion? Why are those things important in your opinion?

6. Is there anything that you might not have thought about before that occurred to you during this interview?

7. Is there anything you would like to ask me?

Appendix S: Confidentiality Agreement for Transcriptionist



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Winnipeg, Manitoba

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Confidentiality Agreement for Transcriptionist

I, [redacted]________________, transcriptionist, agree to maintain full confidentiality in regards to any and all audiotapes and documentations received from Preetha Krishnan, related to her research study entitled "Long Term Care Nurses' Experience with Advance Care Planning: A Constructivist Grounded Theory Study".

Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of digitally recorded interviews, or in any associated documents.
2. To not make copies of any audiotapes or computerized titles of the transcribed interviews texts, unless specifically requested to do so by the researcher, Preetha Krishnan.
3. To store all study-related digital recordings and materials in a safe, secure location as long as they are in my possession.
4. To return all digital recordings and study-related materials to Preetha Krishnan in a complete and timely manner.
5. To delete all electronic files containing study-related documents from my computer hard drive and any back-up devices.

I am aware that I can be held legally responsible for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I will have access.

Transcriber's name (printed) [redacted]________________

Transcriber's signature [redacted]________________

Date 29/10/19

This modified agreement was retrieved from the University of Chicago website:

http://sbsirb.uchicago.edu/page/confidentiality-agreement-transcription

Appendix T: Constructivist Grounded Theory Evaluation Criteria and Questions

Credibility

- Has your research achieved intimate familiarity with the setting or topic?
- Are the data sufficient to merit your claims? Consider the range, number, and depth of observations contained in the data.
- Have you made systematic comparisons between observations and between categories?
- Do the categories cover a wide range of empirical observations?
- Are there strong logical links between the gathered data and your argument and analysis?
- Has your research provided enough evidence for you claims to allow the reader to form an independent assessment – and agree with your claims?

Originality

- Are your categories fresh? Do they offer new insights?
- Does your analysis provide a new conceptual rendering of the data?
- What is the social and theoretical significance of this work?
- How does your grounded theory challenge, extend, or refine current ideas, concepts, and practices?

Resonance

- Do the categories portray the fullness of the studied experience?
- Have you revealed both liminal and unstable taken-for-granted meanings?
- Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?
- Does your grounded theory make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?

Usefulness

- Do your analysis offer interpretations that people can use in their everyday worlds?
- Do your analytic categories suggest any generic processes?
- If so, have you examined these generic processes for tacit implications?
- Can the analysis spark further research in other substantive areas?
- How does your work contribute to knowledge? How does it contribute to making a better world?

Source: Charmaz, 2014, p. 337-338.