THE ROLE OF NURSES IN ADVANCE CARE PLANNING WITHIN LONG-TERM CARE HOMES

by

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Abstract

Residents in long-term care homes (LTCHs), are often diagnosed with chronic life-limiting illnesses, require high levels of care and die with complex comorbidities. Advance care planning (ACP) is crucial in this setting because it empowers residents to have discussions with family, substitute decision-makers and healthcare providers regarding future health and personal care preferences. Evidence suggests, that nurses are well situated to engage residents and their families in ACP.

The purpose of this study was to explore the experiences and perceptions of Registered Nurses (RNs) and Registered Practical Nurse (RPNs) in LTCHs with respect to their role in engaging residents and families in ACP discussions.

Qualitative interpretive descriptive methodology was used. Data were collected from two LTCHs in Southern Ontario with a total sample of 15 nurses (n=7 RNs, n=8 RPNs). Data were analyzed through the use of semi-structured interviews, field notes, and the researcher's reflexivity journal. A constant comparison and inductive approach was used in the analysis of the data.

Power and authority dynamics in LTCH's was an overarching theme in the data, that was highlighted across four sub themes: (1) Nurses lacking clarity about ACP, (2) Nurses' uncertainty regarding their role in ACP, (3) Nurses feeling uncomfortable engaging in ACP discussions, and (4) Nurses struggling to support families in ACP discussions.

The study findings provide many implications for policy, practice, education and research for nurses working in LTCHs, healthcare providers, policy makers and administrators. Recommendations include: (1) development of policies which support from a systemic level, encouraging nurses to practice ACP within the context of Ontario's legislation, (2) reassessing LTCH's hierarchal structure, and developing culture change that allows a team and person-centred approach to ACP and (3) providing more and ongoing education and mentorship for nurses to build greater comfort and confidence when engaging in ACP.

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List of Abbreviations

ACP:	Advance Care Planning
EOL:	End of Life
HCP:	Healthcare Provider
LTCH:	Long-term Care Home
NP:	Nurse Practitioner
RN:	Registered Nurse
RPN:	Registered Practical Nurse

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CHAPTER 1: INTRODUCTION

Current Context of Long-Term Care

Amid an aging Canadian population, there is a growing demand for long-term care homes (LTCH) in Ontario; it is estimated that by 2038 the need will increase 10-fold (Canadian Institute for Health Information [CIHI], 2017; Canadian Nurses Association [CNA], 2016a; Alzheimer's Society 2010). LTCHs in Canada provide care for adults who permanently live there and receive 24 hour personal and nursing care, alongside assistance with daily activities (Government of Ontario, 2018; Ontario Long-Term Care Association [OLTCA], 2019). In 2019, an estimate of 35,000 individuals were waiting for LTCHs with the average wait time being five months (OLTCA, 2019). The higher demand for LTCHs from our aging population has caused the function of LTCHs to change significantly in recent years. Prior to 2010, residents in LTCHs had varying care needs, ranging from low to high. Now, the care needs of residents are more complex, and residents with only high or very high care needs are eligible for LTCH admission (OLTCA, 2019). Recent figures highlight that residents are now admitted to LTCHs with increasing frailty, 90% have some form of cognitive impairment, and 97.5% have been diagnosed with two or more chronic illnesses (OLTCA, 2019). Currently, it is predicted that 86% of residents need extensive assistance with personal care and daily activities such as: eating, toileting and bathing (OLTCA, 2019).

The number of deaths that occur in LTCHs is expected to rise as increasing numbers of residents remain there until the end of their lives (EOL) (Hirdes et al., 2011; Marcella & Kelley, 2015; Menec, 2004). Due to the growing complexities in care needs, and the fact that LTCHs are now a significant site of death, a focus needs to be given to ensuring high quality of care is provided to residents and their families throughout their illness trajectory and until EOL (OLTCA, 2019).

As a result of LTCH residents' high rates of cognitive impairments and their unknown preferences for care, medical interventions such as restraint use, tube feedings, antibiotics, and intravenous therapy are often the default options for care provided by healthcare providers (Di Giulio et al., 2008; Mitchell et al., 2009; Ransbottom & Lou Kelley, 2014). When health issues arise, hospital and emergency room admissions of LTCH residents is a common occurrence due to unknown care preferences (Brink & Kelley, 2015; Martin et al., 2016; Ransbottom & Lou Kelley, 2014). Research indicates that when a resident becomes ill and care needs are increased, most residents and their families prefer to remain in their LTCH and receive care there (Brink & Kelley, 2015; Canadian Hospice Palliative Care Association [CHPCA], 2010; Martin et al., 2016). Yet, it is common for residents to be hospitalized at least once during the last months prior to their death (Brink & Kelley, 2015; Martin et al., 2016; Ransbottom & Lou Kelley, 2014). Undesired hospital admissions and medical interventions due to the lack of communication between the resident, the resident's family, and LTCH staff, is evidence of failure to acknowledge preferences of LTCH residents which is ultimately costly to the healthcare system and to the quality of life of residents (Ransbottom & Lou Kelley, 2014). To avoid this, the CHPCA (2015) has recommended that resources must be allocated towards improving LTCHs' staff capacity to provide a palliative approach to care so that resident and family values and preferences influence EOL care.

Advance Care Planning within a Palliative Approach in LTCHs

A palliative approach to care for residents of LTCHs focuses on holistic improvement of the quality, and not prolonging life for individuals diagnosed with a life-limiting chronic illness, through resident and family-centered care (Canadian Virtual Hospice, 2017; CHPCA, 2015; Sawatszky et al., 2016). The Canadian Square of Care Model developed by CHPCA (2013) emphasizes eight common domains to consider when providing a palliative care approach to patients. The domains include but are not limited to: spiritual, physical, psychosocial, practical, loss/grief and social. The care model reinforces a holistic approach to care through early assessment and management of symptoms and by addressing individuals' and their family's care preferences on various levels (physical, psychosocial, cultural and spiritual) (CHPCA, 2013; Sawatszky et al., 2016). Ideally, a palliative approach to care begins at the point of diagnosis of a life-limiting chronic illness and follows the individual throughout their illness trajectory, encompassing advance care planning (ACP), symptom management, supportive care, EOL care and bereavement (Sawatszky et al., 2016) [See Appendix A for glossary of terms].

ACP is a central component of a palliative approach to care and in its simplest form encourages conversations where individuals, at any age, can communicate their preferences for future care in the case they become incapable of decision-making later on in their illness trajectory (Beck et al., 2017; CHPCA, 2010; Lovell & Yates, 2014; Speak Up 2020; Wahl et al., 2016). The process of holistic ACP, consists of individuals thinking about and planning future health and personal care decisions (CHPCA, 2010; Speak Up 2020; Wahl et al., 2016). The overall goal of ACP is to uncover and understand values, wishes and preferences for care of individuals and inform healthcare providers, substitute decision makers and family members and friends to inform future health and personal care decisions (Beck et al., 2017; Hospice Palliative Care Organization [HPCO], 2011; Speak Up, 2020; Wahl et al., 2016). ACP can be especially beneficial today, as preferences of LTCH residents are often unknown, leading to lack of clarity for substitute decision-makers and healthcare providers when decision-making for residents (once they lose capacity to make decisions for themselves) (Ransbottom & Kelley, 2014). With the potential to bridge incongruencies between the residents' wishes and the actual care they receive, it is essential that LTCH staff incorporate a palliative approach to care that integrates ACP for residents diagnosed with chronic life-limiting illnesses (Capps et al., 2018; CHPCA, 2015).

The Canadian National Advance Care Planning Task Group developed a national framework to improve access to ACP. A part of their initiative was the development of the Speak Up Workbook to guide conversations between families, individuals and health care providers about one's preferences surrounding future care (Speak Up, 2020). While various guides and tools are available in Canada, ACP can be expressed in any form including oral and written (Speak Up, 2020). Documents such as advance directives and living wills can make an ACP document legally binding, although they are not supported through Ontario law (Law Commission of Ontario, 2017). Instead, in Ontario, ACP is understood as an ongoing process and discussion that can be re-examined throughout an individual's illness trajectory (Myers & Incardona, 2016; Wahl et al, 2016).

In Ontario, ACP, goals of care discussions, and health care consent are all components of a process that are considered important for resident centered decision-making and informed consent (HPCO, 2011; Myers & Incardona, 2016; Wahl et al, 2016). ACP is intended to align care with an individual's spiritual, medical, and psychosocial wishes through promoting future-focused discussion. Goals of care discussions are directed towards preparing individuals to make decisions related to care and medical treatment to ensure their needs are met in the current context of their illness (CHPCA, 2015; HPCO, 2011). ACP conversations inform in-moment goals of care, decision-making and consent discussions (CHPCA, 2015; HPCO, 2011; Lum & Sudore, 2016; Robinson et al., 2011; Wahl et al., 2016). It is essential that all stakeholders, policy-makers, and staff understand and educate themselves on a palliative approach to care, ACP, goals of care discussions, and other related processes (Beck et al., 2016; Wahl et al., 2016).

Nurses' Roles in LTCHs

Nurses comprise of one of the largest occupational groups providing care to LTCH residents, along with unregulated workers (e.g. personal support workers and healthcare aides) (OLTCA, 2018; RNAO, 2007; Statistics Canada, 2015). Physicians and Advanced Practice Nurses (Nurse Practitioners and Clinical Nurse Specialists) are rarely on site; thus the LTCH staffing model relies heavily on Registered Nurses (RNs) and Registered Practical Nurses (RPNs) to coordinate safe and competent care for residents (OLTCA, 2018).

The College of Nurses [CNO] (2018) states that RPNs' education is less comprehensive than RNs and more focused on patients with stable, and less complex needs. In contrast, RNs possess greater foundational knowledge in practice, critical thinking, leadership and more years of education than RPNs (CNO, 2018). Factors of complexity, predictability, and risk of negative resident outcomes are used to determine how an RN or RPN is utilized within LTCHs. The more complex, unpredictable, and at risk of negative outcomes a resident becomes, the more necessary it is to involve an RN in providing care (CNO, 2018). Thus, because of the differences in their scope of practice the specific roles nurses take differs across LTCHs.

The Canadian Nurses Association [CNA] (2013) details that the professional responsibility of nurses is to encourage individuals to engage in ACP. Although RNs may have a larger scope of practice, in reality they account for 9% of all healthcare providers in LTCH settings, in comparison to RPNs that account for 17% (Ontario Association of Non-Profit Homes and Services for Seniors [OANHSS], 2015). Due to the limited availability of RNs in LTCHs, a preferred model of care delivery would reflect one where both RNs and RPNs work collaboratively with other healthcare professionals, and to their full scope of practice to optimize the care provided to residents (CNA, 2013). Overall, while nurses appear well situated to play a significant role in engaging residents and their families in ACP, and it is within their scope of practice, it is unclear how they perceive their role in this process.

Need for ACP in LTCHs

Residents in LTCHs are especially vulnerable to receiving care that does not align with their values, because they often do not engage in ACP (Ampe et al., 2015; Ong et al., 2011). A holistic palliative approach to care encompassing ACP can improve the capacity of LTCHs to maintain the quality of life for residents and increase the likelihood of their wishes being known and followed throughout their illness trajectory (Bolig et al., 2016; Cornally et al., 2015; Fernandes 2008; Shanley et al., 2011). Currently, LTCHs may lack a palliative approach to care and preferences of residents are often unknown and therefore may be not incorporated into care (Ampe et al., 2017; Bolig et al., 2016; Jeong et al., 2011).

Across various healthcare settings, individuals are open to discussing ACP and EOL conversations with their health care providers (CNA, 2013; Harris Decima Report, 2013; Kononovas, 2017; Ratner et al., 2001). ACP conversations can inform and facilitate EOL decision-making and care planning. It was found that 60% of Canadians believed it was important to talk about wishes for EOL care, 80% of Canadians are comfortable engaging in EOL discussions with their nurse and 90% of Canadians in general, perceive nurses as trustworthy (CNA, 2016b, Harris Decima Report, 2013). Ratner et al. (2001) found that 99% of participants in a home-care setting, at the EOL (n= 84) were open to discussing EOL decision-making and wishes with their nurses. Although these statistics are not specific to LTCHs and ACP, it is evident that Canadians are open to talking about their values and preferences for care with their nurses. However, there is a lack of engagement in both ACP and EOL conversations, especially in LTCHs where they are much needed (Butler et al., 2014; Harris Decima Report, 2013; Butler et al., 2014; Ong et al., 2011).

LTCHs have a staffing and delivery model that significantly differs from other healthcare settings (OLTCA, 2018). In LTCHs nurses usually oversee or provide care to residents and their families for an extended period and often until the end of their life (OLTCA, 2018). In comparison to acute care units, the staff-to-patient ratio is much lower (ONA, 2017). Currently there are no clear staffing guidelines for nurse to resident ratios in Ontario, other than a requirement that a minimum of one RN be present and working in a LTCH at all times, regardless of the size of the home (RNAO, 2011). This RN is responsible for care coordination in a LTCH, and often may be the most senior person present, adding to the job responsibility and high-pressure environment (RNAO, 2011; O'Brien et al., 2010). While RNs account for approximately nine% of total healthcare providers in LTCHs, RPNs account 17% and unregulated staff (such as PSWs) 66%. Therefore, due to the unique staffing model, engaging in ACP in LTCHs may present a unique set of challenges and experiences for nurses, residents and their families.

Purpose of Study

The purpose of this interpretive descriptive (ID) study is to explore perceptions and experiences of RNs and RPNs working in LTCHs with respect to their role in engaging residents who are diagnosed with life-limiting chronic illnesses and their families, in ACP discussions. While it is recognized that nurses have an essential function in ACP, little is known about how the two subgroups of LTCH nurses (RNs and RPNs) perceive their role in implementing ACP in Canadian or Ontario specific contexts. How they perceive their role is important to investigate in order to recognize strategies, facilitators, and barriers to ACP at an individual and organizational level. Such knowledge gained can assist LTCH nurses in optimizing their role in facilitating ACP and inform the development of training and resources to support them. Overall, an improvement of the quality of care delivered throughout the illness trajectory of residents can be achieved by meeting the preferences and values of residents and their families (Izumi, 2017).

Self-Reflection

I engaged in the process of self-reflection to consider my own personal and professional experiences that led to my interest in ACP. I graduated with a Bachelor of Science in Nursing from McMaster University in 2017. I am presently working as a Care Coordinator with the Palliative Care Team at Mississauga Halton Local Health Integration Network. I have also worked in various healthcare settings as a Registered Nurse, including a general surgery floor at St. Joseph's Healthcare Hamilton, and the acquired brain injury rehabilitation floor at Hamilton General Hospital. In addition to these clinical roles, I actively maintained a research assistant role for the Strengthening a Palliative Care Approach in Long-Term Care (SPA-LTC) team through the School of Nursing at McMaster University.

My previous clinical and research experiences sparked my interest in palliative care. These experiences gave me first-hand insight into many issues that exist in the health system~~s~~ providing EOL care. A common occurrence for me was witnessing older individuals and their families in a state of crisis during EOL care, or through their illness trajectory.

Personally, I come from a traditional Punjabi household where my paternal grandparents have lived with me my entire life. I was raised with the perception that elderly people are wise, guiding figures in family structures. I have always thought that living with and caring for my grandparents is a privilege. Culturally, I have witnessed that as individuals age in our community, children often become their primary caregivers. Both my sibling and I have a shared understanding, that as our parents age, we will both need to take care of them in our homes and have discussed this with our parents. For this reason, I recognize I have an inherent bias that LTCHs could be an unfortunate place for residents as they may be isolated from their families. This stems from cultural beliefs that only family members can truly care and meet the wishes of elderly individuals adequately. Therefore, I recognize the importance of ACP, and communicating future personal and medical decisions to family members. These factors and cultural preconceptions led to my interest in exploring and improving the quality of care of elderly individuals in LTCHs.

These incidents also fueled my interest to explore further and understand topics related to holistic care for individuals with life-limiting illnesses. These interests directed me to find an undergraduate research assistant role through McMaster's School of Nursing, in which I could gain experience working with residents receiving a palliative approach to care in LTCHs. This role eventually led me to gain a more profound interest in ACP and how it supports individuals and their families, by averting the crises at EOL that I witnessed so frequently as a nurse. I often found myself asking how I can optimize my role as a nurse in the ACP process within LTCH settings.

I intended to explore these topics further by focusing my research work and education in this area. I acknowledge the preconceptions I may have with respect to a nurse's role in ACP. Such perceptions may be biased towards a resident’s family members, when available, being responsible and involved in the care of the resident. This would therefore lead me to think that nurses’ roles in ACP would include collaborating heavily with the patient’s family members.

Additionally, in my current role as a Palliative Care Coordinator, I frequently participate in ACP conversations in the community setting. After completing the study, I realize that the setting of LTCHs causes the experiences and perceptions of the role of nurses in ACP to differ vastly. The patient population as well as the staffing structure creates an unique environment for nurses in comparison to a community setting. Therefore, while some findings may be transferable to other healthcare settings, the distinctive nature of LTCHs needs to be considered. In order to document my thoughts and remain reflexive, I maintained a journal throughout the study process.

CHAPTER 2: LITERATURE REVIEW

Overview of Literature Review

This literature review provides an overview of what is known about the experiences and perceptions of nurses (RNs, RPNs) working in a LTCH setting, with respect to their role in engaging residents and families in ACP. This literature review will first detail the search strategy and inclusion/exclusion criteria used to identify articles explicitly addressing the perceptions and experiences of nurses concerning their role in engaging in ACP in LTCHs. Furthermore, it will highlight key benefits and barriers of engaging in ACP from the perspectives of LTCH residents and their families. Lastly, it will summarize the experiences of ACP in LTCHs among nurses, and their perceptions of the nurse’s role in ACP. The ultimate aim is to synthesize related literature to gain an in-depth understanding of the current state of research on the topic.

Search Strategy

Literature searches were conducted by one reviewer using the following four electronic databases: CINAHL, Medline, PsychInfo and COCHRANE. The total number of hits were 255 (after removing duplicates). In consultation with a library liaison at McMaster University the following search concepts were generated with variations of search terms under each concept: (1) Long-Term Care (Residential Facilities, Resident care or residential facility* home* institution*, Assisted Living Facilities, Homes for the Aged, Old age home*, Homes for the elderly, Elder Care home*, Nursing Homes*, Extended Care faciliti*, Skilled nursing facilit*) (2) Advance Care Planning (advance care plan*, advance medical plan*) and (3) Nursing Role (nurs* role*). Reference lists within key articles were hand searched, and experts in the field were also consulted in order to identify any overlooked literature.

Inclusion and Exclusion Criteria of Studies

Studies were included if they met the following criteria: (a) peer reviewed; (b) English language; (c) published between 2008-2020; (d) discussed ACP in the LTCH context; (e) terminology was consistent with the concept of ACP in Ontario (eg. not legally binding, not an advance directive) and (f) addressed the role, perceptions or experiences of LTCH nurses engaging in ACP. Studies were excluded if: (a) they did not discuss ACP in the LTCH context, (b) they discussed only family or resident views, experiences, or roles in engaging in ACP and excluded LTCH nurses and (c) the terminology of ACP was inconsistent with Ontario's use of the concept, and limited to an advance directive. All included articles were assessed for` quality using the Critical Appraisal Skills Program (CASP) checklists, Mixed Methods Appraisal Tool (MMAT, 2018) and Joanna Briggs Critical Appraisal Checklists (CASP, 2019; Joanna Brigg Institute, 2017; MMAT, 2018).

Search Results

A total of 255 articles were identified and 24 articles met the inclusion criteria for this literature review. These articles consisted of systematic reviews (n=2), qualitative studies (n=12), quantitative studies (n=6), mixed method studies (n=2), and narrative reviews (n=2) (See Appendix B for a flowchart of included studies). Studies were conducted in Belgium, United States, United Kingdom, Australia, Norway, Sweden, and the Netherlands. No Canadian studies were identified.

Benefits of Engaging in ACP in LTCHs

First, this review of the literature highlights some of the most common themes in the literature that describe the benefits of engaging in ACP specifically from the perspectives of LTCH nurses, residents and their families. In LTCHs a remarkable disparity exists between individuals' preferences for care, and the actual care they receive (CHPCA, 2015; Ratner et al., 2001). ACP has been shown to be beneficial in increasing the quality of care provided to residents and their families in LTCHs, enhancing communication between residents, their families and healthcare teams, and integrating preference-based care (Ampe et al., 2015; Cornally et al., 2015; Fernandes 2008; Kastbom et al., 2019; Robinson et al., 2011; Shanley et al., 2011). A more in-depth summary of benefits of engaging in ACP for residents and families, from the perspective of residents, their families and LTCH staff will be provided later in this chapter.

Enhanced Communication for Residents, Families and LTCH Staff

Literature suggests that ACP enhances communication and increases familiarity between residents, their healthcare team, and families (Cornally et al., 2015; Stewart et al., 2011; Shanley et al., 2011; Robinson et al., 2012). Cornally et al. (2015) designed a moderate strength qualitative descriptive study with nursing managers to evaluate an ACP program implemented in nursing homes in Ireland. Key benefits of the program included improved culture of LTCHs due to enhanced communication between residents, families and LTCH staff (Cornally et al., 2015). An additional qualitative study by Shanley et al. (2011) found that ACP allowed enhanced communication that can facilitate avoidance of crisis-decision making and unnecessary hospitalizations. It has been known that residents prefer to stay in LTCHs during EOL care, and it is significant that through engaging in ACP, a reduction in unwanted hospitalizations can be achieved (Cornally et al., 2015; Fernandes, 2008; Robinson et al., 2011; Shanley et al., 2011). Thus, ACP in LTCHs can integrate preference-based care that aligns care provided by staff with resident's wishes. This not only has beneficial effects on residents, but also has the ability to improve the culture of LTCHs. (Cornally et al., 2015; Fernandes 2008; Robinson et al., 2011; Shanley et al., 2011).

Family Satisfaction with Care

There are limited studies looking at the benefits that ACP has on residents' family members. However, two qualitative studies have reported some beneficial effects of ACP on families. Cornally et al. (2015) found that an ACP intervention deepened and created open and honest relationships between family members and nursing staff. A second qualitative study found that through engaging in ACP, families were more satisfied with the care provided to their loved on (Fernandes, 2008). Therefore, through engaging in ACP, it is evident that family members can find ease in knowing they are making choices that align with residents' wishes and create a more positive relationship with LTCH staff (Cornally et al., 2015; Shanley et al., 2011).

Importance of ACP for Residents with Cognitive Impairments

A significant benefit of ACP found in the literature is that when initiated early on in the disease trajectory, residents with cognitive impairments can discuss their future care goals and desires with their family and health care teams through increasing shared communication between all parties involved with care (Ampe et al., 2015; Fernandes 2008; Robinson et al., 2011; Shanley et al., 2011). A systematic review was conducted by Robinson et al. (2011) in order to gain an understanding of the effectiveness of ACP interventions designed for residents of LTCHs with cognitive impairments and dementia (Robinson et al., 2011). Of the four studies included in the review, three reported increased documentation of patient preferences in care, and significant reductions in hospital rates (Robinson et al., 2011). As identified earlier, this is an important finding as a majority of residents in LTCHs, have or will develop cognitive impairments (OLTCA, 2018).

Further rigorous research needs to be done to evaluate the benefits of ACP for LTCH residents with dementia, especially for long-term sustainability (Ampe et al., 2017). A moderate strength, pre-test/post-test study evaluating an ACP program designed for residents with dementia in LTCHs found that ACP had a positive influence on improving policies related to ACP (Ampe et al., 2017). However, routine practice in respect to engaging residents with variable cognitive capacity in ACP conversations did not significantly change. Through ACP, residents with cognitive impairments can communicate their wishes and preferences for care early on in their illness trajectory and LTCH staff can reflect this in the care they provide (Ampe et al, 2017). Thus, it is important to consider how to promote staff uptake of ACP, and how to make this practice routine in LTCHs even for residents with dementia and cognitive impairments.

Barriers to ACP in LTCHs

Although the practice of ACP has been proven to be beneficial in LTCHs, it is not a common practice, and is rarely implemented (Butler et al., 2014; Ong et al., 2011). In order to understand this gap between evidence and practice, a summary of identified barriers to implementing ACP in LTCHs will be provided.

Variable Cognitive Capacity in LTCH Residents

Literature indicates that engaging in ACP is a challenge for staff and families of residents when the resident has moderate to severe impairments (Ampe et al.,2015; Cornally et al., 2015; McGlade et al., 2017; Stewart et al., 2011; Thoresen et al., 2019). Stewart et al. (2011) found dementia was a frequent barrier to engage residents in ACP with families, LTCH nurses and nurse managers (Stewart et al., 2011). Cornally et al. (2015) found similar results with nurse managers and directors. In their study, which was an evaluation of an ACP program implemented in three LTCHs in Ireland, nurse managers were unsure if they should engage residents in the ACP program due to residents' level of cognitive impairment (Cornally et al., 2015). This suggests, that LTCH staff and families of residents, have uncertainty about how to engage in ACP with residents with variable levels of cognitive impairments (Ampe et al., 2015; Ampe et al., 2017). Due to the high rates of dementia and cognitive impairments in LTCHs, staff need specialized training and education to effectively engage in ACP with this population.

Evidence suggests that although variable cognitive capacity can be a barrier to engaging in ACP, with staff education and tailored ACP, beneficial effects such as advanced communication between families, residents, and their families can be attained for residents with cognitive mild impairments (Ampe et al., 2015; Ampe et al., 2017; McGlade et al., 2017; Thoresen et al., 2018). Two studies that specifically explored ACP with LTCH residents with mild dementia found the process beneficial, even when some residents could only contribute to a lesser degree (Ampe et al., 2015; Ampe et al., 2017; McGlade, 2017). McGlade et al.'s (2017) moderate strength feasibility study identified challenges in implementing the Let Me Decide Program. This program was designed for engaging residents in ACP, and was implemented in two LTCHs and one community hospital. They found that their program was a feasible option for residents with mild cognitive impairments as they were able to engage them to a sufficient extent and have their family present to assist. The challenges they encountered were ensuring the resident was treated fairly, and remained autonomous (McGlade et al., 2017). A quasi experimental study by Ampe et al. (2015) evaluated the effects of an ACP program developed specifically for residents with dementia. They found that successfully engaging in ACP with residents with dementia was possible to different degrees, as some residents could be more involved than others depending on their cognitive capacity (Ampe et al., 2017). This is important because the findings suggest that ACP can be valuable for residents with cognitive impairments, however the challenge is that the potential is often not realized in LTCH staff (McGlade et al, 2017).

System-wide Support Required

The level of support by management and the degree of involvement of the LTCH organization was also an influencing factor for staff when engaging in ACP with residents (Ampe et al., 2017; Gilissen et al., 2017). A systematic review by Gilissen et al. (2017) examined the preconditions for effectively implementing ACP in LTCHs. A key barrier to overcome was ensuring that a whole system approach within the LTCHs was executed (Gilissen et al., 2017). The authors discussed that various levels of management and employees in LTCHs must be involved and educated on ACP. This includes frontline staff, management, and the larger LTCH organization and stakeholders (Gilissen et al., 2017). They identified that while LTCH healthcare providers, such as nurses, have an essential role in ACP, multiple supports need to be in place for them to successfully engage in ACP with residents and families (Gilissen et al., 2017). Factors include but are not limited to support from management, adequate education, knowledge, and skills (Gilissen et al., 2017).

Two qualitative studies and one interim analysis identified that nurses perceived they did not have enough time to engage in ACP and that more LTCH staff was required in order to engage in it successfully (Hickman et al., 2016; Jeong et al., 2011; Kirsbom et al., 2017). This suggests that support from management and LTCH organizations is required to ensure adequate staffing ratios are in place to effectively incorporate ACP into residents' and their families care. In contrast, one feasibility study conducted to identify challenges of implementing an ACP program reported that when LTCH staff acknowledged the benefits that ACP could have, such as aligning care with families' and residents' wishes, time was not as much of a challenge for staff (McGlade et al., 2017). This suggests nurses themselves may need to see the value of ACP in order to prioritize and build it into their practice. Therefore, while the context and perceived level of systematic and managerial support may be vital to ensure effective engagement in ACP; staff perceptions of ACP also need to be considered.

Lack of Knowledge Related to ACP

Literature indicates that a knowledge gap related to ACP is present for LTCH staff (Beck et al., 2017; Fernandes, 2008; Flo et al., 2016; Gilissen et al., 2017; Hickman et al., 2016; Thoresen et al., 2016). Multiple studies recognize that more targeted education is required for nurses to better understand the process of ACP (Beck et al., 2017; Gilissen et al., 2017; Hickman et al., 2016). A systematic review conducted by Gilissen et al. (2017) identified numerous barriers hindering the successful implementation of ACP in LTCHs. A key barrier identified was the need for LTCH staff including nurses, to better understand attitudes, roles, and skills related to ACP to successfully incorporate ACP into the care process (Gilissen et al., 2017). Four other studies echoed similar findings, suggesting that deficits related to knowledge and education result in low compliance and uptake of ACP by staff (Beck et al., 2017; Fernandes, 2008; Flo et al., 2016; Thoresen et al., 2016).

Common knowledge deficits in nursing and other LTCH staff specifically include: lack of knowledge surrounding dementia and how to engage in ACP with residents with dementia, and confusion around documentation, terminology, legality, purpose, and process of ACP (Beck et al., 2017, Fernandes, 2008, Flo et al., 2016, Thoresen et al., 2016). A cross-sectional study by Baughman et al. (2017) was conducted in the United States to explore social workers' and nurses' judgements regarding ACP in LTCHs. They found that both professional groups significantly felt responsible for ACP, only when they felt the resident was at a high risk for hospitalization (Baughman et al., 2017). This suggests a need for education surrounding the process of ACP, as it is known to be beneficial to residents at any stage of their illness trajectory (Beck et al., 2017; Fernandes, 2008; Flo et al., 2016; Thoresen et al., 2016).

Summary of Benefits and Barriers of Engaging in ACP in LTCHs

In general, this literature highlights that ACP in LTCHs has been known to have beneficial effects for residents and their families, and staff. The most important known beneficial effects include: improving communication and quality of life for residents with cognitive impairments, providing care consistent with residents wishes and enhancing communication between the residents, their families and the staff. It is also evident that there are significant barriers present in LTCHs which prevent ACP from becoming a routine process incorporated into care. A lack of knowledge surrounding ACP, staff roles, and engaging in ACP with residents with dementia, all indicate that LTCHs require staff and family education surrounding ACP.

Overall, there is a lack of high-quality studies examining the experiences of staff, residents and their families engaging in ACP specifically in LTCHs, which may assist in understanding the lack of uptake of ACP implementation in this setting. None of the aforementioned studies were conducted in Canada. Although some findings may provide insight relevant to the Canadian context, differences in ACP terminology, legality, and the environment of LTCHs may significantly differ from Canada. It is essential to consider experiences and perceptions of Canadian LTCH staff to fully understand the challenges that they may encounter when engaging in ACP.

Nurses Experiences and Perceptions of ACP in LTCHs

The primary aim of the literature search was to explore what is known about the experiences and perceptions of LTCH nurses engaging in ACP. It is clear that the environment, staffing and resident needs within LTCHs are different from other healthcare settings yet only a few studies were identified that focus on roles, perspectives, and experiences of nurses in ACP specific to the LTCH context. Seven studies were identified that explored nurses' experiences and perceptions with engaging in ACP in LTCHs (Beck et al., 2017; Handley et al., 2014; Jeong et al., 2011; Kastbom, 2019; Mulqueen & Coffey, 2017; Thoresen et al., 2019; van Soest-Poortvliet et al., 2015).

The limited literature available supports that nurses generally perceive engaging in ACP as of importance to LTCH residents. Mulqueen and Coffey (2017) conducted a qualitative descriptive study based in Ireland to explore the preferences of care of residents with dementia and the perceptions of nurses regarding residents' priorities for care. While some of the resident's priorities for care matched the nurse's perceptions of their priorities several also differed. For example, residents valued comfort, familiar staff, and family presence. In contrast, nurses perceived that good communication, knowledgeable staff, and ACP would be a priority for residents. This study is important because it highlights that nurses value ACP and believe it is crucial for residents to engage in, however were not knowledgeable regarding residents' actual preferences for care (Mulqueen & Coffey, 2017).

A case-study design conducted by Jeong et al. (2011) explored the experiences of RNs with ACP in LTCHs in Australia. It was found that RNs felt families of residents lacked knowledge regarding their role in ACP. This led nurses to fear that families would not comply with residents' wishes discussed in ACP conversations, and discomfort with discussing ACP (Jeong et al., 2011). Nurses in this case-study described a negative experience engaging in ACP and felt they needed more support to educate families (Jeong et al., 2011). This experience is echoed in previously mentioned studies, where nurses felt unsupported by management and felt they needed greater organization support from LTCHs to engage in ACP (Ampe et al., 2017; Flo et al., 2016).

Although Mulqueen and Coffey (2017) and Jeong et al. (2011) gave a glimpse of how nurses may perceive and experience ACP, more rigorous research needs to be conducted to gain an in-depth understanding of LTCH nurses' experiences and perceptions. Mulqueen and Coffey (2017) conducted a qualitative study in Ireland, employing solely nominal group technique with small group discussion for data collection. Jeong et al. (2011) employed a moderate strength case-study design. The aim of the study was clear, and they collected data using numerous strategies: semi-structured interviews, field note recording, participant observation, and document analysis. However, only a small sample of RNs was obtained. This limits generalizability further to the Canadian context, as RPNs are a large part of the care involved in LTCHs in Ontario (OLTCA, 2018). Furthermore, the study was conducted in Australia, and limited information was known about the RNs' previous experience and education, factors which can affect their perceptions and experiences with ACP in LTCHs. To gain a comprehensive understanding of the experiences and perceptions of LTCH nurses in Ontario, a sample inclusive of both RNs and RPNs from Ontario nurses needs to be obtained.

The Lack of Clarity of LTCH Nurses' Roles in ACP

Generally, findings from the literature support that LTCH nurses are unclear about their role in ACP (Beck et al., 2017; Handley et al., 2014; van Soest-Poortvliet et al., 2015). A narrative review conducted by Beck et al. (2017) explored perspectives of LTCH health professionals, including nurses, engaging in ACP for residents with dementia. They found that although healthcare professionals recognize the potential benefits of ACP, they struggle with its implementation in the LTCH setting (Beck et al., 2017). Factors deterring their engagement in ACP included lack of knowledge and education surrounding communication, ACP, and lack of clarity in roles (Beck et al., 2017).

van Soest-Poortvliet et al. (2015) used a qualitative methodology to explore perceptions surrounding ACP of families of residents and staff from Dutch LTCHs. LTCH staff included nurses and physicians. Both nurses and physicians believed they had multiple moments where they could discuss and initiate ACP with residents. However, the majority of nurses and physicians agreed that it was physicians who initiated ACP discussions (van Soest-Poortvliet et al., 2015). Furthermore, Thoresen et al. (2019) conducted a moderate-strong strength, qualitative descriptive study in Norway, where they interviewed nurses and physicians in LTCHs. Similarly, they found that both physicians and nurses perceived that ACP was more aligned with a physician's scope of practice (Thoresen et al., 2019). This suggests that nurses and physicians agreed that it was the physicians who took on the more active role of initiating ACP (van Soest-

Poortvlient et al., 2015; Thoresen et al., 2019). A mixed methods study was conducted by Handley et al. (2014) to describe the experiences of EOL care of older people in LTCHs in East England, and how LTCH staff interpreted their roles. The study briefly described LTCH staff including nurses' interpretations of roles when engaging in ACP. In contrast to the findings from van Soest-Poortvliet et al.'s (2015) study, they suggested both nurses and general practitioners were not sure if it was their responsibility to engage in EOL discussions and were unclear how to contribute to ACP.

A mixed methods study investigated the role of Nurse Practitioners (NP) with respect to ACP in LTCHs in the United States (Mullaney et al., 2016). Data were collected through the use of a convenience sample of NPs, review of medical documents, and two focus groups with NPs (Mullany et al., 2016). This study aimed to examine the impact NPs had on mortality risk assessments and ACP in an LTCH setting. The results suggest ACP conversations lead by NPs had positive clinical outcomes for residents such as: reduction in hospitalizations, comfort-centered care, and decreased full code status (Mullaney et al., 2016). The findings are significant, because they suggest that NPs can play a crucial role in ACP discussions. The study also highlighted that NPs perceived that ACP conversations they led could achieve beneficial outcomes for residents (Mullaney et al., 2016).

While the overall study had a robust methodology, several limitations can also be noted (Mullaney et al., 2016). The sample of NPs is from the United

States, which reduces the transferability of results to the Canadian LTCH context due to differences in setting, the legality of ACP, and unknown characteristics of NPs (e.g., years of education, years of experience in LTCHs, and background). Furthermore, data were only collected from a sample of NPs, and perceptions of RNs and RPNs of roles in ACP were not discussed. As previously discussed, the role of the NP vastly differs from that of an RN and RPN. LTCHs in Ontario often have limited access to NPs; thus, it becomes essential to explore the roles of RNs and RPNs concerning ACP. It is evident that even though LTCH nurses play a central role in the process of ACP, there is inconsistency within the literature as to whose role it is to engage in ACP. By considering the roles of both RNs and RPNs in ACP literature, a broader understanding of the experiences of both sub-groups of nurses can be achieved (CNA, 2013). The lack of clarity related to LTCH nurses' roles, including RNs and RPNs, needs to be addressed, and a deeper understanding of their perspective needs to be gained to optimize engagement in ACP.

Appraisal of Literature

The 24 articles analyzed in this literature review ranged from weak to strong methodological rigor based on a CASP (2019) Checklist, Joanna Briggs Institute (2017) Checklist or Mixed Methods Appraisal Tool (2018) (See Appendix C for appraisal of studies). Two articles in the literature review consisted of systematic reviews (Gilissen et al., 2017; Robinson et al., 2011). Robinson et al. (2011) explored preconditions needed to implement ACP into

LTCHs successfully. Whereas, Gilissen et al. (2017) investigated the effectiveness of ACP in LTCH residents with cognitive impairments and dementia. Gilissen et al. (2017) and Robinson et al. (2011) both had overall moderate to strong methodological rigor. Both systematic reviews had comprehensive search strategies. Multiple databases were used to identify studies, and two reviewers independently screened articles for inclusion and data extraction in both systematic reviews. Gilissen et al. (2017) included four studies, and a table summarizing characteristics of included studies was available. Robinson et al. (2011) identified 38 articles, and a similar table of characteristics of included articles was illustrated. However, limitations of both systematic reviews were present. Robinson et al. (2011) did not include any studies from Canada in the systematic reviews, thus, limiting the generalizability of the study findings to Canada. Gilissen et al. (2017) included one randomized controlled trial from Canada, evaluating family and resident satisfaction with educational workshops for LTCH staff compared to no educational interventions. Further, Gilissen et al. (2017), only included four studies in their systematic review thereby limiting the generalizability, and ability to make meaningful conclusions from the findings.

Two narrative reviews were included in the literature review (Beck et al., 2017; Flo et al., 2016). Beck et al. (2017) explored perceptions of LTCH healthcare professionals of engaging in ACP with residents with dementia. Flo et al. (2016) reviewed implementation strategies of ACP in LTCHs. Both reviews had moderate methodological rigor. Beck et al. (2017) and Flo et al. (2016) used multiple databases to identify studies, and Flo et al. (2016) had multiple authors review and discuss the inclusion of studies and data extraction. Beck et al. (2017) did not describe the process of reviewing articles for inclusion, and it was unclear how many reviewers took part in the process. A total of 14 papers were included in the review, and a table was presented to summarize the characteristics of the study. A majority of the studies were based in the United Kingdom and the United States, and none of the studies were from Canada. This limits generalizability to the Canadian context. Flo et al. (2016) included five studies and a table of study characteristics. The studies had several limitations, including possible selection bias, unclear inclusion criteria, and lack of description of educational interventions.

A total of 12 qualitative studies (Cornally et al., 2015; Jeong et al., 2011; Kastbom et al., 2019; Kirsebom et al., 2017; Mulqueen & Coffey, 2017; Shanley et al., 2011; Stewart et al., 2011, Thoresen et al., 2016; Thoresen et al., 2019; Ong et al., 2011; Reyniers et al., 2015; van Soest-Poortvlient et al., 2015) and two mixed methods studies (Handley et al., 2014; Mullaney et al., 2016) ranging from weak to moderate methodological rigour were included in the literature review. Trustworthiness of findings was often limited as four studies only used one data source for triangulation, by including only one group of LTCH healthcare professionals (Cornally et al., 2015; Jeong et al., 2011; Kirsebom et al., 2017; Mullaney et al., 2016). In order to gain a wholesome understanding of the perceptions of LTCH nurses, both subgroups of nurses (RNs and RPNs) need to be represented.

Five studies included in the literature review only used one source for data collection potentially limiting a comprehensive understanding of results (Cornally et al., 2015; Shanley et al., 2011; Stewart et al., 2011; Mulqueen & Coffey, 2017; van Soest-Poortvliet et al., 2015). Overall generalizability was limited because none of the studies were conducted in the Canadian context (Cornally et al., 2015; Handley et al., 2014; Jeong et al., 2011; Kastbom et al., 2019; Kirsebom et al., 2017; Mullaney et al., 2016; Mulqueen & Coffey, 2014; Shanley et al., 2011; Stewart et al., 2011, Thoresen et al., 2016; Thoresen et al., 2019; Ong et al., 2011; van Soest-Poortvlient et al., 2015).

Six quantitative studies of various methodologies were identified and included in the review [one quasi-experimental (Ampe et al., 2015); pilot test study (Ampe et al., 2017); cross-sectional (Baughman et al., 2017); implementation study (Fernandes, 2007); interim analysis (Hickman et al., 2016) and feasibility study (McGlade et al., 2017)]. Overall the studies ranged from weak-moderate methodological rigor. Five studies had a clear aim and increased trustworthiness by using data source triangulation, through including more than one LTCH healthcare professional in their sample (Ampe et al., 2015; Ampe et al., 2017; Baughman et al., 2015; Fernandes, 2008; Hickman et al., 2016; McGlade et al., 2017). Trustworthiness was limited in one study which used only one source of data collection in the form of a survey (Baughman et al., 2015).

None of the identified quantitative studies were conducted in the Canadian context, again, limiting generalizability (Ampe et al., 2015; Ampe et al., 2017; Baughman et al., 2017; Fernandes, 2008; Hickman et al., 2016; McGlade et al., 2017).

Summary of Literature Review

This literature review, first, provides an overview of the barriers and benefits of engaging in ACP in LTCHs from the perspectives of staff, residents and their families. It is recognized that significant benefits exist when engaging residents and their families in ACP in LTCHs. There are several noteworthy barriers to consider when engaging in ACP in LTCHs. Enhanced communication between residents, their families, and healthcare staff can be achieved through ACP (Cornally et al., 2015; Stewart et al.,2011; Shanley et al. 2011; Robinson et al., 2012). Improving communication between parties can have significant benefits for residents, including those with dementia (Ampe et al., 2015; Fernandes 2008; Robinson et al., 2011; Shanley et al., 2011). Identified benefits include family satisfaction with care, preference-based care for residents and limiting unnecessary hospitalizations (Cornally et al., 2015; Fernandes 2008; Robinson et al., 2011; Shanley et al., 2011).

Irrespective of the identified benefits, numerous challenges exist in LTCHs that prevent staff from routinely engaging in ACP (Butler, Ratner, McCreedy, Shippee & Kane, 2014; Ong, Sabanathan, Myint, 2011). Lack of knowledge surrounding basic foundations of a palliative approach to care encompassing ACP staff (Beck et al., 2017; Fernandes, 2008; Flo et al., 2016; Gillissen et al., 2017; Hickman et al., 2016; Thoresen et al., 2016)., communication strategies for engaging with cognitively impaired residents (Ampe et al.,2015; Cornally et al., 2015; McGlade et al., 2017; Stewart et al., 2011) and need for systemic and organizational support were recognized as central barriers (Ampe et al., 2017; Gilissen et al., 2017).

To better understand how to overcome barriers, this literature review primarily attempted to gain insight into the experiences and perceptions of nurses working in LTCH settings, engaging residents and families in ACP. Although nurses have a crucial role in care provided in LTCHs, there is a paucity of literature exploring their perceptions and experience in engaging in ACP. It was generally found that LTCH nurses were unclear about their role in ACP and also felt families did not completely understand the nurses' role (Beck et al., 2017; Handley et al., 2014; van Soest-Poortvliet et al., 2015). However, due to limited research, it is unclear how LTCH nurses perceive and experience ACP and their role. Through this literature review, it is evident that there is a gap in the literature. Previous research has not addressed this topic in-depth, and although some findings may be transferable none of it was completed in the Canadian, where legality and scope of practice of nurses may significantly vary from other settings.

Furthermore, none of the studies explored the experiences and perceptions of both sub-groups of nursing positions (Registered Nurse, Registered Practice

Nurse). This is important as it has been identified that in order to optimize care, roles need to be clarified (CNO, 2008). Therefore, the need to describe and interpret the experiences and perceptions of long-term care nurses to clarify their role in implementing ACP is emergent.

Research Question

Based on the gaps in the literature, the overarching research question that is posed is: What are the experiences (eg. observed and lived in their practice) and perceptions (eg. awareness and beliefs) of nurses in LTCHs (RNs and RPNs) with respect to their role in engaging residents and families in ACP discussions?

Secondary questions include:

- What do LTCH nurses currently perceive are facilitators and barriers to optimizing their role in engaging in ACP?
- How do different sub-groups of nurses (RNs and RPNs) vary in their experiences and perceptions with respect to engaging in ACP within LTCHs?

CHAPTER 3: METHODS

Research Design

The experiences and perceptions of nurses working in LTCHs with respect to their role in ACP was explored through Interpretive Description (ID) methodology. ID emerged as a qualitative research methodology in recent years and is still relatively new (Thorne, 2008; Hunt, 2009). This methodology was developed by nursing researchers with the intention to produce targeted research relevant to the context of applied health practice (Thorne, 2008; Hunt, 2009). The developer of ID, Dr.Thorne, claimed that traditional qualitative methods were not sufficient to address the complex needs of the field of healthcare (Hunt, 2009; Thorne, 2016). Instead, ID reflects an inductive approach that entails interpreting and describing a phenomenon through a disciplinary lens; specifically, nursing (Thorne, 2016). By exploring a phenomenon through this lens, it allows for acknowledgement of the characteristic social and political complexities of that field (Thorne, 2016).

Instead of searching for themes and meanings similar to traditional qualitative methodologies, ID has an underlying constructivist and naturalistic approach which supports the notion of having infinite variations in one's experiences (Hunt, 2009). This means that it accepts that individuals with common experiences can share subjective realities, and there is no one true reality (Hunt, 2009). These notions encourage the researcher to develop a greater understanding of the experiences of participants, by accepting that contextual factors and external influences create various experiences of the same phenomenon (Thorne, 2008, 2016). Through both description and a rich interpretation of experiences, ID can be used to identify and explore clinical phenomena, and subsequently produce knowledge applicable to professional practice (Hunt 2009; Thorne, 2016).

The ID methodology is meant to bridge the gap between research and practice. Thorne (2016), allowed researchers to move beyond the rigidity of structured rules and traditional worldviews of qualitative methodologies. ID encourages the exploration of questions that are relevant and applicable to practice, by aligning methodology with the underpinnings of the discipline that will consume the knowledge (Thorne, 2016). This methodology presumes the researchers' personal experience and knowledge influences the research process and encourages it be valued (Hunt 2009, Thorne 2016).

ID was appropriate to use for the research study because through this methodology, the uniqueness of each individual experience is acknowledged. Furthermore, LTCH nurses and the researcher can gain an in-depth understanding of a phenomenon directly related to their clinical practice, due to shared knowledge they have regarding their own field (Thorne et al., 2004). This phenomenon directly relates to an emergent problem in the field of nursing, which is my own disciplinary field. Therefore, I engaged in a reflexive process, and recognised how my personal experience and knowledge as a nurse can influence the research process (Thorne et al., 1997).

Using ID, the researcher can describe and interpret the multiple variations in perceptions and experiences that LTCH nurses may have in respect to their role in engaging residents in ACP. Furthermore, Thorne (2016) advises researchers to participate in scaffolding a study. This process consists of two key elements. First, Thorne (2016) recommends building on what is already known in the literature. Therefore, I conducted a thorough review of existing literature, and recognized the emergent need to study the phenomenon at hand. The second step, consists of self-reflection which allowed me to recognize personal experiences and knowledge related to the research question that may influence the study (Thorne, 2016). By examination of the research question through ID, credible new knowledge can be generated and applied back to the LTCH setting (Thorne, 2016). This can have implications for policy development, education, and can facilitate change in practice (Thorne et al., 2004).

Setting

Study data was collected from RNs and RPNs at two LTCHs in a city in Southwestern Ontario, Canada. The first home, is a 127 bed, moderate size, not-for-profit and faith-based LTCH. Today, it offers culturally adapted services for a religious community. However, not only residents of a particular religious community reside in the LTCH as it is publicly regulated and intake is based on the combination of functional need and bed availability (Hamilton Niagara Haldimand Brant Local Health Integration Network, 2019). It is to be noted that I had also established a prior relationship with this LTCH through my role as a

Research Assistant. However, I did not have any pre-existing relationships with managerial or nursing staff.

The second home is a 160 bed, moderate size, not-for-profit, government owned LTCH. This home is city-owned making it unique from other LTCHs. Both homes have features (size, culture, location etc.) that are unique from other LTCHs but they care for similar client populations including residents with chronic, life-limiting illnesses. The factors that make the homes distinctive (i.e., one being faith-based, and the second municipality-owned) will be considered when looking at how they may impact the results.

Sampling

A combination of purposive sampling techniques and snowball sampling were used to recruit participants. Purposive sampling is a type of technique used in qualitative methodologies, where the researcher is able to select participants with desired characteristics in order to gain an in-depth understanding of the phenomenon of interest (Coyne, 1997; Thorne, 2016). Specifically, criterion and maximum variation sampling (two types of purposive sampling methods) were used.

Criterion Sampling

A specific set of inclusion criteria was created to purposefully recruit participants. The inclusion criteria for participants were: English speaking, practicing LTCH RNs or RPNs in one of two LTCHs study sites in Southwestern, Ontario. Additionally participants must have provided or overseen care for residents with a chronic life-limiting illness, within the last six months. These criteria were established to ensure LTCH nurses had adequate, and recent exposure to caring for residents with chronic illnesses, and thus could comment on the phenomenon of interest. If participants did not meet these criteria they were excluded from the study.

Maximum Variation Sampling

Through the use of maximum variation sampling I was able to seek out specific demographic traits in order to gain more perspective related to the phenomenon of interest (Creswell & Poth, 2018). Therefore participants were targeted and recruited throughout the study to ensure a wide range of experiences were captured that would increase the richness of data. For example, I was able to seek out participants that fell outside of known patterns such as individuals who worked on a casual basis, and only worked the afternoon shift. This allowed individuals from a wide range of experiences, employment statuses, and ages to be included. Additionally, participants were recruited from both the RN and RPN sub-groups, which was helpful to gain an in-depth understanding of the phenomenon of interest (Coyne 1997, Thorne, 2016).

Snowball Sampling

A snowball sampling method takes advantage of the social connections of eligible participants to recruit other participants (Wasserman et al., 2005). I was able to do this by asking potential participants, when I initially contacted them, if they knew other nurses that were interested in participating in the study.

Sample Size

The final sample size consisted of 15 participants. To provide more diversity, and a broadened understanding of lived experiences, the researcher chose LTCH nurses of varying education levels within both sub-groups (n= 7 RNs and n= 8 RPNs). It is difficult to determine a sample size a priori due to the flexible nature of ID and the sampling methods used. Thorne (2008) recommends determining an adequate sample size, based on how common the occurrence of a phenomenon is. If the phenomenon of interest is uncommon, a smaller sample size is appropriate (Thorne, 2008). Previous qualitative studies that have focused on experiences of LTCH healthcare providers, or specifically nurses experiences' regarding ACP have varied in range of sample size, from 11 to 41 (Cornally et al., 2015; Jeong et al., 2011; Kirsebom et al., 2017; Reyniers et al., 2015; Shanley et al., 2011; Thoresen et al., 2019; van Soest-Poortvliet et al., 2015). This current study falls within that range, and had a comparable sample size to existing literature.

I was able to be thoughtful throughout data collection and recognize when data had reached sufficient richness based on consensus of the full supervisory committee. Additionally balance in demographic factors was established. For example, a variation in age groups, years of experience and type of employment (casual, part-time, full-time) was established. This was important, because Thorne (2008) suggests that the notion of data saturation alone is not sufficient to determine sample size and conclude analysis. She suggests that in the health sciences field participants often have infinite variations of experiences (Thorne, 2008). Therefore, data collection was completed once it had been determined by the researcher and supervisory committee that the clinical phenomenon had been sufficiently explored through judging the quality of data collected (Thorne, 2008; Guetterman, 2015).

Recruitment

Initially, nursing management (director of care or administrator) at both LTCH sites were contacted through the use of email or telephone. Once the interest of the LTCHs in the study had been confirmed, a follow-up telephone and in-person meeting was scheduled with a member of nursing management (See Appendix D and E for scripts). During this time, permission was sought from the nursing management of the LTCH to display recruitment posters (See Appendix F for recruitment poster). Nursing management was also asked to recommend potential participants, and consent was gained from them to share information related to the study with potential participants. I ensured participants were aware that partaking in the study was voluntary. Once participants were informed of the study and they expressed interest in participating, I screened them for eligibility against the inclusion criteria through telephone or in person. Lastly, written and informed consent to participate in the study was obtained from all participants.

An incentive ($25.00 gift card of participant's choice) was offered to participants who completed interviews. Interested respondents were asked to refer other nurses who were interested in participating. The benefit of using snowball sampling is that it is cost effective and feasible in LTCHs (Sadler et al., 2011). An additional benefit is that it creates trust between the participants and the researchers due to connecting through a mutually identified colleague. With increased trust between interviewee and interviewer, the probability of collecting honest and rich data increases (Sadler et al., 2011). The research study timeline for data collection was approximately 5 months and went from May 2019 to September 2019.

Data Collection Procedures

Semi-Structured Interviews

Semi-structured interviews were conducted in person and by telephone. Interviewing was an appropriate strategy for the purpose of this study and ID methodology because it offered a way to uncover data from the individual participants' point of view (Creswell & Poth, 2018; Thorne, 2008). If potential participants were deemed eligible, they were given a consent form in person, via mail or e-mail. A mutually agreeable time, date and location was set for the interview. Participants were given a choice to have either an in-person interview at the LTCH, a location most convenient for them, or a telephone/web-based interview. The interviews were done during or after the participants' work hours (e.g. lunch break, before work, after work or day off) and ranged from 30-60 minutes. Giving participants a choice of location ensured the interview was conducted in a place that was deemed most convenient and comfortable for them. I ensured that they were completed in an appropriate and private environment. A quiet and private room at each LTCH was made available for participant interviews. Participants were also allowed to choose the time and location within the building to ensure privacy. Two participants chose to be interviewed over telephone after work hours. To further protect the privacy and confidentiality of participants all data and transcripts was kept in a locked cabinet where only I had access to it. All data and transcripts had no identifying information on it (names were not used). Data and transcripts kept on a computer are protected by a password. Prior to the interview commencing, participants were given a demographic form to complete, or if the interview was over the telephone, it was read out loud to them and recorded. This demographic form included questions related to: age, sex, gender identification, position in LTCH, how many years working as a LTCH nurse, and formal education regarding ACP (See Appendix G for demographic form). This permitted the research team to have background data about the participants, inform maximum variation, and enrich the analysis.

The questions asked during the interview were open-ended and tailored towards generating knowledge which addressed the aims of the study (Thorne, 2004). These questions were developed through feedback from the investigators of the study, and the findings of the literature review. Questions were initially focused on experience and perceptions of LTCH nurses with ACP in a broad sense, but eventually become more targeted with respect to perceptions of their individual role in ACP (See Appendix H for an interview guide). The interview guide was reviewed with the full supervisory committee. Upon their suggestion, probes where participants would be offered to share examples and scenarios of their experiences with ACP were added to the interview guide. The same interview guide was used for both RNs and RPNs. After two interviews, small changes were made to the interview guide to accommodate for differences between RNs and RPNs. For example, RNs and RPNs were specifically asked what they perceived their role to be in comparison to the role of the other sub-groups of nurses. Pilot interviews with two nursing colleagues were also conducted prior to implementation and small changes to sentence structure were made. The interview guide was refined after the first two interviews by embedding a definition of ACP into the guide. These changes were made in order to ensure an accurate representation of the perceptions and experiences of participants.

The researcher made notes of key points throughout the interview while ensuring the participant was the primary focus (Thorne, 2016). Interviews were recorded using a recording device and transcribed following the interview. When the interview was concluding, I ensured a summary of key points was shared with the participant in order to obtain their perspectives. This allowed participants the opportunity for clarification and evolvement of interpretations (Thorne, 2016)

Field Notes

Supplementary field notes were written immediately following each semi-structured interview, in order to ensure the focus remained on the participant (Thorne, 2016). Field notes were appropriate to use in this study because I was able to record observations. By doing so, I was able to view the data from different angles and engage in preliminary data analysis. Contextual understanding of subjectivities within the data, and a broader interpretation of the phenomenon of interest was gained. For example, I recorded if the participant's body language matched what they were verbalizing - this process may have lead to new understandings (Thorne, 2016).

Data Analysis

In qualitative research, data collection and analysis are an iterative process, occurring simultaneously (Creswell & Poth, 2018). I transcribed all interviews and re-checked the transcripts against the audio recording to ensure accuracy. I immersed in early data analysis by reading and re-reading field notes and transcripts to familiarize myself with the data (prior to commencing the coding process) (Thorne, 2016). This allowed the formation of initial thoughts and ideas, which were documented through memoing in my reflexive journal.

In ID, Thorne (2004) supports moving past original theoretical scaffolding, to participate in thorough inductive reasoning. She encourages researchers not to limit themselves to traditional analysis approaches and instead create a method that focuses less on structure than it does on critical inquiry (Thorne, 2004). I was constantly exploring meanings, asking questions and deepening interpretations of a phenomenon (Thorne, 2004). This process was also kept in mind when a data analysis plan was created.

Coding

To analytically code the data an inductive approach was utilized. A line-by-line hand coding process was used for all transcripts. Thorne (2016) stresses that in ID, the interpretations are made through patterns and ideas. Therefore, a suitable coding framework does not focus on meticulousness early on in the process (Thorne, 2016). I initially coded three interview transcripts. Once completed, the three coded transcripts were reviewed against coding conducted on the same transcripts by my supervisor. After receiving feedback and discussing initial patterns, a preliminary coding scheme was developed together. Using discussion, and organizing transcripts into a chart, similarities, differences, and patterns in nurses' experiences were grouped and coded. These codes were broad initially but were compared to one another to look for emerging patterns. Due to the nature of ID, I was always questioning the reasoning behind emerging patterns and why they may be appearing (Thorne, 2016). The strategy of constant comparison was employed into the inductive analysis plan. Constant comparison is a process Thorne (2000) described whereby the researcher is comparing pieces of data with other similar data in order to develop conceptualizations and explore potential patterns. Therefore, I was always comparing results across participants and adjusted the interview guide according to what I wanted to explore deeper (e.g. added the definition of ACP to explore perspectives and thoughts pertaining to it). This fleshed out a pattern or theme if necessary. Emerging patterns, themes and data were also reviewed by my supervisory committee members. This iterative process continued until the clinical phenomenon of interest was thoroughly explored, and the aim of the study was met.

Memoing

Thorne (1997) encourages researchers to use a journal to document their analytical thought process and reflective notes. To do this, I used the process of memoing and wrote notes in a journal throughout the study and data analysis process specifically. Through these notes, I was able to constantly document interpretive questions and personal responses to these questions. For example, a question was, "What does this data mean"? Reviewing these notes alongside field notes and transcripts allowed for the expansion of ideas (Thorne, 2016). Additionally, in this journal I tracked the development of the coding framework and design decisions (Thorne, 1997). Through this process I was able to maintain reflexivity and track my personal biases (Thorne, 1997).

Conceptualizing

The eventual objective in analysis using an ID approach is to develop relationships between the themes that are identified (Thorne, 2016). By reviewing the codes and knowing the data – patterns were extended to develop an interpretation of connections that occur. I was able to thoughtfully engage and expand on ideas until new themes were not appearing, and the phenomenon of interest had been thoroughly explored.

After completing 12 interviews I met with my thesis supervisor to discuss recurring patterns from transcripts. At this point it was decided to complete 2-3 more interviews to ensure data richness. After 15 interviews, preliminary findings were discussed with the full committee and recruitment was stopped because the research questions had been adequately and feasibly addressed, with recurring patterns being sufficiently rich and flushed out. The findings were then synthesized and applied back to the practice of LTCH nurses (Thorne, 2016).

Strategies to Promote Rigor or Trustworthiness

To increase credibility, rigor, and trustworthiness of findings, multiple strategies were embedded in this study. Thorne (2016) recommends using Lincoln and Guba's (1985) criteria to promote rigor (credibility, dependability, transferability, and confirmability).

First, I maintained a reflexive and analytical journal throughout the process of this study. Initially, I acknowledged and documented biases and preconceptions I intrinsically held regarding the phenomenon of interest (Creswell & Poth, 2018; Thorne, 2016). I also engaged in an ongoing reflexive process throughout the study and documented it in a journal. As mentioned previously, all study decisions thereafter were recorded in the journal creating an audit trail (Morse, 2015). This process increases dependability and trustworthiness in the findings (Thorne, 2016).

Secondly, investigator and data source triangulation were implemented throughout the study. Both RNs and RPNs, were recruited for the purpose of the study. Semi-structured interviews, field notes, and reflexive journaling were used as data collection methods. Having multiple sources of data allowed verification of the findings and increased their credibility (Sandelowski, 1995; Thorne, 2016). I was also working closely with the supervisory committee at points in the study allowing for investigator triangulation (Morse, 2015). For example, the committee was asked to review transcripts and preliminary findings.

Ethical Considerations

Ethical approval was obtained by the Hamilton Integrated Research Ethics Board in April 2019 (project number: 5707). This study is non-invasive and only minimal emotional risks were anticipated. The research team acknowledged that the discussion of ACP and relatedly EOL can be difficult for some nurses and therefore, the subject material was managed sensitively and followed the Tri Council Policy Statement (Government of Canada, 2018).

A benefit to participants may be the rewarding feeling of contributing to nursing practice, their workplace, and the community. I acknowledge the ethical principle of respect for persons by ensuring voluntary written, informed and verbal consent was obtained before data collection and analysis (Government of Canada, 2018). I obtained written consent from nurses willing to participate in the study. The consent form included the purpose of the study, possible risks, and benefits, and addressed privacy and confidentiality (See Appendix I for participant consent form). Participants were also informed that consent could be withdrawn at any point in the study. Gift cards were offered to participants as incentives ($25.00) and for participation in research. This incentive was deemed not too large or attractive, posed limited risks and due to low monetary value, voluntariness is maintained (Panel of Research Ethics [PRE], 2018).

I exercised the principle of respect for privacy and confidentiality by ensuring data collected was not shared with anyone except with the investigators, or as required by law (Government of Canada, 2018). Lastly, the data that were collected and analyzed (field notes, transcriptions, recordings, forms) will be protected by ensuring that they are kept in a locked cabinet or stored in password protected, coded files for two years post-publication as recommended by HiREB (2018). After five years, the data will immediately be removed/destroyed confidentially as per requirements.

CHAPTER 4: RESULTS

The purpose of this chapter is to summarize the key findings of this study. This chapter begins by describing the characteristics of study participants. The major patterns and themes that emerged in the data analysis will be addressed and supported by direct quotes from the interviews. Finally, the chapter concludes with a brief summary of study results.

Demographics

The study sample consisted of 15 nurses working in two different LTCH settings (Table 1). None of the enrolled nurses withdrew from the study. Of the 15 nurse participants, seven were RNs (47.0%) and eight were RPNs (53.0%); with 93.3% of the total sample being female. The average age of nurses was 47.8 years (SD 12.1), with ages ranging from 25-60 years of age. Collecting data regarding gender and age allowed for greater variation of nurses' experiences and perceptions.

The mean number of years worked in the LTCH setting was 15.0 (SD:9.2) and ranged from two to 25 years. Most nurses had not received any training regarding ACP (60%, n=9). Of the nurses that had been trained in ACP, one participant had received it within the last six months and five had received it over a year ago. The format of training varied from a previous course (n=3), informational brochure (n=1), presentation (n=1) or general content obtained in undergraduate education (n=1).

Table 1: Characteristics of Study Participants **Total (N=15)**	
Variable	***n (%)***
Sex	
Male	1 (6.7)
Female	14 (93.3)
Profession	
Registered Nurse	7 (47.0)
Registered Practical Nurse	8 (53.0)
Employment Status	
Part-time	1 (6.7)
Full-time	13 (86.7)
Casual	1 (6.7)
Training in ACP received?	
Yes	6 (40.0)
No	9 (60.0)
How recently was ACP training received?	
Within a month	0 (0)
Within the past 6 months	1 (6.7)
Within a year	0 (0)
Over a year ago	4 (26.7)
Not applicable	10 (66.7)
Format of ACP training	
Brochure	1 (6.7)
Course	3 (20.0)
Other	2 (13.3)
Not Applicable	9 (60.0)
	mean (SD)
Age	47.8 (12.1)
Years worked in LTCH	15 (9.2)
Years worked in current LTCH facility	15.7 (9.1)

Overview of Major Findings

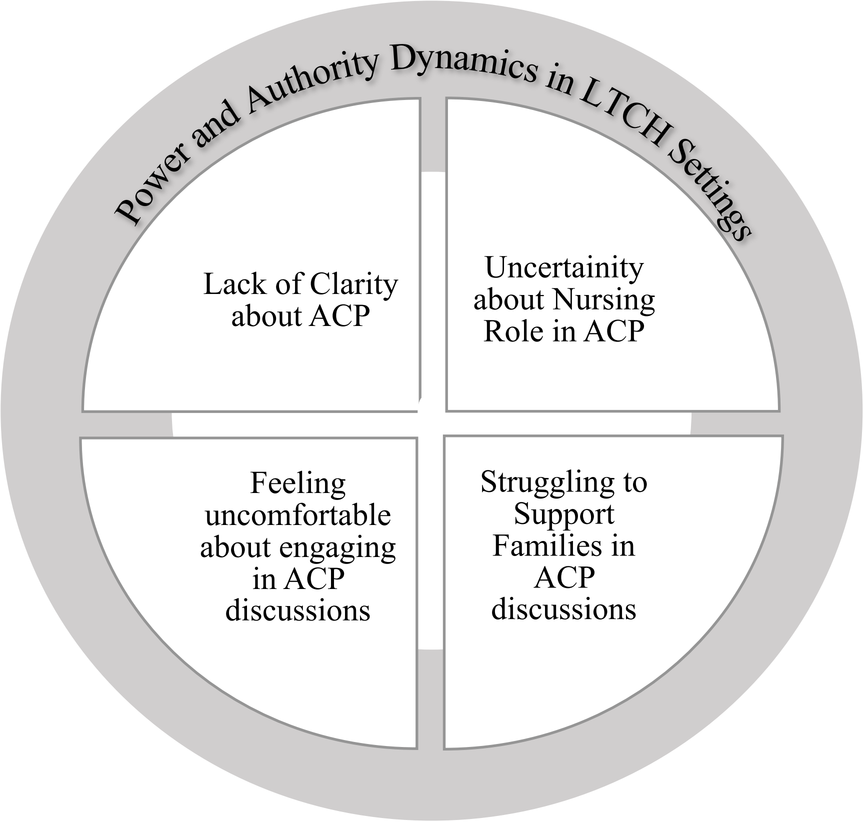
The study findings highlighted that participants had varying perceptions of their role in ACP and experiences engaging residents and their families in ACP.

An overarching theme, ACP for Nurses in LTCHs: Power and Authority Dynamics was underlying in four smaller themes including: (1) Lacking clarity about ACP, (2) Uncertainty of the nursing role in ACP, (3) Feeling uncomfortable engaging in ACP discussions with residents and families, and (4) Struggling to support families in ACP discussions. While the overarching theme seems to underlie all four themes, each theme can be considered interconnected. RN and RPN perceptions are compared and highlighted across all themes and supported by the data.

All themes were found to be interconnected with barriers and facilitators interfacing at different levels (personal, societal, and systematic) that were perceived by nurses with respect to engaging in ACP. The following visual diagram illustrates how each theme contributes to nurses' lack of engagement in ACP (the middle circle). The middle circle, is connected to each main theme; and the separation between the main themes showcases that the lack of nurses engaging in holistic ACP, is due to a disconnect between them. The shadow behind the four main themes depicts that the detachment between the themes relates to the overarching theme of factors of power and authority in LTCH settings. This model will be further discussed in the findings and discussion.

Figure 1

Visual Depiction of Patterns Related to Lack of Nursing Engagement in Holistic ACP



Power and Authority Dynamics in LTCHs

The data analysis revealed an overarching theme of power and authority dynamics in LTCHs as a prevailing and influential context across all themes. It became clear that the organizational staffing and management structure and context of LTCHs influenced the experiences and perceptions of nurses related to facilitating and engaging in ACP. The hierarchal staffing dynamic (where it was perceived that a singular group of people with power were at the top, followed by employees at various levels under them) of LTCHs contributed to some nurses feeling a lack of empowerment and support to engage in holistic ACP with families and residents. Evidently, an organizational and team approach to ACP was lacking on multiple levels and contributed to nurses not holistically engaging in ACP.

One participant acknowledged that although nurses may be in an ideal position to have conversations with residents, the context of LTCHs does not currently optimize their role and ability to participate in ACP conversations. As such, nurses did not feel prepared, supported or encouraged by LTCH management to have ACP conversations:

> Some nurses feel a bit harnessed and they don't feel either prepared or encouraged to have those ACP conversations and I think that is a huge mistake, particularly, in long-term care. We are the central player in all of this to get in contact with the physician, and 99 percent of the time we go through a nurse. So, let's empower the nurses to have those conversations. (Participant 1, RN)

This lack of preparation, support and/or encouragement by LTCH management to have ACP conversations rang true for RPN staff as well:

> There is [a role for RPN's in ACP] but it's just kind of the hierarchy here that it's I don't [engage in ACP], it'd be hard to say because as RPN's it's just not really expected of us. More, when someone starts to go we usually call the RN and say you know the family is here we need to you know call the doctor. So definitely not to the full potential but I certainly could do that (Participant 12, RPN)

This participant reflected on an underlying hierarchal structure present in LTCHs that limits how RPNs perceive their role in ACP to task-based duties. They perceived that professionals who have greater "power" or a higher position are better suited to have active ACP conversations. This supported the notion that the structure of LTCHs themselves make it difficult for nurses to perceive they have a role in ACP and take ownership of it. Lastly, another RPN further emphasizes the lack of a team approach to engage in ACP due to power dynamics. Specifically, the deference to physician authority, feeling constrained and oppressed working in LTCHs is highlighted when a nurse stated:

> We have closer contact with the resident on a daily basis, versus the doctor, but I think the doctor have more authority for them to say that "I think this is it", for example "I can't do no more treatment, say somebody has cancer, right we have exhausted everything and I think this is this." There's not a whole lot I can do but as a nurse, I don't think you could say that. (Participant 14, RPN)

This emphasizes that while RPNs feel they are familiar with residents and develop long-standing relationships with them, they do not feel authorized to engage in ACP. Participants appear to identify ACP as equivalent to discussing prognosis and medical decision-making conversations that align better with a physician's scope of practice. Therefore, they feel unable to participate in those conversations since they perceive it would be more legitimate if relayed to families by the physician. A team approach, along with guidance and support, may enable RPNs to feel empowered to engage in conversations while recognizing their role in ACP and being aware of potential limitations in their scope of practice.

Another element adding to nurses' lack of empowerment and oppression of role in ACP is that they feel they do not have the support to effectively engage in ACP conversations from their organization, even though it is within their scope of practice. An RN states,

> According to our facility and policies and laws we have to have a DNR or CPR form in 24 hours. Then, I have to call the family back, if they don't respond, my manager will come and say you know what you have 24 hours you have to put that in place, I cannot initiate any order because I don't have an answer and these are hard discussions (Participant 7, RN)

This illustrates that nurses appear to not be functioning autonomously and feel limited in what they are allowed to do within their role. This RN adds, "We are working at a full capacity, yes. I try to explain [ACP] to the best of my understanding to them [families and residents]…but more than that I really do not have any option to explain more (Participant 7, RN). This reflects that they feel it is not within their control to engage in holistic ACP due to constraints from management and their organizational policies. Evidently, power and authority were prominent notions in conversations with both sub-groups of nurses and this overarching theme will be further discussed and supported throughout the main the themes in the findings.

Lacking Clarity about ACP

This theme highlights the uncertainty nurses felt regarding what the content and process of ACP is. Most nurses initially perceived their engagement of ACP with residents and their families from the viewpoint of determining resuscitation status. As previously discussed, a definition of ACP was added to the interview guide as it was found that many nurses in the study were unable to describe the concept. This definition of ACP that was shared with nurses was holistic, and emphasized that the overall goal was to uncover values, wishes and preferences of residents for future personal and healthcare decisions (Beck et al., 2017; HPCO, 2011; Speak up, 2020, Wahl et al., 2016). Yet, both RNs and RPNs failed to move from knowing the concept of ACP on a narrow level that focuses on medical directives, to embodying it holistically. Few RNs were able to appreciate that they are not activating ACP to its full potential in LTCHs. This highlighted that while knowledge of the content and process of ACP may be a factor for nurses not embodying it holistically, it does not fully explain this finding.

Most participants' views regarding ACP were restricted to the decision-making process of a resident's code status in the context of the LTCH setting. Participant 4 (RN) stated, "The advanced care plan we have here is the DNR (do not resuscitate) or the full code - is that what you're looking at?" Less frequently nurses also interpreted ACP as medical decision-making and legal advance care directives. A participant shared their thoughts after being presented with a holistic definition of ACP:

> …On the first day we have admission we discuss palliative care, the end of life or if that decision is made in front of us, then they have to sign a paper which is the advanced care directive and that will be placed on the resident's chart and will be again for our facility…it's [ACP] like introducing initiatives in order, DNR (do not resuscitate) or CPR (cardiopulmonary resuscitation)... (Participant 9, RPN)

This participant was not able to elaborate on the holistic elements of ACP. Instead, there seems to be an importance given to determining the code status of a resident that aligns with an advance directive. Therefore, they seem to perceive and place an importance on ACP as simply as death and dying decisions on admission in the context of LTCHs. An RN shared their understanding of ACP and further supported the narrow focus on ACP and uncertainty regarding the process:

> So, um, advanced care planning is specifically mostly the code status. Yes or no? As far as I know… Advanced care planning is only about that, I think it is really very important, in a way that it serves as a guideline. (Participant 2, RN)

This participant was uncertain and required confirmation of what ACP truly entailed. After further discussion in the interview and being presented with the holistic and broader definition of ACP, Participant 2 (RN) later reflected, "I mean advance care planning is all of those; the values of the individuals and things like that. It's not only the code status." Evidently, through the interview process this participant was able to reflect on their perceptions surrounding ACP and acknowledge that it does go beyond code status. This may reflect that while nurses can recognize that ACP encompasses comprehensive discussions surrounding wishes and values of a resident, they do not enact it as such into routine practice. Therefore, since eliciting the holistic elements of ACP is not common practice, they seem to have a predisposition to discuss ACP in the context of code status. The focus on code status is likely reinforced by organizational policies and protocols. To further the idea that nurses struggled to operationalize holistic ACP one participant used it interchangeably with decision-making capacity:

> The advanced care planning - usually the topic that they discuss on the admission day with the substitute decision maker, or the resident, - depends on their cognitive capacity and we make the decision in the first day - if the resident will make personal decisions or the POA [power of attorney] will make decisions on behalf of the resident, that for me is advanced care planning. (Participant 7, RN)

Not only did most nurses perceive ACP in the context of LTCH to be largely about code status, there are multiple concepts such as advance care directives, current care planning, and decision-making that they often used interchangeably with ACP. There was an emphasis on ACP being limited to a single conversation to discuss code status, decision-making capacity, and substitute decision makers, instead of ongoing conversations to revisit on a regular basis. A participant further reflected on how and when they initiate what they perceive to be ACP conversations with residents and their family members:

> …Like if a resident suddenly declined – I immediately ask if their code status is no code, or allow natural death, and then I talk to the doctor communicating palliative measures. We utilize the palliative card when we notice that a resident suddenly declines, not eating anymore for the past few days, but it's just when they have an acute change that we initiate those [conversations], and we talk to the family about some changes that we noticed on the resident, and we start being more proactive in maintaining the comfort for the resident, but it's mostly during when they have an acute change (Participant 6, RN).

This participant's account strengthens the idea that nurses can inaccurately perceive ACP to be about current care-planning and medical decision-making. The participant activates conversations around what they perceive to be ACP only when a resident has an acute and physical decline in health status. Therefore, it appears nurses presently may prioritize engaging in ACP when they anticipate a person may be near end of life since they need to know at that point how to proceed with a resident's care. It seems nurses lack an in-depth understanding of the holistic nature and elements of ACP and therefore may only perceive it to be relevant when it is emergent to know a resident's healthcare wishes. This reflects a lack of understanding of a palliative approach to care and engagement in ACP. One participant engaged in self-reflection on the use of ACP in the LTCH context and described the lack of clarity they have:

> When I started talking about advance care planning, I realized how little I know about it… so that is definitely eye-opening for me and I want to go talk to my colleagues already. So, it's I don't know where this is going to go but definitely, we will be looking into it for sure. Because we don't talk about it, not much, right? (Participant 3, RN)

The interview process created space for reflection on practice where the participant examined their current practice and realized it did not align with holistic elements of ACP. Similarly, one RN recognizes:

> I think that nurses should be a patient advocate, we should be initiating those conversations not only when they have an acute change but when they are first admitted into long term care or just before the admission to long term care. But right now, I think the only focus for me is to develop a plan of care is when they have any acute change. (Participant 6, RN)

This nurse was able to reflect on their practice and identify that ideally ACP should be occurring prior to an acute change in a resident's status. However, in reality, what they perceive to be equivalent to ACP is actually goals of care and decision-making conversations that are not occurring in advance. Later on, they suggest:

> I think we need to do better in terms of those important conversations [ACP conversations] because if we don't know the prior wishes of a resident then they always experience unnecessary transfers to the hospital and it puts a resident who is not at risk, by not honouring their prior wishes. (Participant 6, RN)

While they were able to appreciate the need for ACP, there seemed to be a disconnect between enacting it into actual practice. This suggests, nurses may need more clarity around when and how ACP can be activated in the context of LTCHs. Overall both sub-groups of nurses expressed an appreciation and need for ACP, however, focused on very narrow notions surrounding it and did not address it holistically. The only notable difference between both sub-groups was that three RN participants engaged in reflection of their own perception of what ACP encompasses, and recognized their engagement in ACP in the context of LTCHs is limited, while RPNs did not. This could be because the context of LTCHs reinforces very focused notions of determining code status and medical directives. Determining a patient's code status is a measurable and physical document in most LTCHs, which nurses are often required to fill out or acknowledge. Nurses need to know how to act in a situation where a resident's heart and/or breathing stops; therefore, it is a priority to address. Other holistic elements of ACP are not empirically measurable, and consequently not adopted by LTCH policies and in practice as efficiently. Thus, nurses may tend to activate their knowledge surrounding ACP in a very detached way in their practice because it is what is perceived as applicable in the current context of LTCHs.

There was a general lack of clarity among nurses regarding when to engage in ACP in the LTCH setting. There were varying perceptions of whether ACP should happen during the admission process, care conferences, on an ongoing basis or an isolated occurrence. Nurses shared their thoughts around when they perceive engaging in ACP is possible.

Multiple nurses suggested that care conferences or on admission day is the best time to engage in ACP. Care conferences occur a few times a year with the multidisciplinary team, RN, family and resident present. It should be noted that RPNs are often not present at care conferences. Admission refers to the day (or a few days after) a resident first comes to the LTCH. One RPN explored the idea that the admission and shortly after at a care conference would be the best time to engage in ACP discussions:

> I feel it is something we should be talking about more right from the admission instead of waiting. Mind you on admission is a very emotional time for families also but we have like a six week post admission care conference and I feel that's really when we should start talking about it because yes it may not happen for three or four or ten years in some cases, but I think it's really important that it needs to be discussed early on. (Participant 12, RPN).

While care conferences were perceived to be a good time to discuss ACP, in actuality they are often used for current care planning and goals of care discussions. A nurse reflects on what transpires during care conferences:

> Yeah, especially when the residents go for like a health status change we can call for a care conference that involves the doctor, all the care team members could come there and talk about the advanced care planning and then we can go from there to decide you know what're the next plans for the until the end of life. (Participant 9, RN)

It appears that although care conferences are perceived to be a valuable opportunity to discuss ACP, currently they are used to initiate medically driven decision-making conversations. One participant further supports how medically driven care conferences can be:

> No, yeah so it's just like okay for some times like I guess on admissions a person might be CPR right and then after if they go through the care conference then we bring that topic up again and they say well now we want to

> be a DNR and you know we want the person to be here and be comfortable so those things may come up like in advanced as you would say (Participant 13, RN)

Two other nurses shared that ACP only occurs during the admission process. Participant 7 (RN) shares, "It's just admission as I told you, nothing more than that. It's just when I have a new admission that's the day when I engage in advanced care planning in my role, that's it." Similarly, another nurse expressed the importance of engaging in ACP during the admission process:

> I think advanced care planning is very important during the admission process… so that we would know the future plan of care, not future but the plan of care of patients coming into long term care because I know it would really drive – it would be a bit more on a patient centred approach wherein we know the desires of individual when they can still make decisions or probably their substitute decision maker. (Participant 6, RN)

Overall, a majority of the nurses of both sub-groups talked about ACP as an isolated practice that may occur during admission or a care conference; typical practices in LTCHs. ACP was rarely discussed from the perspective of a process of ongoing conversations that were embedded into practice. The current structured approach given to care conferences and the admission process in LTCHs may reinforce that nurses do not need to participate in ACP autonomously. Therefore, it appears nurses may feel less authorised to engage in these conversations in routine practice and on an ongoing basis. This supports the finding that although some nurses may understand that ACP is holistic, they only activate it as a one-time event that reflects residents' wishes to be narrow and static in nature.

Uncertainty about Nursing Role in ACP

In addition to lacking clarity in respect to knowledge supporting holistic ACP and when to engage in it, nurses also revealed lack of clarity around whose role it is to engage residents in ACP. Nurses reflected on what their current experience with their role in ACP is, and their perceptions of whether they should have a role in it. There were variations between both designation sub-groups of nurses of whether or not they believe ACP is a part of the nurses' role and what their role encompasses. In some instances, both sub-groups of nurses believed that the social worker and doctor should have a prominent role. In other cases, there were discrepancies on whether or not the RNs can engage in ACP with residents and their families.

In general, participants expressed lack of clarity of their responsibility in ACP. They also displayed a general underlying and multifactorial fear of engaging residents and their families in ACP and subsequently struggled to take ownership of this role. A participant explored why nurses in a particular LTCH may not engage in ACP discussions and rely on other professionals to take ownership. They stated, "So, I think some of it is about workload and some of it is about perception as well, that that's not within my scope of practice or my realm of practice and so that's a social worker thing" (Participant 1, RN).The participant explored how nurses may perceive that ACP is not within their scope of practice, and depend on social workers to actively engage in conversations with residents and their families. One RPN similarly reflected that they believed social workers were well positioned to engage residents and their families in ACP discussions:

> A social worker, she can [engage in ACP conversations], because that is kind of one of her specialties, so I think the social worker and the doctor have more leverage, more leeway, more authority to go in depth. We can kind of lead the person if that person initiates that conversation but at the same time you have to be careful right, you kind of have to listen to what they say (Participant 14, RPN).

This participant explored the perceived need to be careful when engaging in ACP conversations. This may stem from nurses being afraid to upset families and residents by engaging in ACP conversations which they may feel to be equivalent to discussions around code status. They further acknowledged the belief that the doctor and social worker have more "power" or "authority" ability to go in depth. This supports the notion that nurses do not feel they have power or influence to have ACP conversations with families, and therefore do not want to be held accountable for having discussions. One nurse commented that they were reluctant to engage in ACP since they felt they did not have authority to do so:

> I wouldn't say that it's part of my role to have the conversation, I think that's between the family and the doctor. I just follow what their wishes are, I don't think it is part of my role...I guess if you were really close to a resident, then you could ask them, and if they're cognitive, you know, you could have the conversation. (Participant 15, RPN)

This participant explored the idea that unless a nurse feels they have built a close, and perhaps trusting relationship with the resident, they feel ACP should be between the family and the physician. This suggested that nurses are able to initiate and engage in ACP, but they do not perceive they should be primarily held responsible within their role. Another participant further explored why nurses may perceive the physician's role in ACP as more central. The participant states:

> The communication from the social worker, this nursing home is really good, because the doctors really engage with residents. And that is really important for them [the families]… Because in my experience, no matter how much I explain to the family, it is different when the doctor does. It's not that they don't believe me, but you know some people, it's the doctor is telling me this. (Participant 2, RN)

This quote explored the notion that nurses may not feel empowered to have ACP discussions with families because of the perception that families will be more inclined to have them with physicians. This suggests they perceive families have greater trust in physicians due to their perceived superior authority, and legitimacy over nurses when discussing EOL decisions (that include topics such as code status and life-saving measures). Overall, the belief that physicians and social workers are better suited for the ACP discussions was shared by both sub-groups of nurses. A general understanding that it is not within the nurses' scope of practice, or that physicians and social workers have greater authority to engage with families were some of the factors influencing their perceptions.

While some RNs and RPNs seemed to perceive that the social worker and physician have greater ability to engage in ACP, the majority of RPNs believed that RNs are better suited for the role in engaging residents and families in ACP. A participant stated, "I don't think I really have a role as an RPN in advanced care planning. Like I said as an RPN here we don't have much opportunity because the RN is in charge right" (Participant 10, RPN). This perception was shared by another RPN participant who stated:

> I think the closest [to engaging in ACP I have come to] would be when the RN or the higher ups just ask us in general what we think would be the best for that resident but that's pretty much all (Participant 11, RPN)

As supported earlier, this participant later reflected on why RPNs may not engage in ACP as significantly:

> I don't think I am [able to engage in ACP] because like being a practical nurse I deal more like the resident's medications, doctors' orders and more. Like I don't think I would have time to just sit down and really just talk with the family and stuff, more of the RNs have that power and the DOC [director of care] and stuff (Participant 11, RPN)

Both RPNs explored the perceptions that they feel it is not within their role because they may not have as many opportunities to engage in ACP conversations as RNs due to their day to day duties. There also seems to be uncertainty around whether RPNs have as much power to engage in these conversations. As was stated earlier, RPNs do not typically attend care conferences, where it was perceived ACP conversations can occur - while RNs do. This suggests that there is a perception of hierarchy between RNs and RPNs in the context of LTCHs. An RN explores the notion that they may have a greater role in ACP due to the fact that during care conferences with the residents and their families the RN is usually present. Participant 2 (RN) stated, "The RPN doesn't really participate in that [care conferences]. Mostly the RN. It is an exception that I use the RPN to engage." Another RPN echoed this idea:

> The RN is there most of the time and most of these conversations happen on days and the charge [nurse] is right there and most family members come in on days to you know to have care conference and stuff like that, that's when they discuss all these things too. (Participant 10, RPN)

The notion that RNs are participating in care conferences and RPNs generally do not emphasizes a hierarchal approach and may be why RPNs feel less empowered to participate in ACP discussions. Additionally, it may be perceived that RNs have a wider scope of practice than RPNs and therefore it is not required of them to participate. In general, nurses suggested multiple factors for the lack of participation in ACP and the lack of clarity in their role. Authority, power, and opportunity were factors that both sub-groups of nurses mentioned. Since RPNs are not expected to participate in care conferences, they do not feel enabled or responsible to discuss ACP within their role. Therefore, a greater priority is put on task-orientated aspects of their job. It is clear that both sub-groups of nurses have varying perceptions of what their and the multidisciplinary team members' roles are in engaging residents and their families. Overall, a great uncertainty of whether it is within their scope of practice to engage in ACP exists and it is not supported as a team process within LTCHs.

Feeling uncomfortable about engaging in ACP discussions

This theme describes the perceived lack of comfort nurses felt engaging in ACP discussions. While workload and time were mentioned as barriers by nurses, upon deeper reflection it is apparent that most nurses agreed that their lack of comfort with ACP made it difficult for them to engage residents and their families in conversations.

Two nurses discussed the demanding workload present in the LTCH setting as partially contributing to a challenge in engaging in ACP. Participant 1(RN) reflected on this perceived barrier by expressing:

> …I think some of it is about workload, so people are not sure that they have the time to devote to that kind of conversation – as I said before, it's not one conversation. I could speak to you a little bit about the advance care planning, and I can speak to you more tomorrow and the next day and four weeks from now.

While this participant does acknowledge that a demanding workload can be perceived as a barrier it is clear there are additional contributing factors inhibiting nurses from engaging in ACP conversations. She later reflects on this possibility further, by stating:

> So, long-term care is always going to tell you we don't have the time and we don't have the money. And I'm going to tell you that I don't agree with that. So, HAH. I think that's a great barrier, but I think we're erecting that. Uhm and I think we can tear that down.(Participant 1, RN)

While this participant viewed workload and limited time as a barrier that is being erected, another participant recognized it as an ongoing challenge to meeting basic care needs of residents and consequently engaging residents and their families in ACP as well. Participant 3 (RN) states, "We need more time for sure. Forgive me one of the main challenges in meeting the needs of the residents [in LTCHs] are really the limited funding…". It is clear that a few nurses perceive the context of LTCHs to be a challenge due to demanding workloads however only as a partial barrier. Multiple participants expanded on challenges and explored their lack of comfort with engaging in ACP. A participant shared his lack of comfort with initiating conversations:

> I think lacking would be our communication skills, like how would you acknowledge a family member or a resident if they said "these are the things I wanted to do, and I am passing." I think the comfort level of nurses to that varies, sometimes they're comfortable sometimes they don't [feel comfortable] (Participant 6, RN).

This gives insight into how nurses may not have confidence in their communication abilities with ACP conversations. While they may not completely understand why they don't feel comfortable, they can acknowledge that there may be multiple factors affecting their ability to communicate with family members and residents with respect to ACP. Another nurse elaborated on the perceived barriers of comfort and communication when engaging residents and their families in ACP. They reflected on the idea that it is their intrinsic personal values which surround the topic of ACP that make it uncomfortable for nurses to engage in conversations if they don't share the same beliefs as the resident or their family. They state:

> The big gap is the communication. And I would say the comfort as well – to be discussing it [ACP]. I think it is unavoidable on their [nurses] part for them to interject with their own perceptions, their own decision. (Participant 2, RN)

This suggests that the lack of comfort that nurses experience related to engaging in ACP discussions can stem from their personal biases and beliefs regarding death and dying as well. Another participant provided insight into the perceived lack of comfort with ACP that nurses may perceive:

> I guess it's not like the training, I guess people are just not comfortable talking to families. It's not like we don't know what to say. But I guess it's just that limitation like you being so limited to what we can say, or you know, whether we can do that. (Participant 4, RN)

This participant provides insight into another layer of why nurses may feel uncomfortable engaging in ACP. While they may feel they have the knowledge to initiate ACP conversations on a personal level, they feel limited in terms of what they are professionally able to say while discussing ACP with residents and their families. They perceive they are going to cross a boundary they are not authorized to; therefore, they struggle to begin that conversation. Another participant shares similar thoughts about feeling constrained and not supported to have holistic ACP conversations. Participant 14 (RPN) explored needing to feel supported and stated:

> ...Some clarification [scope of nurses in respect to ACP] is needed because as a nurse, as I said, you might say the wrong thing, and then the wrong thing is interpreted differently, but you have to, you have to have a protective measure.

This reflects that there is a need for a guiding document or policy to be in place pertaining to the role and scope of practice of nurses in LTCHs in respect to ACP. They further elaborated on why they feel the need to have a protective measure when engaging in ACP by saying:

> College of Nurses can say yes, you can say that, or you can't say that, because there's boundaries, ethical boundaries for you to be telling that resident. And residents some of them have dementia, some of them will twist things around, so yes, you, you have to be protected (Participant 14, RPN).

This strengthens the overarching notion that nurses struggle to feel empowered and authorized to have ACP conversations. Participants described perceptions that if they say the "wrong thing" they don't have a protective measure and therefore are concerned about the potential liability involved with having these conversations. Overall, both sub-groups of nurses perceived the lack of communication and confidence with conversations led to greater discomfort in engaging residents and their families in ACP. This lack of comfort may be due to personal values, however there are also broader factors to consider. Both RNs and RPNs seemed hesitant to participate in ACP conversations due to not feeling supported or authorized to do so. They also perceived these conversations as sensitive for families and residents, and there is no clear guideline or protective measure in place for them. Only a two RNs perceived barriers of workload and time inherent to the LTCH context challenging to overcome while RPNs did not express this.

Struggling to Support Families in ACP Discussions

This theme describes how nurses perceived their relationships with resident's families and how it impacted their ability to engage in holistic ACP. This section will also discuss potential factors for the perceived tension between nurses and families and how it inhibits them from supporting residents with ACP discussions.

Most nurses perceived that families can be challenging to engage in ACP. A nurse discusses her experience engaging in ACP with a family member when they were not open to listening to their father's values and wishes due to cognitive impairment:

> To be honest, I think I had advance care planning conversations with the family for a year now and they're ongoing. And we've had different team members have conversations with them, we've chatted with the dad to the extent he can participate too. And he can tell us some information, but they are not that interested in what he has to say. Because he has a diagnosis right – so as soon as you have dementia people think you can't make decisions which is not true. (Participant 1, RN).

This participant discusses how family members may not initially have an understanding of capacity, decision-making, and degree of participation in ACP possible for residents diagnosed with cognitive impairments. This may make it difficult to get all parties to communicate and participate in ACP. However, in these situations, and in general, the participant stresses ongoing conversations and greater support to family members can assist in the process of ACP. Another participant described their experience when engaging residents and their families in ACP and expanded on the potential discrepancies that can arise between them. They stated:

> Difficulty is the family understanding of it. So, the family members - you talk to them about it but when a situation arises it's different sometimes, they're still in denial so it's hard to deal with that situation. The resident himself might be okay with it but then sometimes the family is not so then you have that tug of war between family and the resident that makes it difficult for you to deal with that resident. You dealing with the resident that comes first but you also have to comfort and explain to the family what they still don't get because they're still in denial. (Participant 13, RN)

This participant explored family members and residents having a differing understanding regarding preferences for care. There is a sense of tension experienced by the nurse who voiced frustration when family members do not come to terms with the care needs, wishes, and trajectory of a resident's illness. The nurse expressed it being difficult for them to enact a resident's wishes and to be in this dynamic with family members and residents. This may be because nurses feel they understand the wishes of a resident and want to enact and support their desires however they perceive family members may not have the same understanding. One nurse explored the notion of families being "problematic" when engaging in ACP by stating:

> We attend [care conferences] if there is a challenging family that the RN couldn't handle – nurses at management level participate in that. It all depends on the RN working – you can gauge who is working, who has the knowledge and communication skills and things like that [to engage in ACP]. So yes, if we are safe enough, and the family is not being problematic we participate. (Participant 2, RN)

This perception of family members being "problematic" is recurring for both RNs and RPNs. An RPN echo similar perceptions of family members. A participant explained:

> I think it's a great idea [ACP], I think what happens quite often is people come in here and then, they haven't really thought about what they want, what they want to do, and the families argue, and then you end up in a you know, a dispute with the families. Do whatever you can to save my mother, just keep her comfortable. You get family members not on the same page. (Participant 15, RPN)

It is evident that multiple nurses within both sub-groups perceive and experience challenging interactions with residents and family members and they assume and expect that families will not respect the wishes of a resident. Furthermore, there is a general belief that even if ACP is activated, the wishes and preferences of residents will not be validated due to the potential conflicting values that may be present between residents and family members regarding care decisions. These notions appear to develop a hesitation for nurses to engage in ACP with residents and families. A nurse reflected on the fear of upsetting families: "I think it's just the families [in respect to a barrier to ACP], mostly it's about family being mad. Or family – for example the substitute decision maker might have conflicting values in regard to future plan of care" (Participant 6, RN). Generally, it seems nurses struggle to support family members through this process when there is perceived tension between parties. The fear of engaging in ACP with residents and their families appears multifactorial. A majority of nurses seem to have a preconceived notion that families will not be receptive to ACP conversations activated by healthcare team members. It appears there is a presumption that they may react negatively or even become angry with nurses engaging in ACP, if the resident and family member's values and wishes for future care do not align.

A participant explored potential factors behind perceived and experienced hesitance to speak to families:

> So, some of that might be historical referrals – I think some people [nurses] don't want to talk about it because they don't want to have that conversation with the family – because the family might get upset. Or they misinterpret it when I start talking about advance care planning – like when you introduce morphine people are pretty sure the end is near – and you have weeks, right – we're talking weeks here. And that's not really the case – I think there's just reluctance, there is a resistance and I don't really know why but I think its multifactorial (Participant 1, RN)

This nurse expressed that while they are reluctant to engage residents and families in ACP, it is not always clear why. It appears multifactorial and could be due to general discomfort discussing death and dying, or when families and residents do not have the same understanding or acceptance of the illness trajectory as nurses. One nurse further explored the issue of facing potential consequences when engaging in ACP discussions with families:

> …Sometimes if you say something, what happens is the family will take down your name and number or whatever and go and complain about you and then you get called in. Why did you say that or that wasn't right? So here the family is always right. It's you know, I tried to have that conversation, but the family's always right kind of right (Participant 4, RPN)

This participant highlights that they are hesitant to engage in ACP discussions due to personal experiences of upsetting the family and consequently not feeling supported by management. Another participant similarly expressed fear to engage resident's families in ACP discussions, due to the thought it will not be perceived as acceptable and may result in a complaint:

> Because some residents will act as if they're receptive, they like the idea, but they can still go back and complain to their family and say I'm not sure what the nurse was trying to tell me, or you know, she wants to talk to me about putting things into perspective and it's not her place (Participant 14, RPN)

It is possible, that nurses would rather avoid a potential conflict with residents and family members which may lead to complaints up the hierarchy to management. Overall, there is perceived tension and fear experienced by both sub-groups of nurses when engaging residents and their families in ACP. This seems to be multifactorial and could be due to a personal discomfort with death and dying conversations. There also seems to be a general presumption that there is a potential for families to react negatively towards ACP conversations. Multiple nurses also indicated they do not have enough support and protection by their organisation to engage in ACP conversations with residents and families. It is evident that they need more encouragement to feel empowered to engage in ACP conversations with residents and families.

Summary of Results

To summarize, it is clear that nurses have limited involvement in engaging in the process of holistic ACP with residents and their families. First, study results revealed that the majority of participants within both sub-groups of nurses lacked clarity about ACP and their role in it. Both sub-groups perceived ACP in a narrow sense often limited to code status, and medically-driven decision-making conversations. RNs, however, were able to recognize their narrow approach and that they did not engage in ACP in their practice. Findings support that both sub-groups take a narrow and less holistic approach to ACP and that this is related to the structural context of LTCHs. An organizational model supporting a team-based and ongoing approach is needed for nurses to activate ACP with residents and their families. Both RNs and RPNs also struggled to take ownership of their role in ACP. While RPNs tend to perceive that RNs have greater authority to participate in ACP, RNs also hesitated to take ownership of that role and perceived that physicians and social workers may have more authority.

Secondly, the responses highlighted an overall lack of confidence as a perceived barrier within both sub-groups of nurses. There may be an inherent fear to engage residents and families in ACP that is multifactorial. On a personal level, nurses may struggle to approach conversations that may be perceived to revolve around death and dying. They do not feel prepared to have conversations that they fear may be upsetting to families and residents.

Lastly, the findings illuminated that both sub-groups of nurses perceived potential conflicts when engaging residents and their families in ACP. They struggled to support families when residents' and family's views did not align. They perceived they may cross a boundary when discussing ACP with families and residents that would result in punitive measures against them. Overall, it was clear that they perceive a lack support from their organization, and do not feel empowered or authorized to participate in ACP conversations. Study, findings suggest that a greater degree of organizational support is needed to optimize the nursing role in engaging residents and their families in ACP. Overall, it is clear that the dynamics of power and authority combined with the key findings of the study within the context of LTCHs may be inhibiting nurses from engaging in ACP.

CHAPTER 5: DISCUSSION

This study provided new insights into the experiences and perceptions of both RNs and RPNs working in LTCHs with respect to their role in engaging residents with chronic life-limiting illnesses and the residents' families in ACP discussions. It also detailed the perceived barriers and facilitators towards nurses optimizing their role in activating holistic ACP.

In this chapter, the overarching theme and key study findings have been discussed in light of current literature. New insights on nurses' perceptions and experiences that have not been previously explored in existing literature have also been discussed. Specifically four key findings were detailed: (a) culture of LTCHs and lack of support and empowerment for nurses; (b) need to develop nurses' knowledge, comfort, and capacity to engage in ACP; (c) interdisciplinary team and nursing collaboration and; (d) relationship-based care to support ACP with families and residents to engage in ACP.

Culture of LTCHs and Lack of Support and Empowerment for Nurses

One of the most significant findings of this study is that the culture of LTCHs does not consistently support or empower nurses to engage residents and their families in ACP. It became clear that notions of power and authority influenced how RNs and RPNs perceived and activated ACP, limiting them from engaging in holistic and broader elements of ACP. The hierarchal staffing structure of LTCHs, and lack of empowerment and support from management, directly affected and decreased the level of comfort nurses felt engaging in ACP with residents and families.

ACP is at the essence and a key component to providing a quality palliative approach to care for residents in LTCHs (CNA, 2013; CHPCA, 2015). It encourages residents to communicate their wishes, preferences and values for care related to physical, psychosocial and spiritual aspects (CHPCA, 2015). It has been documented in previous literature that psychological empowerment is a factor in predicting nurses' confidence in delivering a palliative approach to care to residents in LTCHs (Frey et al., 2019). An explanatory sequential design was utilized in a mixed-methods study that took place in New Zealand. This study explored the factors that predicted confidence in healthcare staff engaging residents in a palliative approach to care (including Registered Nurses, Health Care Managers, and Health Care Assistants) in 22 LTCHs (Frey et al., 2018). They reported that hierarchy and authority of management in LTCHs can limit empowerment and prohibit nurses from practicing and engaging in a palliative approach to care autonomously (Frey et al., 2019). In the current study, nurses evidently felt similarly as they perceived a hierarchal structure with management at the top and with the greatest authority, and subsequently levels of healthcare staff below them; such as RNs, and then RPNs. Since nurses did not feel supported by management, the perceived highest level in this structure, they did not feel they entirely had the control or authority to engage in ACP.

The current study adds to the existing body of literature by revealing that both sub-groups of nurses felt a lack of power related to an organizational culture in LTCHs that is hierarchal in nature. This perceived lack of power and authority however varied for each sub-group. RNs often felt physicians and social workers have more authority to engage in ACP conversations whereas RPNs felt ACP discussions were more within the role of RNs. What further strengthened the RPNs' perceptions was the finding that management encouraged RNs over RPNs to attend care conferences, where ACP discussions were perceived to take place. Notably, a lack of role ownership, and hesitancy to engage in holistic ACP between both sub-groups of nurses could be associated with a perceived hierarchal structure in LTCH that does not hold members equally accountable or responsible for ACP.

Furthermore, previous literature identifies LTCH culture and specifically the level of support by management, as a key factor that motivates staff to engage in ACP with residents (Ampe et al., 2017; Gilissen et al., 2017). A systematic review by Gilissen et al. (2017) examined the preconditions for effectively implementing ACP in LTCHs. Their systematic review found that in order for LTCH healthcare staff to engage in ACP, they need a system approach where various levels of management, stakeholders and frontline staff are open and willing to participate in it (Gilissen et al., 2017). In order to support this approach, it is critical to foster a supportive culture in LTCHs where management and subordinate staff work together to put systems in place that encourage effective in ACP with residents and families (Gilissen et al., 2017). Other highlighted preconditions include: availability of resources, sufficient time, having a palliative approach to care system in place, and supportive resources that enable ACP to be embedded into routine practice (Gilissen et al., 2017).

The current study echoed similar findings as existing literature by confirming a lack of organizational support as a barrier that inhibits nurses from engaging in ACP (Gilissen et al., 2017). This current study also added to previous literature by exploring on a deeper level the impact of LTCHs' culture, and perceived hierarchal structure on resident and family-centred ACP. Notably, a key finding was that nurses were hesitant to engage in ACP due not feeling permitted or authorized to. They explored that this fear may partially stem from feeling discouraged to engage in ACP conversations that they assumed could cause families and residents distress; and consequently lead to negative consequences for them from management.

Overall, the current study further supported the existing body of literature in understanding on a deeper level the impact of the culture and subsequent individual and organizational barriers present for LTCH nurses when engaging residents and their families in ACP. The findings indicated that both sub-groups of nurses need to feel empowered and supported in order to activate and engage in holistic ACP with residents and families. Fostering a supportive organizational environment can help build self-confidence in nurses and subsequently optimize their role in holistic ACP (Ampe et al., 2015; Frey et al., 2019; Gilissen et al., 2017).

Need to Develop Nurse's Knowledge, Comfort, and Capacity to Engage in ACP

The findings of the current study are consistent with previous research that accentuates the substantial need to develop nursing knowledge, comfort and capacity to engage in holistic ACP (Ampe et al., 2015; Ong et al., 2011). In the current study, it was evident that nurses often activated and perceived ACP through a narrow and medically-driven lens that was limited to code status and treatment preferences. Furthermore, on an organizational level, nurses often perceived ACP as an isolated event that took place during structured time frames (i.e. care conferences and at time of admission). Nurses were not able to identify when ACP should be initiated, which suggested that ACP is not currently supported or understood as an ongoing and holistic process in LTCHs.

Previous literature has reported a knowledge gap related to ACP in LTCH staff. A need for more education for nurses regarding the fundamental knowledge, terminology, purpose and process of ACP was often identified (Beck et al., 2017; Fernandes, 2008; Flo et al., 2016; Gilissen et al., 2017; Hickman et al., 2016; Thoresen et al., 2016). This current study echoed similar conclusions such as nurses often used inconsistent terminology and concepts to describe ACP and lacked knowledge regarding the process. However, other new factors that add to the existing body of literature were also identified.

ACP from a nursing perspective may have a narrow focus on code status discussions, current care planning and medical decision-making, not solely due to a knowledge gap but also due to the context of LTCHs. Nurses may perceive their role is confined to ensuring code status and medical decision-making has been discussed due the hierarchical structure of the organization. Therefore, any action outside of this may be met with negative consequences from superiors. This context of LTCHs may be further accepted by both sub-groups of nurses because tasks such as ensuring code status and medical decision-making is supported through current policies and documentation systems.Therefore, they prioritize and feel responsibility to ensure those elements are discussed and documented. In the current study, RNs in particular recognized there was a need to have a more comprehensive approach to ACP, and acknowledged it is currently not part of their practice.

Previous literature also has reported a lack of clarity and comfort related to how to engage residents with cognitive impairments in ACP (Beck et al., 2017; Fernandes, 2008; Flo et al., 2016; Gilissen et al., 2017). It has also been reported that nurses and LTCH staff may require greater support and training regarding documentation, legality, and effectively incorporating ACP into practice (Beck et al., 2017; Gilissen et al., 2017; Fernandes, 2008; Flo et al., 2016; Thoresen et al., 2016). This study echoed similar findings and added that some nurses specifically felt they needed a protective measure to engage residents in ACP. They discomfort stemmed from the perception that engaging in ACP, especially with residents with cognitive impairments, may be crossing a certain boundary that could result in upsetting families and leading to complaints. Therefore, support from management, with clear guidelines and policies in place regarding their role in ACP, especially with residents with cognitive impairments would be beneficial.

The common focus throughout this current study on medically driven ACP (eg. code status and treatment decision-making) contradicted the current legislation in Ontario which does not support legally binding advance directives (Law Commission of Ontario, 2017). Instead, there is a focus on patients being able to express wishes for treatment and personal care through various forms of communication (written, oral, creative alternatives) (Wahl et al., 2016). Legislation in Ontario describes ACP as a process that one may discuss future wishes with their substitute decision maker(s). It does not equate to healthcare decisions or consent (Law of Commission of Ontario, 2017; Wahl et al., 2016. Still, the culture of LTCHs described by participants in the current study appeared to encourage nurses to ensure formal documents specific to code status and choice of a substitute decision marker are in place for residents. This current study found that nurses perceived there is insufficient organizational support and policies in place that give priority to greater elements of ACP (eg. psychosocial, spiritual and personal preferences). Therefore, the current study adds that nurses perceive they have minimal opportunities to engage in holistic ACP conversations with residents and families. If a more person-centred approach to ACP not specific to medical decision-making was encouraged at an organizational level they may feel more comfortable to have those conversations.

In general, previous literature has explored the lack of communication and comfort around conversations surrounding death and dying among LTCH staff and residents (Alftberg et al., 2018). Specifically, an ethnographic study design conducted in Sweden interviewed nurses in seven LTCHs to explore their experiences with conversations around death and dying. This study identified that the nurses experienced a general uncertainty and consequently lack of communication with death and dying conversations with residents (Alftberg et al., 2018). Nurses often managed these conversations through disregarding, distracting and comforting the resident when they perceived their personal biases towards a good dying process did not align with the resident's (Alftberg et al., 2018). It was evident in the current study findings that nurses perceived and experienced a general level of discomfort when talking about ACP with residents and their families. They evidently only activated and engaged in ACP when they perceived death was imminent. This current study added a new contribution to the existing literature by exploring in-depth a general hesitance to discuss ACP, and death and dying conversations, due to fear of crossing a "boundary" with residents and their families. Most nurses agreed they felt uncomfortable and questioned whether they were "allowed" to discuss ACP with residents and families and how to communicate it.

Interdisciplinary Team and Nursing (RNs and RPNs) Collaboration

A key finding that emerged from the current study was that a majority of nurses were unsure of their role in ACP. Most believed they did have a role in ACP but were uncertain of their scope of practice in delivering ACP. Others understood they had a role but felt uncomfortable taking ownership of it. Notably, this study identified a lack of a team-based approach, and collaborative effort by RNs and RPNs engaging in ACP.

A systematic review was conducted by Li-Shan et al. (2015) to explore nurses' views regarding implementing ACP for older adults. Their findings similarly reported that nurses working in various clinical settings have conflicting views of ambiguity around whose role it is to engage residents and their families in ACP. They found some nurses believed it was within their scope of practice however did not want to be responsible, and others reported they were well positioned to engage in ACP (Li-Shan et al., 2015).

This current study added to the existing body of literature by exploring the lack of ownership and accountability nurses feel towards engaging in ACP with residents and their families. This lack of ownership and accountability may be the direct result of the sole medical focus that is given to these conversations. Nurses may be uncomfortable to engage in ACP, since they perceived it to be medically driven, and may lack the knowledge or confidence to communicate illness trajectories, prognosis, or give medical advice. Therefore, RNs perceived that physicians may be responsible to engage in these medically driven conversations.

If nurses perceive ACP to only involve medically orientated discussions, naturally, they may overestimate the physician's role and underestimate their own. Overall, the systematic review revealed that nurses perceived ACP roles to be overlapping within multidisciplinary teams adding to even more uncertainty (Li-Shan et al., 2015). However, the systematic review was not specific to nurses working in LTCH settings, therefore it is not entirely reflective of perceptions within LTCHs. The current study added to the existing body of literature since it compared the experiences and perceptions of RNs and RPNs with respect to engaging in ACP. The key finding was that RNs and RPNs perceived their roles and authority to participate in ACP to be different. Most RPNs expressed that ACP is a responsibility that should fall on RNs, as they are better prepared to engage in it. Most RPNs perceived that RNs have more authority to participate in ACP, and that the RPN role was to engage in more frontline, clinical-orientated tasks, and thus have less time for ACP discussions.

Recent literature suggested that RNs' work roles in LTCHs are now more complex and comprise of traditionally non-nursing tasks such as care coordination and management (Montayre & Montayre, 2019). In the current study, nurses often rationalized that an ACP discussion is more within the scope of a physician as they assume the responsibility to communicate prognosis and medical diagnoses. Similarly, the legal aspects of ACP, including discussions, were perceived as being sensitive and therefore better suited for social workers. However, to the researcher's knowledge there is not evidence in current literature that suggests physicians and social workers are better suited or equipped to have these conversations. It was the hierarchal system of care in addition to the lack of role clarity that was found within LTCHs that made it not only difficult to approach conversations holistically, but also contributed to the perception that nurses are not as well equipped for ACP discussions.

Overall, previous literature has reported that a team-based approach in LTCHs is needed to increase staff autonomy, responsibility and participation (Barry et al., 2019; Montayre & Montayre, 2019). In a mixed methods study, it was found that nurses working in LTCHs who felt included by co-workers and management perceived a higher level of empowerment (Barry et al., 2019). Similarly, a qualitative study explored the impact of an inter-professional, heart failure intervention on LTCH staff outcomes (Boscart et al., 2017). It was found that LTCH staff engagement and knowledge was improved when they were supported and encouraged to contribute ideas and innovation solutions for existing issues (Boscart et al., 2017). Through the use of action orientated learning, and reflection staff felt enabled and motivate to make changes to their current practice (Boscart et al., 2017).

Evidently, previous literature has explored strategies to improve inter-professional collaboration in LTCHs (Barry et al., 2019; Boscart et al., 2017). This current study adds that both sub-groups of nurses currently do not feel valued and equally included in the team process and this limits their level of empowerment to engage in holistic ACP. This current study added, that along with interdisciplinary team member collaboration the scope of practice between RNs and RPNs, needs to be addressed in order to optimize nursing roles in holistic ACP. Additionally, a lack of a holistic approach to ACP within LTCHs can prohibit nurses from realizing their role in ACP. Therefore, although a need for individual education and training may have been a component of why nurses did not actively engage families and residents in ACP, a greater emphasis needs to be put on providing organizational support for nurses to build the capacity to engage in a team-based approach to ACP.

Relationship-based care to encourage families and residents to engage in ACP

In this current study, it was evident that multiple participants perceived that engaging in ACP would result in potentially strained relationships between families, healthcare providers and residents. There was a general reluctance to engage families and residents in ACP within both sub-groups of nurses.

Past literature and guidelines indicate that providing care for individuals is a family and person-centred process (RNAO, 2015). Substitute decision-makers and families are often involved in a resident's care in LTCHs especially since residents can often present with cognitive impairment (OLTCA, 2019). In this study, it became clear that activating ACP with residents who are cognitively impaired increases hesitancy in nurses to engage in ACP especially when capacity is unclear. A narrative review conducted by Beck et al. (2017) explored HCP perspectives of ACP for residents with dementia in LTCHs. They found that many of the studies included in the review identified the impact of "family issues" on ACP. Specifically, they stated that while HCPs recognized the integral role of families in decision-making, they did not always view this in a positive lens (Beck et al., 2017). This review suggested that numerous studies identified that HCPs often felt that family involvement in ACP was a barrier to implementing ACP, as it complicated the process (Beck et al., 2017).

This current study echoed these results, as nurses often perceived and assumed that ACP would lead to tensions between themselves and family members. It appeared that nurses had a unique role in ACP as they not only had the opportunity to develop close relationships with residents, but also had the expertise required to communicate and translate information to residents and their families. Previous literature emphasized that family members' wishes regarding future care do not always align with resident's wishes (Martin et al., 2016). This current study adds to previous findings, by providing an in-depth exploration of this discomfort. Nurses felt discouraged when they perceived residents' wishes regarding future care, and families' decisions did not align. They (RPNs specifically) may have underestimated the power of the rapport they develop with their residents and families to bridge communication and encourage ACP. Ideally, this rapport can allow nurses to address discrepancies between families by encouraging communication of their wishes. However, nurses seemed to want to avoid being a part of this conflict. While this could partially be due to a lack of organizational support, on an individual level it is often overlooked that it is the responsibility of nurses to provide education to patients and families, and the onus is on the nurse to ensure the information is accurately perceived.

A recent cross-sectional study conducted in Italy, investigated LTCH staff member knowledge, experiences and perceptions related to ACP (Ottoboni et al., 2019). They elaborated on the notion that nurses working in LTCHs are apprehensive to engage in ACP with families due to the fear of upsetting them (Ottoboni et al., 2019). They also indicated that a key barrier was organizing inter-professional meetings with residents and their family members (Ottoboni et al., 2019). They suggested that both staff and family involvement in ACP was lacking (Ottoboni et al., 2019).

While the findings from previous literature are echoed in the results of this current study, it also added that the impact of the context and culture of LTCHs influences nursing perceptions of their role in ACP with families. When communication is not effective between nurses, LTCH management and families, it may create a cycle of frustration for the nurses who feel they are trying to honor the wishes of the resident but feel, due to the lack of support are fearful of potential conflict. Nurses perceived that families may reject the involvement of nurses in ACP discussions because they feel it is not within their role, or that their idea of a good death does not align with residents and their families. The current study addressed the critical need to support nurses to recognize that on a deeper level, their role is to educate families and residents regarding ACP, and not to place their personal biases on their values and preferences.

In contrast to these ideas, other literature has highlighted there could be beneficial effects for nurse, resident and family relationships by engaging in ACP (Cornally et al., 2015; Fernandes, 2008; Shanley et al., 2011). A study reported that relationships between residents, family and nursing staff were actually strengthened through engaging in open and honest ACP conversations (Cornally et al., 2015). Specifically, it has been noted in recent literature that ACP can provide residents in LTCHs with control over their death by expressing their wishes to family members. In turn, this reduces the stress, suffering and burden on family members. When residents openly and honestly communicate their wishes with family members and healthcare providers, both parties can be confident that they are following the person's wishes (Fan et al., 2019).

This current study emphasizes that nurses need to implement a relationship and person-centred approach to ACP in order for the resident to receive the beneficial effects of it. Previous literature has stressed relationship-based care models to increase quality of care for older people in multiple healthcare settings (Dewar & Nolan, 2013; McGilton, 2012). This approach emphasized gaining comfort to explore opinions of parties involved even if they may not hold the same beliefs. Furthermore, it stressed supporting nurses to engage in deeper, and compassion centred conversations with patients and families (Dewar & Nolan, 2013; McGilton, 2012). The present study highlighted that nurses may perceive potential conflicts and varying opinions between them and patients and families, and therefore hesitate to engage in conversations. However, in order to truly support families and residents by engaging in ACP, an environment where open and honest discussions can flourish needs to be a shared responsibility between LTCH organizations, interdisciplinary team members and both RNs and RPNs.

Summary of Discussion

In summary, based on the findings of the current study it is evident that there are key new factors to consider regarding the nursing role in engaging resident's and their families in ACP. Previous literature has explored the lack of knowledge and comfort related to ACP as barriers for nurses to engage and activate it in LTCHs (Beck et al.,2017; Fernandes, 2008; Flo et al., 2016; Gilissen et al., 2017; Hickman et al., 2016; Thoresen et al., 2016). Previous literature has also recognized that support from management and team and person-centred approaches are crucial to empowering nursing staff and residents in LTCHs (Barry et al., 2019; Gilissen et al., 2017; Monyayre & Montayre, 2019)

This study adds that an overarching notion of power and authority dynamics in LTCHs impacts how nurses engage families and residents in ACP as well as what they perceive their role to be. Specifically, nursing engagement in ACP can be limited due to knowledge related gaps but also due to the hierarchal culture of LTCHs. Furthermore, the organizational policies and context of ACP currently focus on medically driven conversations surrounding code status and treatment which limits the ability of nurses to in engaging in holistic elements of ACP. Lastly, both sub-groups of nurses require greater support in order to optimize their role in providing a person and family-centred approach to ACP.

CHAPTER 6: STRENGTHS, LIMITATIONS AND IMPLICATIONS

To my knowledge, this is the first Canadian study to have investigated LTCH nurses' perceptions of their role related specifically to ACP. The study findings have highlighted the perceptions and experiences of both RNs and RPNs working in LTCHs with respect to their role in engaging residents and families in ACP. In this chapter, the strengths and limitations of the current study have been discussed. Following that, key implications for nursing practice, policy, education and research have been highlighted. Lastly, this chapter concluded with recommended strategies for knowledge translation and exchange.

Study Strengths and Limitations

The strengths of the study included an in-depth exploration of the experiences and perceptions of nurses working at two different LTCH settings. There was a variation of ages and years of experience of nurses working in LTCHs. The inclusion of both RNs (n=7) and RPNs (n=8) working in LTCHs allowed for representation of these nursing role perspectives, perceptions, and experiences with respect to ACP. Their viewpoints furthered deeper clinical understanding and relevance of the findings.

There were also a few limitations in the study. The study was limited to two LTCHs in the geographical area of Southern Ontario. ACP legislation, policies and education varies between provinces within Canada. Therefore, LTCH nurses working outside of Hamilton Ontario., may have different perceptions and experiences of their role in ACP, and the results may not be transferable.

Secondly, nurses were recruited from only two homes. One home was a faith-based not for profit home, and the second was a municipal home. Most participants were recruited from the municipal home (n=12). While all homes in Ontario are approved and licensed by the Ontario Ministry of Health and Long-Term Care, due to the different ownership styles (private, not-for-profit, municipal or other), the experiences and perceptions of nurses may vary between LTCHs (Ministry of Long-term Care, 2019).

They majority of participants were also female, and only one male participant was recruited. However, this serves as a representation of the nursing population in Canada, where only 9.5% of members are male (CNA, 2020). Lastly, recruitment of participants was limited to RNs and RPNs in order to determine their thoughts and perceptions specific to the nursing role in engaging residents and families in ACP. Personal Support Workers (PSWs) are also a prevalent profession within LTCHs and work closely with residents and their families (OLTCA, 2019). In future studies, it would be useful to examine the experiences and perceptions of other healthcare providers (eg. physicians, nurse practitioners, allied health and PSWs) who may engage in ACP, in order to gain insight into their roles. By ensuring all LTCH professionals are aware of their role in ACP, enhanced engagement would ultimately ensure the wishes of residents and their families are being communicated effectively.

Implications on Practice, Policy, Education and Research

Implications on Practice

The study findings raised critical implications for practice for nurses working in LTCH settings. ACP is within the scope of nursing practice as outlined by the College of Nurses (CNO, 2018). Therefore, LTCH nurses need to increase their comfort with ACP, take ownership of this role, and integrate engaging in holistic ACP with residents and families into their routine practice (CNO, 2018). In particular, nurses need to identify the value of engaging in holistic ACP and moving beyond discussions surrounding code status to broader values and wishes residents may have regarding personal and medical care. Therefore, it is recommended that communication guidelines and strategies that encourage a holistic and team-based approach to ACP be put in place for LTCH nurses and healthcare staff. These guidelines can clarify the role of various interdisciplinary team members, as well as provide strategies for collaboration in engaging resident's and families in ACP.

Furthermore, on a practice level, nurses need to identify and address cultural and individual biases with respect to conversations around death and dying in the context of ACP. Personal biases can have an impact on therapeutic communication, and family and resident-centred ACP. Nurses need to engage in reflexive practice and delve into their perceptions and experiences in order to assess inherent biases, values and a priori knowledge. This process can allow nurses to hold themselves accountable for their personal values and beliefs and be mindful of how it can impact their approach to engaging residents and their families in ACP.

Implications on Policy

The study findings provided various important implications for policy around nurses working in LTCH settings. Standards for ACP need to be clarified and outlined to ensure ACP is identified as best practice. If policies are in place that encourage ACP on a regular basis, then nurses may feel more obligated to prioritize and integrate it into routine practice. To support these policies, routine and specific documentation should be encouraged so all parties within the resident's circle of care are informed of past and future ACP discussions. Clear documentation can also promote ongoing discussions and continuity with families, residents and healthcare staff.

Additionally, a person and family-centred approach to ACP was recommended based on the findings of the current study. Nurses need to recognize the integral part families play in ACP, in a positive light, considering the tension and potential for conflict that is perceived. Families are heavily involved in the care of residents, especially those with cognitive impairments (Brazil et al., 2018). ACP has shown to be effective and beneficial for families of residents who have dementia, for various reasons including reducing future family uncertainty in decision-making (Brazil et al., 2018). Therefore, nurses need to explore the manner in which they communicate and engage in ACP with families as well as residents. A person and family-centred approach is pertinent and will support the process of ACP. It has previously been well supported that relationship-based approaches can improve the experience of individuals, families and healthcare staff (Wilson, 2017). Therefore, an approach where nurses perceive family engagement in ACP as an important contribution is critical (Wilson, 2017).

Organizationally, the hierarchal structure of staffing needs to be reassessed and a team approach to ACP needs to be encouraged by LTCH administration. It was evident that nurses felt powerless in the medical staffing hierarchy with respect to activating and engaging ACP. Both RNs and RPNs, need to be included in shared-decision making processes. When decisions and policies are only being made by higher management, the environment can be centralized and bureaucratically controlled, constraining participation in ACP (Katz et al., 2009). Therefore, it is recommended a critical effort be focused on changing the culture of LTCHs to encourage an interdisciplinary approach to ACP.

Culture change in LTCHs has previously been described in literature as encouraging a resident and person-centred approach to care (Lynch et al., 2018). Significant efforts need to be made to develop and foster positive relationships with staff, families, and the community; empowering LTCH staff and a decentralized management approach (Chisholm et al., 2018). The need to shift the culture of LTCHs to implement person-centred approaches that encompass the needs of staff, families and residents has been encouraged (Lynch et al., 2018). Having person-centred approaches that encourage staff to develop meaningful relationships with residents and families can foster a culture where ACP can be engaged in effectively (Lynch et al., 2018). Empowering nurses through culture change can potentially result in confidence, role ownership and clarity in engaging residents and families in ACP. This empowerment through a decentralized management approach would also enable health care providers at all levels in LTCH to have opportunities to contribute to decision-making hierarchies, operate autonomously and within a team-based approach, and have the freedom and support to make their own decisions to solve everyday problems.

Implications on Education

The current study provided several recommendations for education for nurses, students, and healthcare providers. It is clear that due to the beneficial effects ACP has on the quality of life of residents and families, it is crucial that ACP becomes a concept that is integrated into nursing education. First, it is recommended that education regarding a palliative approach to care encompassing ACP becomes a mandatory requirement in undergraduate education.

The Canadian Association of Schools of Nursing (CASN) developed competencies to facilitate greater integration of education specific to a palliative approach to care in undergraduate curriculum. A key competency is to utilize relational skills, empathy and compassion to facilitate ACP and end of life conversations (CASN, 2011). Furthermore, a key component is to demonstrate the ability to collaborate with inter-professional team members, individuals and family members to address priorities, wishes and preferences for a palliative approach to care (CASN, 2011). Within this, it would be beneficial for undergraduate curricula to integrate teaching strategies that encompass the context of LTCHs and the legislature, terminology, and process specific to ACP. This can ensure all future nurses attain a basic understanding of ACP and its critical importance in providing person-centred care.

Continuing educational opportunities and policies addressing a fundamental palliative approach to care concepts including ACP, in addition to guidelines on how nurses can incorporate a holistic approach to ACP in LTCHs, are also crucial. Training regarding the process, concept and legislature behind ACP is pertinent for organizations to provide, considering the lack of clarity nurses highlighted.

On an individual level, nurses need to recognize it is a mandatory requirement to seek continual and self-directed learning. LTCHs should be promoting continual and self-directed learning to fill gaps regarding ACP as mandated by the College of Nurses. Therefore, in addition to any training on ACP provided by the organization, it is recommended and within nursing practice to seek learning opportunities if a knowledge gap regarding the concept and process of ACP is present. In addition to training, active forms of professional development and continuing education such as mentorship opportunities should be explored.

Lastly, current ACP training programs can be modified to address supporting nurses to integrate a relationship-based model of care. The current study identified nurses' lack of comfort with engaging residents' families in ACP. Therefore, a particular emphasis needs to be given to communication strategies for nurses to engage families in ACP.

Implications for Research

There are some implications for future research that arose from the current study. This study focused on nurses alone, however the findings indicate that exploration of experiences and perceptions of the roles of other healthcare providers is also important. Further qualitative studies could build on this study by exploring the perceptions and experiences of allied health, physicians, Nurse Practitioners, and PSW staff with respect to ACP. Additionally, it would be useful to explore the experiences and perceptions of residents and families related to ACP and the nursing role. These studies may further describe and identify barriers, facilitators and strategies to optimize the role of nurses and other healthcare providers in LTCHs.

The majority of studies on LTCH nurses regarding their experiences and perceptions with respect to ACP have applied qualitative methodology. Future research applying quantitative or mixed methodology would be beneficial as well. Studies focusing on identifying the differences in perceptions towards ACP and factors such as stress, preparedness to engage in ACP and EOL discussions, between nursing management and frontline staff would be valuable. Furthermore, it would be beneficial to explore the differences in perceptions towards ACP amongst healthcare staff who work in LTCH organizations implementing culture change compared to LTCHs that are have not implemented these strategies. Lastly, it would be valuable to explore supports for ACP in different types of LTCHs in Ontario (i.e. for profit, not for profit, municipal and faith-based). Existing data highlights that not for profit organizations that are owned by the government or religious facilities have significantly higher levels of direct hours of nursing staff care and higher staffing levels (Berta et al., 2006). This analysis could provide further in-depth data regarding barriers and facilitators related to staffing in respect to ACP implementation. Therefore, these findings can potentially impact strategies to assist LTCH staff in engaging in ACP amongst various LTCH organizational structures.

Conclusion

Both RNs and RPNs working in LTCHs lacked clarity and were uncertain about ACP and their role in engaging families and residents in ACP. They experienced discomfort with the idea of activating family and resident-centred approaches to ACP. As such, they were not effectively engaging residents and their families in holistic ACP, and therefore the needs and quality of life of residents may have suffered. A relationship-based approach to ACP, rooted in compassion and empathy, can activate conversations between nurses, residents and their families, in a positive lens. This study highlighted the urgent need for LTCH organizations to address contextual and cultural barriers to better support both RNs and RPNs in optimizing their role in ACP. The experiences of perceptions of RNs and RPNs varied in respect to how they may perceive their role due to the hierarchal structure of LTCHs. Therefore, developing education strategies, clear communication guidelines for nurses, and cultural change initiatives can improve nursing engagement in ACP, as well as allow residents to communicate their values and preferences for future care to all parties.

Knowledge Translation and Exchange

The research findings from this study have several important implications for LTCH stakeholders and policy makers. Ultimately, these findings have the potential to empower residents, families and healthcare staff to engage in crucial ACP conversations. For this reason, it is important to consider strategies to share findings with the larger community. To enable the knowledge from these findings to be applied, these results will be shared at applicable conferences. Furthermore, the researcher plans to publish this paper in a peer-reviewed research journal. Lastly, the researcher will contact LTCHs in the Greater Toronto and Hamilton Area and offer to present findings of the study if interested.

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Appendix A: Glossary

Advance Care Planning: A process where individuals can reflect on and communicate their values and wishes for future health and personal care to healthcare providers, family and substitute decision makers. It may consist of ongoing conversations, writing down wishes and alternative forms of communicating (Speak Up, 2020)

Advance Directive: An advance directive may be used to describe a legal document that articulates an individual's wishes for care, choice of substitute decision maker and power of attorney (finance and health care decision-making) in the event they are unable to communicate it. The regulations around advance directives vary within Canadian provinces and internationally (Speak Up, 2020).

Goals of Care Conversations: Discussions meant to ensure a person with a chronic life-limiting illness (or their substitute decision-maker) develops decisions/goals regarding treatment centred off of their values in the current context of their illness (Ontario Palliative Network, n.d)

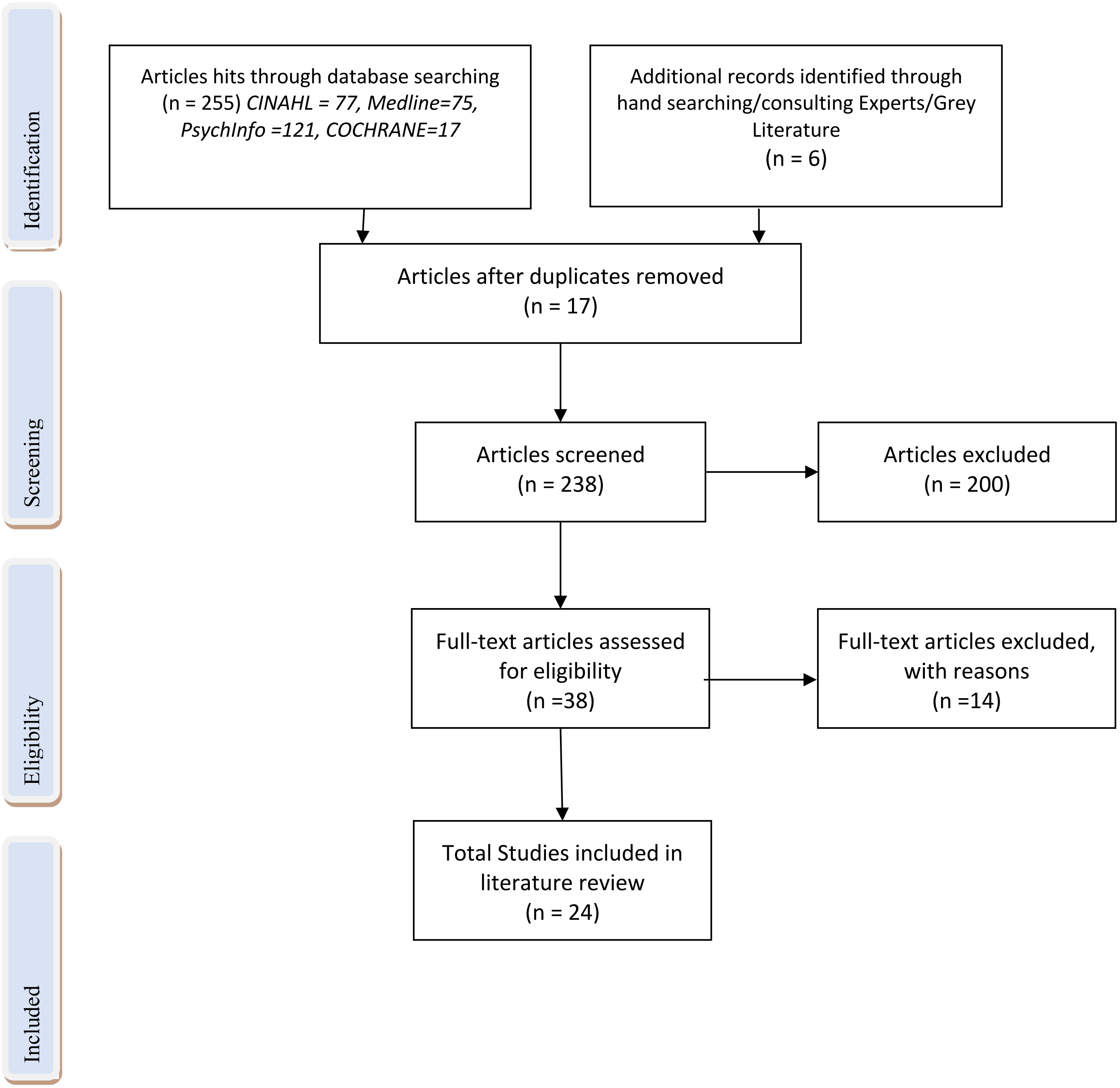
Long-term Care Home: Facilities designed for adults who require 24-hour nursing and personal support services. Residents receive assistance with activities of daily living and are monitored for well-being. In Ontario, all long-term care homes are approved and funded by the Ministry of Health and Long-term Care (Ontario Long Term Care Association, 2020).

Palliative Approach to Care: Improves the quality of a person and their family through focusing on holistic needs (physical, psychosocial and spiritual) throughout their stages of chronic illness, frailty and end of life. The approach to care promotes autonomy and control for people in their care choices through encouraging earlier and ongoing conversations about goals of care (Canadian Hospice Palliative Care Association [CHPCA], 2015; World Health Organization, 2020)

Registered Nurse: Registered Nurses in Ontario, are currently required to have a four-year undergraduate degree. They obtain comprehensive education in areas including: clinical practice, critical thinking and research. They are prepared to take care of patients with complex and unpredictable conditions (Registered Nurses' Association of Ontario, 2020).

Registered Practical Nurse: Registered Practical Nurses in Ontario, are typically required to have a two-year college diploma. They have a focused education and are prepared to care for patients with less complex needs in stable conditions (Registered Nurses' Association of Ontario, 2020).

Appendix B: Flowchart of Included Studies



Appendix C: List of Characteristics of Included Studies

Author Year Country	Study Design	Sample/Methods/Results	Strengths	Limitations	Appraisal
Ampe, S., Sevenants, A., Coppens, E., Spruytte, N., Smets, T., Declercq, A., & Van Audenhove, C 2015 Belgium	Quasi-experimental pre-test-post-test study Study protocol	• **Sample**: 19 nursing homes in Belgium – participants are nursing home staff • **Methods**: Used a scale and questionnaire to evaluate the effects of an educational intervention) for nursing home staff - on shared decision-making and participants views (context of advance care planning for residents with dementia) • **No results** – it is a study protocol. Hypothesis is that educational intervention will lead to increased implementation of ACP and ultimately higher quality of life for results	• Clear cause and effect • Control and Experimental Group • Group comparison completed – for starting levels of competence	• No clear mention of follow-up • No clear mention of statistical analysis technique • Nursing homes recruited on a voluntary basis • Nonequivalent Control Group – assignment not random	Tool: Joanna Briggs Institute Checklist for Quasi-Experimental Studies **Rating: Moderate**
Ampe, S., Sevenants, A., Smets, T., Declercq, A., & Van Audenhove, C. 2017 Belgium	Quasi-experimental pre-test-post-test study	• **Sample**: Intervention and control group - 18 dementia care units from eighteen different nursing homes • 90 participants including (nurse mangers, nurses, occupational therapist, social worker, pastoral staff, physical therapist) • **Methods**: Pre-test post-test study. Used a scale to determine degree of involvement of residents and families in ACP conversations. ACP-audit of policies. • **Findings**: Improvements in ACP policy after educational intervention. No changes in daily practice.	• Clear cause and effect • Control and Experimental Group • Group comparison completed – for starting levels of competence • Descriptive statistics used to evaluate the policy and actual practice of ACP in dementia care units – mentioned use of data analysis software	• No mention of follow-up • Nursing homes recruited on a voluntary basis • Nonequivalent Control Group – assignment not random	Tool: Joanna Briggs Institute Checklist for Quasi-Experimental Studies **Rating: Moderate**
Baughman, K. R., Ludwick, R., Jarjoura, D., Kropp, D., & Shenoy, V. 2017 United States	Quantitative Cross sectional Study	• **Sample**: Nurses and social workers (n = 350) within 29 urban homes completed surveys and rated scenarios • **Methods**: Surveys completed by participants. Linear mixed modeling were used to examine factors that affected ratings of need and responsibility related to ACP • **Results**: No association between race of the provider, resident, and the interaction of the two • Healthcare providers rated residents at high risk for hospitalization as more in need of ACP and then felt more responsible for ensuring ACP	• Demographic chart of study participants was included with their descriptions • Appropriate statistical analysis was used	• Did not state clearly what inclusion criteria was • No confounding factors were identified • Vignette study – difficult to say if it was reflective of practice • Limited representation of race – measured racial differences • Low response rate – 31% • Only urban nursing homes included	Tool: Joanna Briggs Institute Checklist for Cross-Sectional Studies **Rating: Weak-Moderate**

Author Year Country	Study Design	Sample/Methods/Results	Strengths	Limitations	Appraisal
Beck, E. R., McIlfatrick, S., Hasson, F., & Leavey, G. 2017 Ireland	Narrative Review	• Total of 14 papers in the study • **Methods:** Narrative review methodology to synthesize knowledge on topic. PRISMA guidelines were utilized – ensured reliability. 4 databases used. • **Results:** HCPs recognize potential benefits of ACP but struggle to implement it into LTCH.	• Multiple data bases • Characteristics of study present in table	• Unclear how many reviewers took part in the process	CASP: Qualitative Checklist **Rating: Moderate-Strong**
Cornally, N., McGlade, C., Weathers, E., Daly, E., Fitzgerald, C., O'Caoimh, R., & Molloy, D. W. 2015 Ireland	Qualitative Descriptive Approach	• **Sample**: Three homes in South Ireland. 15 Clinical Nurse Managers and two Directors of Nursing • **Methods**: Evaluation of the implementation of the Let Me Decide-ACP programme in the homes through focus groups were conducted. • A semi-structured guide was used. • **Results**: Benefits of programme included: enhancing communication, changing the care culture, promoting preference-based care and avoiding crisis decision making. Barriers: establishing capacity among residents and indecision reported by staff	• Clear aim for study • Appropriate methodology and design for aims of the study	• No clear mention of second reviewer for transcripts • No mention of data triangulation • No clear explanation of researcher's own potential bias, and influence during analysis • Only nursing managers included in sample	Tool: CASP Checklist **Rating: Moderate**
Fernandes, G. 2008 Australia	Quantitative Implementation Study – Quality of Improvement Project	• **Methods**: There were four stages to the project. The first stage involved interpretation of the five audit criteria, staff training regarding ACP, the records of staff and resident were audited • **Results**: Several Improvements made to facility's documentation system – however still low uptake of ACP from staff.	• Clear Aim of study	• Not conducted in the Canadian context • Unclear methodology	Tool: CASP - Quantitative **Rating: Weak**
Flo, E., Husebo, B. S., Bruusgaard, P., Gjerberg, E., Thoresen, L., Lillemoen, L., & Pedersen, R. 2016 Norway	Narrative Review	• Scoping Review with 16 studies included • **Methods**: Extracted and synthesized content of studies in chart • **Results**: ACP intervention studies in nursing homes are few and heterogeneous. Variation in ACP definitions, sparse information about procedures	• 16 studies included – clear inclusion and exclusion criteria • Clear search strategy with flow diagram of review process	• Meta-analysis beyond scope of review • Standardized study quality systems were not used	Tool: CASP **Rating: Moderate**
Gilissen, J., Pivodic, L., Smets, T., Gastmans, C., Vander Stichele, R., Deliens, L., & Van den Block, L. 2017 Belgium	Systematic Review	• Included 38 publications • **Methods**: Two authors independently screened. Thematic synthesis for textual data. • **Results**: Multiple preconditions related to effectively executing ACP in LTCHs in different areas (knowledge/skills, willing and able to participate, administrative system, contextual factors).	• Two authors independently screened publications • Search strategy well described • 4 databases	• No comparison between methodological quality scores • Unclear description of rigor and strength • Considerable bias involved in analysis and coding of precondition	Tool: CASP checklist **Rating: Moderate**

Author Year Country	Study Design	Sample/Methods/Results	Strengths	Limitations	Appraisal
Handley, M., Goodman, C., Froggatt, K., Mathie, E., Gage, H., Manthorpe, J., ... & Iliffe, S. 2014 England	**Prospective Mixed Method study**	• **Sample**: 129 residents from 6 nursing homes in East England; 63 residents, 30 staff with assorted roles, 19 national health service staff interviewed • **Methods**: Prospective study • **Results**: Living and dying: responsibility for end-of-life care in care homes without on-site nursing provision-a prospective study	• Clear research questions • Appropriate qualitative methodology – detailed review analysis • Large Sample	• Authors stated they did not engage with homes there were recognized problems with quality of care. • Randomization not appropriately performed • Did not take bias into account • Did not take cofounding variables into account • Not clear aim or search strategy	Tool: Mixed Methods Appraisal Tool (MMAT) **Rating: Weak-Moderate**
Hickman, S. E., Unroe, K. T., Ersek, M. T., Buente, B., Nazir, A., & Sachs, G. A. 2016 United States	**Quantitative** **Interim Analysis**	• **Sample**: 19 nurses working in LTCHs, 6 nurse practitioners – 19 nursing homes in urban/suburban areas of central Indiana • **Methods**: Structured ACP interview guide used to engage in ACP - audit. • **Results**: During initial implementation phase – there was an 87% change in documented preferences. Most reported barrier lack of time.	• Clear aim • Data triangulation	• Non comprehensive methodology or analysis process • Data represents only initial phase	Tool: CASP/JBI Quantitative tool **Rating: Weak-Moderate**
Jeong, S. Y. S., Higgins, I., & McMillan, M. 2011 Australia	**Qualitative Study – reporting findings from a case study**	• **Sample**: 13 Registered Nurses residential care settings in Australia • **Methods**: A case-study design involving participant observation, field note recording, semi structured interviews and document analysis was used • **Results**: The enhancing factors included: it is their essence of who they are', and 'back-up from family members and other nursing staff'. Barriers: are 'lack of time', 'a culture of do everything and don't go there', and 'lack of family involvement'.	• Data triangulation (multiple data collection strategies) • Clear aim and objectives aligned with qualitative methodology • Described thematic data analysis strategies	• Not a clear description of search strategy • Recruitment strategy unclear	Tool: CASP Qualitative Checklist **Rating: Moderate**
Kastbom, Milberg & Karlsson 2019 Sweden	**Qualitative – Descriptive Study**	• **Sample**: Nine nursing homes in Sweden. Participants included 14 physicians and 11 nurses • **Methods**: Participants recruited through maximum variation sampling and interviewed • **Results**: 1) ACP helps align care of resident's with their preferences 2) Nurses seen as the party that would defend the patient's preferences and align family views	• Clear aim	• Poor description of methodology	CASP: Qualitative Checklist **Rating**: Weak-moderate

Author Year Country	Study Design	Sample/Methods/Results	Strengths	Limitations	Appraisal
		3) Nurse's and physicians uncomfortable and fear speaking about death and end of life			
Kirsebom, M., Hedström, M., Pöder, U., & Wadensten, B. 2017 Sweden	**Qualitative Description Study**	- **Sample**: Fifteen general practitioners assigned to a nursing home - **Method**: Semi-structured interviews - **Result**: Medical assessment is the responsibility of Practitioners - Registered Nurses competence perceived as crucial to the quality of care, but inadequate staffing, lack of medical equipment and less-than-optimal IT systems barriers	- Clear aim and objectives - Analysis using NVivo – adequate description - Nursing home characteristic chart - 6 homes – adequate sample size	- Excluded homes with recognized "problems" with quality of care - Did not describe if there were multiple reviewers of coding/transcripts	Tool: CASP Qualitative Checklist **Rating: Moderate**
McGlade, C., Daly, E., McCarthy, J., Cornally, N., Weathers, E., O'Caoimh, R., & Molloy, D. W. 2017 Ireland	**Quantitative** **Feasibility Study**	- **Sample**: Two nursing homes and one community hospital. Nursing and medical staff n=83 - **Methods**: Two phase: (1) staff education on advance care planning and (2) structured advance care planning by staff with residents and families - **Results**: Need for staff training/ongoing/education around end of life planning	- Clear aim - Data triangulation	- Lack of participant characteristics chart - Lack of clear data analysis/recruitment strategy	Tool: CASP/Joanna Briggs quantitative checklist and tool **Rating: Weak-Moderate**
Mullaney, S. E., Devereaux Melillo, K., Lee, A. J., & MacArthur, R. 2016 United States	**Mixed Methods Study**	- **Sample**: 14 NPs in focus groups – 61 patients. - **Methods**: Two focus groups. Quantitative data from convenience sample. Analyses included descriptive statistics, bivariate ANOVA, and logistic regression - **Results**: Positive clinical outcomes following ACP discussions include more patients with a comfort goal of care (86% increase), fewer patients with a full code status (26% reduction), and a reduction in hospitalizations	- Clear research question - Clear and appropriate methodology	- Specific to only Nurse Practitioners - MRA tool not assessment for reliability or validity	Tool: Mixed Methods Appraisal Tool (MMAT) **Rating: Moderate**
Mulqueen, K., & Coffey, A 2017 Ireland	**Qualitative Study**	- **Sample: "**Small" sample of residents and nurses in one care facility - **Methods**: Residents' preferences were compared with nurses' perceptions of their preferences in a qualitative study in which the nominal group technique was adopted for data collection - **Results**: Some of the residents' preferences for their end of life care matched nurses' perceptions of their preferences, but differences were identified.	- Clear aim - Appropriate methodology	- Not a comprehensive literature review - Unclear search strategy - One long-term care home (small sample) - Unclear recruitment strategy	Tool: CASP Qualitative Checklist **Rating: Weak-Moderate**

Author Year Country	Study Design	Sample/Methods/Results	Strengths	Limitations	Appraisal
Ong, A. C. L., Sabanathan, K., Potter, J. F., & Myint, P. K. 2011 United Kingdom	**Qualitative Study – Retrospective Case Analysis Study – Unclear methodology?**	• **Sample:** 3722 older people admitted to Department of Medicine (340) from care homes. Investigated eight nursing homes with highest level of admissions into hospital. • **Method**: Case Analysis Study. Questionnaire for staff • **Results:** Most cited reason for admission into hospital was the lack of advance care planning	• Clear Aim	• Unclear sample/methodology • Participants characteristics unclear	Tool: CASP Qualitative Checklist **Rating: Weak-Moderate**
Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., ... & Exley, C. 2011 United Kingdom	**Systematic Review**	• All studies in nursing home setting • 4 studies included related to efficacy, 257 for barriers and facilitators • **Results:** Some evidence that ACP has potential to reduce hospital admissions and healthcare costs for people with cognitive impairments/dementia	• Comprehensive search strategies • Hand searching/grey literature • Clear search strategy • Two reviewers and third for disagreements	• Did not include an Canadian studies • Only English studies • Unclear which "key" databases were searched	CASP: Systematic Review Checklist **Rating: Moderate-Strong**
Reyniers, T., Houttekier, D., Cohen, J., Pasman, H. R., & Deliens, L. 2014 Belgium	**Qualitative Study- did not identify methodology – Descriptive?**	• **Sample:** family physicians (n=39). 16 nurses from different settings (hospital, home care, nursing homes) in a focus group – and one focus group with 7 nurses from a nursing home • **Methods:** Focus groups/ Constant comparative approach • **Results:** Nurses and family physicians warranted hospital admissions in numerous situations. ACP can reduce hospital deaths.	• Clear Aim/purpose • Appropriate Sample • Different care settings • Participant characteristics shared	• Unclear methodology	Tool: CASP Qualitative Checklist **Rating: Moderate**
Shanley, C., Whitmore, E., Conforti, D., Masso, J., Jayasinghe, S., & Griffiths, R. 2011 Australia	**Qualitative Study**	• **Sample**: Qualitative interviews with 41 nursing home managers from south-western Sydney, Australia • **Methods** Semi-structured interviews • **Results**: Factors affecting the decision to transfer a resident to hospital include acuteness of their condition; role of family members; skill/competence of staff; and concern about criticism for not transferring to hospital.	• Purpose quota sampling process described • Large sample	• Only specific to nursing home managers • Unclear recruitment strategy	Tool: CASP Qualitative Checklist **Rating:** Moderate
Stewart, F., Goddard, C., Schiff, R., & Hall, S. 2011 United Kingdom	**Qualitative Explorative Study**	• **Setting**: All care homes in two London Boroughs. Participants included staff • **Methods**: nurses, managers, and care assistants, community nurses and families • Semi-structured interviews • **Results**: Staff and family support ACP, benefits and facilitators of ACP included family involvement, early initiation	• Participant triangulation	• Unclear search strategy • Unclear methodology	Tool: CASP Qualitative Checklist **Rating: Moderate**

Author Year Country	**Study Design**	**Sample/Methods/Results**	**Strengths**	**Limitations**	**Appraisal**
Thoresen, L., Ahlzén, R., & Solbrække, K. N. 2016 Norway	**Qualitative Study**	• **Sample**: Unclear sample size 8 conversations? • **Methods**: Participant observation of 7 conversations, interviews with healthcare staff and resident and relative (together) not individual • **Results**: Nursing home staff wanted to contribute to open awareness/ACP - but little reflections about the purpose and content of the conversations	• Appropriate aim/clear purpose	• Unclear recruitment process • Unclear analysis and methodology	Tool: CASP Qualitative Checklist **Rating: Weak**
Thoresen, Pedersen, Lillemoen, Gjerberg & Forde 2019 Norway	**Qualitative – Descriptive Study**	• **Sample:** 20 health care professionals (11 nurses, 8 physicians, 1 nursing assistant) • **Methods:** Semi-structured group interviews with qualitative content analysis. • **Results:** All staff members found being a part of and activating ACP stressful and demanding. They found they were sensitive conversations • Some staff found usually residents with mild cognitive impairments could participate in ACP – but overall it is difficult • Physicians were the most active party and nurses were very passive. Nurses were more comfortable leaving these conversations to physicians.	• Clear aim • Large sample size • Appropriate methodology and data analysis	• Unclear search strategy/literature review	CASP: Qualitative Checklist **Rating**: Moderate-Strong
van Soest-Poortvliet, M. C., van der Steen, J. T., Gutschow, G., Deliens, L., Onwuteaka-Philipsen, B. D., de Vet, H. C., & Hertogh, C. M. 2015 Netherlands	**Qualitative Descriptive Study**	• **Sample: 65 interviews – 24 nurses** • **Methods:** Interviews held with families, physicians and nurses. Analytic thematic coding • **Results:** Family, nurses, and physicians of all patients indicated they had moments where care goals and treatment decisions were discussed. • Majority of interviewees indicated that physicians took the initiative for these ACP discussions. • Terminology to describe care goals varied between facilities. • Code status and hospitalization were always discussed	• Large sample • Appropriate methodology • Characteristics of study participants presented clearly and compared • Two researchers independently coded	• No literature review/search strategy/inclusion exclusion criteria unclear	Tool: CASP Qualitative Checklist **Rating: Strong**

Appendix D: Telephone/In-Person Script

Good morning/afternoon/evening [nurses' name]

*My name is Harveer Punia and I am calling about a research study I am conducting, happening at **[insert LTCH name]**.* I am a Master of Science in Nursing student at McMaster University. *This study is a collaboration between **[insert LTCH name]** and McMaster University.* This study has been reviewed by the Hamilton Integrated Research Ethics Board under project #5707

I received permission from [insert LTCH recruitment partner's name] to contact you because you fit the criteria to participate this study. I am contacting you today tell you a little bit about the study and to see if you might be interested in participating. This will take about 5 minutes, is this a good time?

IF Not, *is there another time I could call you?*
_______________ time

IF Yes,
This purpose of the research study is to gain an in-depth understanding of your experiences and perceptions caring for individuals diagnosed with life-limiting chronic illnesses, in respect to your role in engaging in advance care planning. This interview will be conducted either over the phone, online, or in a setting that best suits you, and is safe, accessible and quiet.

Would you be interested in scheduling a 30-45-minute interview with me?

IF Yes –

1. *When would be the best time to for me to reach you?*
   ___________ time/day
2. *Would you prefer, telephone, online (skype or google hangouts) or in-person?*
   A) If telephone or online –I have a consent form for the study that I would like to review with you and if agreeable you can sign it, prior to the interview. I can email or mail the consent form to you, whichever works best, and we can review it (over the phone, or through online meeting) prior to the interview. [Depending on response – ask for email/mail address]. I will answer any of your questions and concerns prior to the interview. The form also mentions, that you are welcome to leave this study at any time, even after signing.
   B) If in person – I have a consent form I would review with you and if agreeable you can sign it. I can bring this form with me the day we meet for the interview and review it with you prior to the interview. I would answer any of your questions and concerns. The form also mentions, that you are welcome to leave this study at any time, even after signing.

IF No – *Thank you for considering participating in the study*!

Appendix E: Email Script

Hello [nurses' name],

My name is Harveer Punia. I am a Master of Science in Nursing student at McMaster University. I am conducting a researcher study which is a collaboration between **[insert LTCH name]** and McMaster University. The purpose of the study is to explore perceptions and experiences of nurses (both RN and RPNs) working in LTCH's with respect to their role in engaging residents who are diagnosed with life-limiting chronic illnesses and their families in ACP. This study has been reviewed by the Hamilton Integrated Research Ethics Board under project #5707

I received permission from [insert LTCH recruitment partner's name] to contact you because you fit the criteria to participate this study. I am emailing you today to set up a time to tell you a little bit about the study and to see if you might be interested in participating.

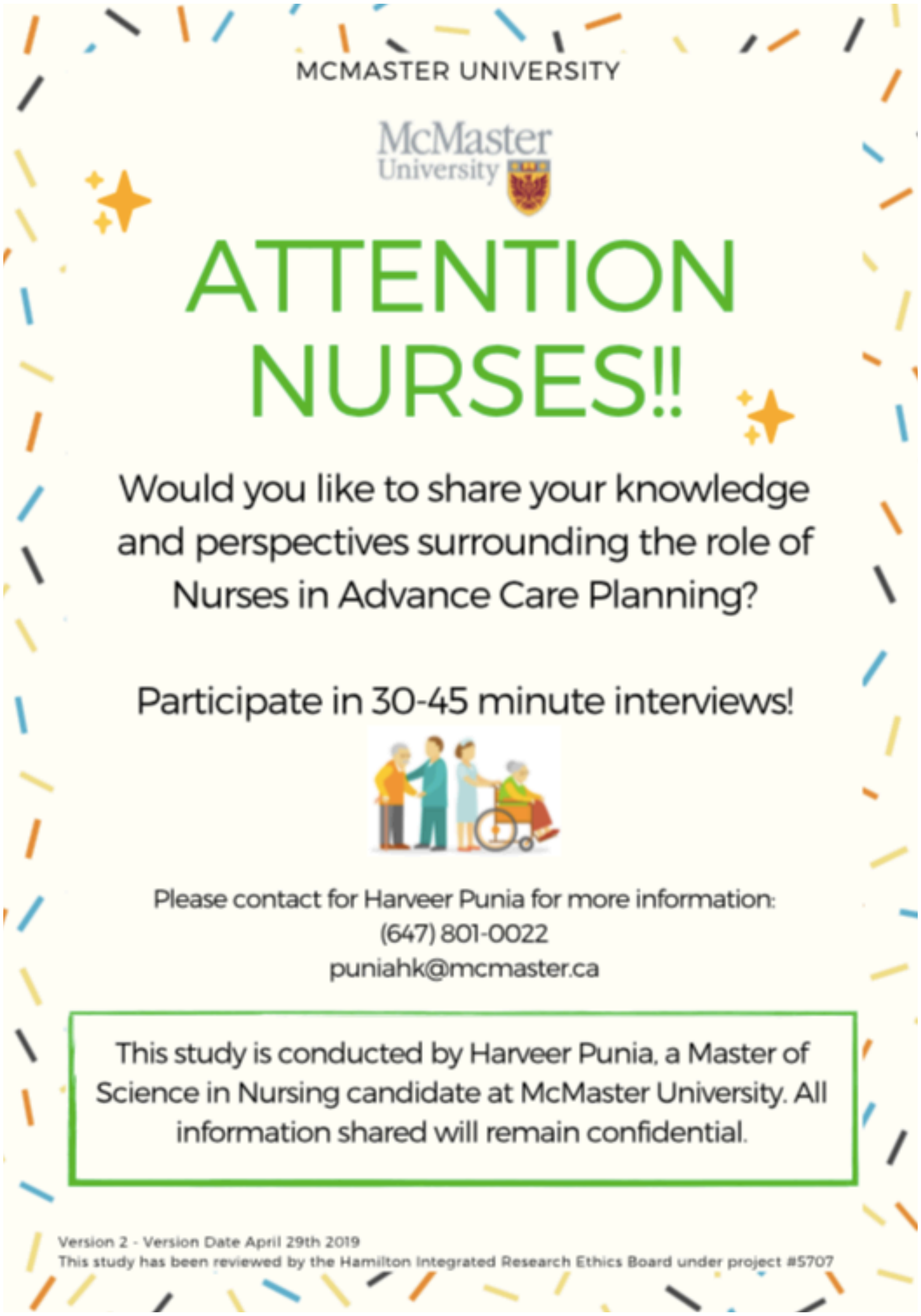
I will be conducting 30-45-minute interviews with nurses. The questions that will be asked intend to explore your understanding of advance care planning, what your role is and how you collaborate with healthcare professionals. No previous understanding of advance care planning is required. Participants will receive a gift card (whichever they prefer) valued at $25.00.

Agreeing to speak with me in no way commits you to take part in this study. Please contact me via email or telephone, whichever works best for you, in order to set up a meeting time (over the phone or in-person) where I can tell you more about the study and answer any questions. I greatly appreciate your time!

Sincerely,

[Sign off with name]
[phone number of student researcher]
[email of student researcher]

Appendix F: Recruitment Poster



MCMASTER UNIVERSITY

McMaster University

ATTENTION NURSES!!

Would you like to share your knowledge and perspectives surrounding the role of Nurses in Advance Care Planning?

Participate in 30-45 minute interviews!

Please contact for Harveer Punia for more information:
(647) 801-0022
puniahk@mcmaster.ca

This study is conducted by Harveer Punia, a Master of Science in Nursing candidate at McMaster University. All information shared will remain confidential.

Version 2 - Version Date April 29th 2019
This study has been reviewed by the Hamilton Integrated Research Ethics Board under project #5707

Appendix G: Demographic Form

Date:
Participant ID:

Thank you for consenting to participate in this interview today. Please answer the following questions about yourself. The purpose of collecting this information is so we will be able to describe, as a group, the participants for this study. <u>This study has been reviewed by the Hamilton Integrated Research Ethics Board under project #5707</u>

1. What is your gender?
   ____
2. What is your age?
   ____
3. What is your primary profession or job at this facility?
   ☐ Registered Nurse
   ☐ Registered Practical Nurse
4. Which best describes your employment status?
   ☐ Part-time ☐ Full-time ☐ Casual
5. Approximately how many years have you worked in this long-term care home?
   ______years
6. Approximately how many years have you worked in the long-term care sector?
   ______ years
7. Have you received any training specific to Advance Care Planning?
   ☐Yes ☐No
8. How recently did you receive this training?
   ☐ Within a month ☐ Within the past 6 months
   ☐ Within a year ☐ Over a year ago
   ☐ N/A
9. What was the format of your training?
   ☐ Brochure ☐ Course
   ☐ Other (please describe):____________________________
   ☐ N/A

Thank for taking the time to answer some preliminary questions regarding your experience with falls. We look forward to hearing your thoughts and experiences in the interview.

Appendix H: Semi-Structured Interview Guide

November 2018

RN/RPN: INTERVIEW GUIDE

Document: Interview guide targeted towards Registered Nurses and Registered Practical Nurses
Used by: Primary Researcher
Purpose: The purpose of this study is to explore experiences and perceptions of long-term care (LTC) nurses caring for individuals diagnosed with life-limiting chronic illnesses, in respect to their role in engaging in ACP.

Introduction
Hi _____,
My name is (name), I am a Researcher at McMaster University. I am contacting you about a study that is being done by McMaster University to explore experiences and perceptions of LTC nurses in respect to their role in facilitating ACP.

I believe you have already spoken with ____ from ______ and gave permission for me to contact you and do a brief interview.

Depending on response

I want to start by saying thank you for agreeing to participate in this interview today. I do understand some questions during this interview may be difficult and emotional topics. Please only share what you feel comfortable sharing and tell me if you prefer not to say anymore on a topic I have asked you about.

Go over:
- Consent (review and sign)
- Demographic Form
- Address for gift card
- Begin Recording
- This study has been reviewed by the Hamilton Integrated Research Ethics Board under project #5707

Background Questions
1. Based on your experiences, what are your thoughts regarding advance care planning in the LTC setting?
    a. What do you know about advance care planning?
        - What things would you want to know more about?

   b. Why do you think can help facilitate advance care planning in your setting?
   c. What are some of the things that make facilitating advance care planning difficult? Why?

2. How do you feel that you currently engage with your clients with chronic life limiting illnesses, when it comes to advance care planning?
   a. Do you think you are working to your full capacity to engage in advance care planning?

Role Specific Questions

1. Can you describe your role in advance care planning is?
   a. Do you think you have a role?
   b. Can you describe a scenario where you engaged in ACP?

2. Do you think other staff (nurses, social workers, doctors) have a role in advance care planning?
   a. Describe their role?
   b. How do you collaborate with them? Can you describe a scenario where you did?

3. What kinds of activities do you think **<u>in a perfect world</u>** can help you facilitate ACP to your best potential?
   a. How do you think these activities would be useful to your patients?
   b. What barriers do you anticipate?
   c. Do you have suggestions of how to overcome barriers?

4. Do you think it would be beneficial to have more information regarding your role and scope when it comes to advance care planning?
   a. What specific things would you want more training about?

5. Is there anything else that you would like to share about your experience with advance care planning in respect to your role?

Appendix I: Participant Consent Form

LETTER OF INFORMATION / CONSENT

The Role of Nurses in Advance Care Planning within Long-Term Care

Investigators:

Local Principal Investigator:
Dr. Sharon Kaasalainen
School of Nursing
McMaster University
Hamilton, ON, Canada
(905) 525-9140 ext. 22291
E-mail: kaasal@mcmaster.ca
puniahk@mcmaster.ca

Student Investigator:
Harveer Punia
School of Nursing
McMaster University
Hamilton, ON, Canada
(647) 801-0022
E-mail:

Purpose of the Study

As a part of my Master of Science in Nursing degree requirements, I am conducting a research study to explore the experiences and perceptions of long-term care (LTC) nurses caring for individuals diagnosed with life-limiting chronic illnesses, in respect to their role in engaging in advance care planning (ACP). No prior knowledge surrounding ACP is required.

I want to interview nurses (Registered Nurses and Registered Practice Nurses) who are working in LTC and want to share their experiences. If you are a Registered Nurse or Registered Practical nurse who is working in LTC, and are interested, you are invited to take part in this study and share your experiences. I hope to learn more about your perceptions, experiences and role in ACP within the LTC setting.

What will happen during the study?

If you are interested and you have given permission, I will first collect demographic information like your education and years of experience in LTCH from you to determine if you are eligible to participate in the study. If you are eligible, you will be asked to participate in a 30-45-minute one-on-one interview with me, the primary researcher.

The purpose of this interview is to gain an in-depth understanding of your experiences and perceptions caring for individuals diagnosed with life-limiting chronic illnesses, in respect to your role in engaging in ACP. This interview will

be conducted either over the phone, online, or in a setting that best suits you, and is safe, accessible and quiet.
Some example questions include:

1. *How do you feel that you currently engage with your clients with chronic life limiting illnesses, when it comes to advance care planning?*

2. *Can you describe your role in advance care planning is?*

Potential Harms, Risks or Discomforts:

The risks involved in participating in this study are minimal. You may feel uncomfortable with the topic of the interview. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable and you can stop to take a break. You can withdraw and stop taking part in the study at any time.

Potential Benefits

The research will not benefit you directly. I hope to learn more about your experiences and perceptions surrounding ACP. I hope that what is learned as a result of this study will help us to better understand this topic, and may contribute to further research, education, and policies.

Payment or Reimbursement
To compensate for your time, you will receive a $25 gift card of your choice.

Confidentiality

Every effort will be made to protect your confidentiality and privacy. You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me (or other members of the research team) will know whether you participated unless you choose to tell them. Your manager, or anyone at your place of work will not know if you participated, nor will results be shared with them.

The information/data you provide will be kept in a locked desk/cabinet where only I will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, the data will be destroyed.

b) Legally Required Disclosure

If legal authorities request the information you have provided, I may be required to reveal it.

Participation and Withdrawal

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study.

If you decide to withdraw, there will be no consequences to you and you have the option of removing data already collected. If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision whether or not to be part of the study will not affect your work at [name of LTCH].

Information about the Study Results

I expect to have this study completed by approximately August 2019. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at:

puniahk@mcmaster.ca
647-801-0022

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB) under project #5707. The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT

I have read the information presented in the information letter about a study being conducted by Harveer Punia, of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand that if I agree to participate in this study, I may withdraw from the study at any time. I will be given a signed copy of this form. I agree to participate in the study.

Name of Participant (Printed)	Signature/Date

Consent form explained in person by:

Name and Role (Printed)	Signature/Date