Nurses' Perceptions of Advance Care Planning Communication with Patients and Families in Long-Term Care Settings

by

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Abstract

Advance care planning (ACP) communication falls under nurses’ scope of practice, yet we have limited understanding of the experiences of nurses working in long-term care (LTC) settings with these future-oriented or end-of-life discussions. The purpose of this study was to explore nurses' perceptions of ACP communication with residents/patients and families in LTC settings. The qualitative method of interpretive description was used to answer three research questions: “What are LTC nurses' ACP experiences”; “What are nurses’ perceptions of their ACP roles”; and, “What barriers and facilitators to ACP communication exist in their practice?” A convenience sample of fifteen registered nurses and licensed practical nurses working in LTC settings in Manitoba, Canada volunteered for the study. Individual one-on-one telephone interviews were conducted using a semi-structured interview guide. Using Braun and Clarke’s thematic analysis process two themes were identified: *A Sense of an Ethical Obligation to Engage in ACP Communication*; and *Sensibility of the Determinants of ACP Communication*. Nurses described how their ethical obligation to engage in ACP communication was influenced by their definitions of ACP, the approaches to ACP in their workplaces, and their personal and professional ACP experiences. Nurses identified roles and actions that flow from this ethical obligation and factors, both personal and structural, that hinder and catalyze ACP communication in LTC. This study adds to the scholarly literature related to LTC nurses’ ACP communication. The study findings point to the need for improvements in ACP policies, procedures, practice, and education, and research for nurses in a variety of settings.

Keywords: advance care planning, nurses, long-term care, interpretive description

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List of Abbreviations

Abbreviations (in alphabetical order)	**Full Words/Phrases**
ACP	Advance Care Planning
AD	Advance Directive
CHPCA	Canadian Hospice Palliative Care Association
CLPNM	College of Licensed Practical Nurses of Manitoba
CNA	Canadian Nurses Association
COVID-19	Coronavirus Global Pandemic in 2020/2021
CRNM	College of Registered Nurses of Manitoba
ENREB	Education/Nursing Research Ethics Board
EOL	End-of-Life
GOC	Goal(s) of Care
HCD	Health Care Directive
HCP	Healthcare Provider/Practitioner/Professional
LMS	Learning Management System
LPN	Licensed Practical Nurse
LTC	Long-Term Care
MAID	Medical Assistance in Dying
MN	Master of Nursing
PCH	Personal Care Home
PHIA	Personal Health Information Act
PID	Participant Identification (number)
PSDA	Patient Self-Determination Act
RN	Registered Nurse
WRHA	Winnipeg Regional Health Authority

Chapter 1: Introduction

Nurses are often described in scholarly literature as the healthcare professionals (HCPs) who develop an enhanced level of rapport and trust with residents or patients and their families in long-term care (LTC) settings; consequently, this puts nurses in an integral, unique, and important position to have meaningful healthcare-related conversations with LTC residents or patients and families (Briggs & Colvin, 2002; Canadian Hospice Palliative Care Association [CHPCA], 2012; Head et al., 2018; Hebert et al., 2011; Ke et al., 2015; O'Conner-Von & Bennett, 2020; Rietze & Stajduhar, 2015). Furthermore, nurses who work in LTC settings are often faced with challenging issues that they are obliged to discuss with their residents or patients as part of their scope of practice (Black & Emmet, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Canadian Nurses Association [CNA], 2017; Head et al., 2018; Hebert et al., 2011; Jeong et al., 2009; Rietze & Stajduhar, 2015). One such potentially difficult subject to broach with LTC residents or patients and their families is advance care planning (ACP), a process of discussions related to future medical care wishes and preferences (Ampe et al., 2016; Arnett et al., 2017; Black & Emmet, 2006; Briggs & Colvin, 2002; Cornally et al., 2015; Ke et al., 2015; Moore, 2005; Rietze & Stajduhar, 2015; Schickendanz et al., 2009; Stewart et al., 2011; Sudore et al., 2016; Teno et al., 1994; Yokoya et al., 2018).

As the population of LTC patients dealing with chronic or life-threatening illnesses grows, the need for appropriate, patient-centered, end-of-life (EOL) care also grows (CHPCA, 2012; Ludwick et al., 2018; Rietze & Stajduhar, 2015; The SUPPORT Principal Investigators, 1995; Yokoya et al., 2018). ACP affords nurses ongoing opportunities to discuss and respect their residents' or patients' EOL wishes by opening up channels of communication between the nurse, the patient, and their family about desires for future healthcare (Briggs & Colvin, 2002;

Black, 2006; Head et al., 2018; Jeong et al., 2009; Ke et al., 2015; Ludwick et al., 2018; Moore, 2005). Nurses are on the front lines of patient care, and as such it is important to study and document nurses’ experiences and perspectives related to a variety of patient care issues, including ACP communication.

The topic of interest for this Master of Nursing (MN) thesis study was the exploration of nurses' perceptions of ACP communication with residents/patients and families in LTC settings. A qualitative study was conducted to help elucidate and describe LTC nurses' views, opinions, thoughts, and feelings related to the ACP communication that they have experienced, observed, and/or participated in as part of their nursing practice. This study also examined nurses’ perceptions of the ideal in relation to ACP communication in practice. This thesis aimed to shed light on the emerging and ever-evolving topic of ACP communication with patients and families in LTC from a nursing perspective, which has not been prominently featured in ACP scholarly literature thus far.

The introductory section of this thesis includes a discussion of the history of ACP, the definitions of key terms, and information related to my background and assumptions as the researcher/principal investigator. Additionally, the background to the problem is described, the role of nurses in ACP is discussed, and the purpose (including research questions) and significance of the study are identified. The introduction will be followed by a review of the existing and relevant scholarly literature pertaining to nurses' ACP communication with residents or patients and families in LTC settings; furthermore, the gaps in current ACP research from a LTC nursing standpoint are highlighted. This will be followed by a description of the research design and methods that were used to explore research questions related to the study of nurses’ perceptions of ACP communication with patients and families in LTC settings. For the purposes of this thesis, the term “patient” will be used throughout to indicate the residents or patients in the care of LTC nurses.

History of Advance Care Planning

The catalyst for the use and development of ACP communication was the *Patient Self-Determination Act* (PSDA) that went into effect in the United States of America in the year 1991 (Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Prendergast, 2001; Teno et al., 1994; Teno et al., 1997; Teno et al., 2011; Weiner & Cole, 2004). The PSDA is an act that came about due to several precedent-setting court cases involving patients and families that wanted the right to dictate their own healthcare wishes, especially in cases of patient incapacitation or incompetence (Prendergast, 2001; Teno et al., 1994; Teno et al., 2011). In addition to the introduction of the PSDA, a document called an advance directive (AD) (also known as a health care directive [HCD]) was (and still is) used to help patients and families keep a written, legally-binding medical care contract of sorts with their HCPs (Black, 2006; Black & Emmet, 2006; Jeong et al., 2009; Ke et al., 2015; Seymour et al., 2004; Teno et al., 1997). In the province of Manitoba, under the *Health Care Directives Act,* patients and families can use an AD to describe and detail what their wishes are for medical care in the future, to be used at a time when the patient can no longer make decisions for himself or herself (Manitoba Health, 1993, 2017).

After the introduction of the PSDA, the success of the PSDA in the United States was often measured by how many AD documents were completed in healthcare facilities (Black, 2006; Briggs & Colvin, 2002; Prendergast, 2001; Teno et al, 1994; Teno et al., 1997; Teno et al., 2011). Unfortunately, the PSDA did not translate to practice in many cases because ADs were not completed; moreover, when ADs were present they were often completed with very little discussion held between the healthcare team and the patient and family with regards to future goals of care (GoC) (Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Jeong et al, 2009; Johnstone & Kanitsaki, 2009; Prendergast, 2001; Seymour et al., 2004; Teno et al., 1994; Teno et al., 1997; Teno et al., 2011; Weiner & Cole, 2004). In a review of relevant PSDA and AD literature a decade after the legislation was enacted, Prendergast (2001) emphasized that "one reason the standard approach to advance directives has failed is because it has not attended to the importance of communication with patients" (p. N37). Therefore, ACP communication developed out of the need for HCPs to better understand and respect their patients' true and evolving wishes for future medical care in a timely and ever-changing manner (Baron et al., 2015; Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Cornally et al., 2015; Counsell, 2015; Flo et al., 2016; Head et al., 2018; Ke et al., 2015; Moore, 2005; Prendergast, 2001; Rietze & Stajduhar, 2015; Sudore et al., 2016; Teno et al., 1994; Weiner & Cole, 2004; Winnipeg Regional Health Authority [WRHA], 2011).

Definitions of Terms

Advance Care Planning (ACP)

In a seminal article by Teno et al. (1994), the authors discussed how the implementation of the PSDA could be influenced by ACP, and they defined ACP as:

> A process of communication that aims to ensure that clinical care is consistent with patients' preferences for care. In some cases, this may lead to the completion of written advance directives, while in other circumstances the result will be a detailed note in the medical record regarding the patient's preferences. (p. S36)

A more current consensus definition of ACP was developed by a 52-person, international, multidisciplinary Delphi panel made up of ACP experts that was led by Sudore et al. (2016), and it reads as follows:

> Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness. (pp. 2-3)

Overall, the literature appears to define and describe ACP in similar terms. To summarize the definitions, ACP is an ongoing process of discussion and documentation involving patients, their families, and HCPs to determine patients' wishes, values, and preferences for future medical and/or EOL care before patients become unable to make their own decisions (Abdul-Razzak et al., 2014; Ampe et al., 2016; Arnett et al., 2017; Baron et al., 2015; Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Cornally et al., 2015; Flo et al., 2016; Ke et al., 2015; Moore, 2005; Oliverio & Fraulo, 1998; Rietze & Stajduhar, 2015; Schickendanz et al., 2009; Stewart et al., 2011; Sudore et al., 2016; Teno et al., 1994; van Soest-Poortvliet et al., 2015; Weiner & Cole, 2004; WRHA, 2011).

Advance Directive/Health Care Directive (AD/HCD)

An AD/HCD is a legally-binding, self-initiated, written document that allows patients to detail their future, anticipatory medical care wishes or refusals should they become unable to express these wishes in a time of crisis and/or incapacitation (Black, 2006; Black & Emmet, 2006; CHPCA, 2012; Jeong et al., 2009; Manitoba Health, 1993, 2017; Seymour et al., 2004; Teno et al., 1997; WRHA, 2011). Filling out an AD may also involve naming a person or persons (usually family or friends) who will act as a substitute decision-maker or healthcare proxy responsible for advocating on behalf of an incapacitated or incompetent patient if the medical care situation calls for a particular decision to be made (Black & Emmet, 2006; CHPCA, 2012; Jeong et al., 2009; Johnstone & Kanitsaki, 2009; Manitoba Health, 1993, 2017; Teno et al., 1997; WRHA, 2011; Yokoya et al., 2018). If an AD exists and HCPs are made aware of the document, a copy of the AD is meant to be kept on file in the patient's chart so that it is easily accessible by the healthcare team as needed (WRHA, 2011).

Nurse

For the purposes of this MN thesis, a nurse is defined as a healthcare professional who has graduated from an approved nursing education program (diploma or degree), has passed a nursing registration examination, meets the yearly requirements of their licensing body, maintains the required practice hours, and practices nursing under a code of ethics for their profession (CNA, 2017; College of Licensed Practical Nurses of Manitoba [CLPNM], 2016; College of Registered Nurses of Manitoba [CRNM], 2018).

Long-Term Care (LTC)

In an overview of LTC in Canada, Banerjee (2007) remarked that LTC generally "refers to ongoing, indefinite, care for individuals who can no longer fully care for themselves" (p. 5). The Manitoba Centre for Health Policy (MCHP) states that LTC includes any "chronic and rehabilitative services provided by any long term care facilities, such as Personal Care Homes (PCH), chronic care (CC) facilities and long term care beds in acute care hospitals" (2018, para. 2).

Personal Care Home (PCH)

According to DeCoster et al. (1996), a personal care home (PCH) provides housing and care for:

> Patients who require some degree of long term care in a 24 hour supervised setting, who can no longer be cared for at home, and whose care needs could be met by admission to a long term care facility licensed as a personal care home. (p. 16)

Similarly, the Government of Manitoba website states that "Personal care homes are designed for individuals who require 24-hour daily nursing care as well as other care needs that cannot be met in the community" (2021, para 4). Additionally, a PCH is a type of licensed LTC unit or facility that is required to adhere to a specific set of regulatory accreditation standards that are reviewed "every two years" (WRHA, 2013, p. 2). Essentially, PCH residents/patients usually require basic, daily nursing care for health conditions/diseases that are stable and/or manageable without invasive acute care treatments.

Non-PCH LTC Unit or Facility/Chronic Care (CC) Unit or Facility

Non-PCH LTC or chronic care (CC) care units provide housing and care for:

> Patients who show little or no potential for rehabilitation, whose care needs cannot be met at home, and who require equipment, treatment or a level of professional supervision (e.g. nursing, medical, respiratory) not usually provided in a personal care home. (DeCoster et al., 1996, p. 16)

In other words, non-PCH LTC units are residential, CC units that provide healthcare to patients who are long-term residents and require long-term specialized, complex, and at times acute/invasive care and treatments due to complications from their progressive diseases and/or injuries that were suffered prior to admission to LTC. According to the WRHA, "Chronic care services are for individuals who need specialized care due to a chronic health condition or who need more care than a Personal Care Home can accommodate" (2021, para 1). Non-PCH LTC units offer many of the same personal care services that are offered on PCH units, but non-PCH

LTC units adhere to a different set of accreditation standards than licensed PCHs (WRHA, 2013).

End-of-Life (EOL) Care

The WRHA defines EOL care as "an approach to care which focuses on comfort and quality of life for people of all ages affected by life-threatening illness" (2018, para. 1). Manitoba Health (2017) adds that EOL care is an approach to care that is:

> appropriate for any individual and/or family living with a life-threatening illness due to any diagnosis, with any prognosis, regardless of age. It may co-exist with and enhance therapy of a disease, or it may become the total focus of care. (para 1)

Background and Assumptions of the Researcher

I became interested in the area of ACP communication during my time working as a registered nurse on a LTC unit. I worked for over a decade on a non-PCH LTC (i.e., chronic care) unit, providing nursing care to residents who required specialized, and at times acute, care on a daily basis. At that time, ACP communication with residents/patients and families on my unit occurred with the nurse during patient admission, and each patient's ACP status and wishes were reviewed at least once a year during interdisciplinary meetings with patients and their families.

I had a particularly interesting ACP communication situation occur during my time as a nurse on that non-PCH LTC unit that left an impression on me. A patient identified care wishes for comfort care (i.e., ACP-C), with no transfers to hospital. The patient was competent and initially made those decisions independently with the unit's physician. The patient told family members about the ACP decisions later that week and the family were not in agreement with the ACP choices. Several days later, I was asked by the physician to join an impromptu ACP meeting between the physician and the patient. The patient indicated at that time a desire to change the ACP wishes (i.e., to ACP-Medical or ACP-M with transfer to hospital) in order to please and appease family members. After the physician and I had a more in-depth discussion with the patient and confirmed that these were the new wishes, this patient's ACP form was changed to ACP-M. When the patient did eventually become ill, the patient was transferred to the hospital and died there.

I knew at the time that my ethical practice as a nurse involved respecting my patient's wishes and following ACP goals of care as documented. This situation caused me to reflect on the complexity of decision making for patients in LTC, the roles of families, nurses, and other healthcare team members in discussions regarding future care, and the implications of these decisions for all involved. This and other experiences in LTC with ACP discussions stayed with me.

When I decided to pursue my MN degree, I had to pick a thesis focus. I knew that I wanted to do something related to nursing ethics, because I personally have a deep sense of justice and ethical nursing practice is important to me. I had not realized how the ACP communication experience mentioned above impacted me at the time, but I remembered that specific ACP situation and the ethical uncertainty that it caused for me. Therefore, I decided to explore other LTC nurses' experiences with ACP communication in their practice. And as I progressed in my MN program and realized that few ACP studies feature nurses, and even fewer feature LTC nurses, I thought that it was a perspective that needed highlighting in ACP communication research.

It is important to articulate assumptions as a study is being planned. With this study, assumptions were made. It was assumed that:

1. LTC nurses recognize the importance of identifying patient wishes.
2. ACP was something LTC nurses were aware of and encountered in their practice.
3. LTC nurses could speak to their experiences with ACP discussions in their practice and the roles nurses play in the discussions.
4. LTC nurses' experiences with ACP are varied, ranging from positive to negative experiences.
5. LTC nurses have insight into factors that facilitate ACP discussions or serve as barriers to these discussions.

Background to the Problem

There is growing consensus among HCPs (including nurses) and the general public about the importance of ACP communication in the healthcare system (Beck et al., 2016; Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012, 2020; Cornally et al., 2015; Flo et al., 2016; Head et al., 2018; Moore, 2005; Ottoboni et al., 2019; Rietze et al., 2018; Stewart et al., 2011; van Soest-Poortvliet et al., 2015; Yokoya et al., 2018). In fact, ACP discussions become more important as our aging population continues to grow, live longer, and require the use of more healthcare resources than previous generations (Basky & De Coster, 2004; CHPCA, 2012, 2020; Ludwick et al., 2018; Ottoboni et al., 2019; Rietze & Stajduhar, 2015; Yokoya et al., 2018). The strain on our tertiary-care hospitals and LTC facilities is felt even more acutely when patients and their families report a general dissatisfaction with the EOL care that they are receiving (Basky & De Coster, 2004; Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Flo et al., 2016; Hebert et al., 2011; Lenherr et al., 2012; Moore, 2005; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015).

According to the literature, the overwhelming stance on ACP is that it is a positive and important process of discussion that HCPs should be engaging in with patients and their families on a more frequent basis in both acute care and LTC settings (Baron et al., 2015; Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Cornally et al., 2015; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Ludwick et al, 2018; Moore, 2005; Ottoboni et al., 2019; Rietze & Stajduhar, 2015; Rietze et al., 2018; Teno et al., 1994; van Soest-Poortvliet et al., 2015; Weiner & Cole, 2004; Yokoya et al., 2018). Teno et al. (1994) stated that the principles and policies contained in the PSDA are enhanced with the use of ACP, which is a process that "offers an appealing possibility of maintaining control over medical treatment decisions even at a time when one has become incapacitated" (p. S36). In fact, most of the literature posits that there are benefits of ACP communication that can positively affect patients, their families, and the HCPs involved; in particular, patient autonomy and improved EOL care were highlighted in the literature reviews and studies that were analyzed for this thesis study.

Patient Autonomy

Several of the articles reviewed for this thesis list the promotion of patient autonomy as an important benefit of engaging in ACP discussions (Black, 2006; Black & Emmet, 2006; Jeong et al., 2009; Lenherr et al., 2012; Oliverio & Fraulo, 1998; Weiner & Cole, 2004). Moreover, demonstration of support for patient autonomy and self-determination, as well as respecting patients' wishes and healthcare preferences, are in keeping with the Canadian code of ethics for registered nurses (CHPCA, 2012; CNA, 2017). The code of ethics (CNA, 2017) makes clear that ethically responsible nurses present patients and families with clear, honest, and understandable health information, so that patients can make informed and autonomous healthcare decisions. Therefore, helping patients achieve their goals for EOL care is an important benefit of ACP communication that nurses can and should be active in, whilst encouraging, defending, and respecting patient autonomy (CHPCA, 2012; CNA, 2017).

Improved End-of-Life Care

The literature also claimed that ACP may lead to improved palliative and/or EOL patient care, resulting in patients' achievement of EOL preferences, increased satisfaction with EOL care, decreased crisis-based decision making, and reduced rates of EOL hospital admissions and deaths (Baron et al., 2015; Basky & De Coster, 2004; Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Cornally et al., 2015; Counsell, 2015; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Moore, 2005; Oliverio & Fraulo, 1998; Rietze & Stajduhar, 2015; The SUPPORT Principal Investigators, 1995; van Soest-Poortvliet et al., 2015; Yokoya et al., 2018). The literature also notes that high quality EOL care received by patients that have made their care wishes known via ACP can increase patient and family satisfaction by virtue of decreasing patient and family guilt, burden, fear, and anxiety associated with the EOL situation (Black & Emmet, 2006; Brooke & Kirk, 2014; Cornally et al., 2015; Counsell, 2015; Flo et al., 2016; Jeong et al., 2009; Ke et al., 2015; Moore, 2005; Rietze & Stajduhar, 2015). It can be said that the overall goals of ACP involve listening to and following through with patients' and families' wishes, and that these goals of ACP are foundational elements of delivering good, patient-centered EOL nursing care (CHPCA, 2012; CNA, 2017; WRHA, 2011).

Role of Nurses in ACP

The role of nurses in ACP communication has been described, supported, and encouraged by several healthcare organizations in Canada (CHPCA, 2012; CNA, 2017; WRHA, 2011). The CNA (2017) stated that "Nurses, along with other health-care providers and with substitute decision-makers, consider and respect the best interests of the person receiving care and any previously known wishes or advance care planning that applies in the situation" (p. 12). The WRHA (2011) ACP policy, the CHPCA (2012) national framework for ACP in Canada, and the CHPCA (2020) pan-Canadian framework for ACP in Canada are documents that emphasize that HCPs who deliver direct patient care are essential to the success of ACP communication. Nurses in a variety of healthcare settings (including LTC) are seen as the main caregivers for patients on a 24-hour basis; therefore, nurses are more likely than other HCPs to have care-related discussions with patients and their families, both formally and informally (Black & Emmet, 2006; Briggs & Colvin, 2002; CHPCA, 2012; CNA, 2017; Head et al., 2018; Hebert et al., 2011; Jeong et al., 2009; Rietze & Stajduhar, 2015; Rietze et al., 2018).

Despite nurses being well-positioned to carry out ACP discussions with patients and families in acute care and LTC settings, the literature indicates that nurses engage in ACP communication inconsistently or sparingly as part of their nursing practice (Beck et al., 2016; Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Cornally et al., 2015; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Moore, 2005; Rietze & Stajduhar, 2015; Rietze et al., 2018; van Soest-Poortvliet et al., 2015; Weiner & Cole, 2004; Yokoya et al., 2018). For instance, in a recent quantitative study conducted by Yokoya et al. (2018), the researchers used a self-report questionnaire to survey head nurses (n = 844) working in geriatric health service facilities (GHSFs) in Japan to inquire about the "practice and perceived importance of ACP and the difficulties in providing palliative care in GHSFs" (p. 464). These researchers found that there were substantial discrepancies between head nurses' belief that ACP is important (79.6%) versus their initiation of, and participation in, ACP communication as part of their nursing practice (27.5%) (Yokoya et al., 2018).

Similarly, Rietze et al. (2018) conducted a mixed method, cross-sectional, descriptive survey study with nurses working in acute and nonacute healthcare settings entitled “Identifying the Factors Associated with Canadian Registered Nurses’ Engagement in Advance Care Planning” (p. 230). Of the total registered nurse participants (n = 125), 92.4% agreed or strongly agreed that ACP discussions with patients and their families were an important part of a nurses’ work and/or role in EOL care (Rietze et al., 2018). However, more than half (58.4%) of the total 125 nurse respondents indicated that they participate in ACP with their patients “occasionally to never” (Rietze et al., 2018, p. 233).

The discrepancy evident in these two recent examples between nurses’ overall acknowledgement of the importance of ACP and their actual involvement in ACP communication with patients is echoed and reported in many of the descriptive articles and studies that were reviewed for this study (Arnett et al., 2017; Beck et al., 2016; Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Cornally et al., 2015; Flo et al., 2016; Head et al., 2018; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Moore, 2005; Rietze & Stajduhar, 2015; Rietze et al., 2018; van Soest-Poortvliet et al., 2015; Weiner & Cole, 2004; Yokoya et al., 2018). According to the literature, nurses across the healthcare spectrum are not engaging in ACP communication with patients and families often or well enough, even though it is within a nurse’s scope of practice to do so (Beck et al., 2016; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; CNA, 2017; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Rietze & Stajduhar, 2015; Rietze et al., 2018; Yokoya et al., 2018). It was apparent that a disconnect still existed between what is possible in terms of ACP conversations based on nursing's position on the healthcare team, and nurses' engagement in and practice of ACP communication with patients and families. Additionally, the scarcity of ACP literature that focuses on nurses working in LTC settings was concerning when one considered that this patient population would undoubtedly benefit from a nurse-led ACP process.

Purpose of the Study

A gap was identified in the scholarly literature in relation to ACP communication research that focuses on nurses working in LTC settings. The purpose of this qualitative, interpretive description study was to shed light on the experiences of nurses working in LTC settings with respect to ACP communication with patients and families. The focus of this study was to elucidate the thoughts, feelings, opinions, and overall experiences that full-time and part-time LTC nurses have had with ACP communication in their nursing practice. In particular, this thesis aimed to answer the following three research questions:

1. What are LTC nurses' experiences with ACP communication in their practice?
2. What are LTC nurses' perceptions (e.g., thoughts, feelings, opinions) of their roles in ACP communication with patients and families?
3. What do LTC nurses see as barriers and/or facilitators to ACP communication with patients and families in their practice settings?

Significance of the Problem

Palliative care, concepts such as "dying with dignity" and/or "a good death", and new laws and policies surrounding Medical Assistance in Dying (MAID) in Canada, are currently in the news; therefore, the public may be more aware of their rights in identifying their EOL care wishes before they lose the capacity to do so (CHPCA, 2012, 2020; CNA, 2017; CRNM, 2017;

Manitoba Health, 1993, 2017; WRHA, 2011, 2016, 2018). ACP is a process of anticipatory communication that HCPs can engage in to respect patient autonomy, and to use patient values and wishes to inform the most appropriate future medical and/or EOL care for the patient and their family (Arnett et al., 2017; Baron et al., 2015; Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012, 2020; Cornally et al., 2015; Counsell, 2015; Flo et al., 2016; Jeong et al., 2009; Ke et al., 2015; Moore, 2005; Rietze & Stajduhar, 2015; Rietze et al., 2018; Sudore et al., 2016; Teno et al., 1994; van Soest-Poortvliet et al., 2015; Weiner & Cole, 2004; WRHA, 2011; Yokoya et al., 2018). Moreover, Teno et al. (2011) point out that the use of ACP in "educating patients about their condition and prognosis, ascertaining their preferences for care in the present and future, and formulating a plan of care is thought to lead to an ethically acceptable reduction in health care costs" (p. 1041). In fact, several ACP literature reviews and studies have reported that ACP communication can help reduce unwanted (or unnecessary) hospital admissions and invasive life-sustaining treatments for patients; thus, overall healthcare cost reductions are potentially seen when the ACP process is efficaciously utilized (Baron et al., 2015; Basky & De Coster, 2004; Cornally et al., 2015; Counsell, 2015; Flo et al., 2016; Head et al., 2018; Jeong et al., 2009; Prendergast, 2001; Rietze & Stajduhar, 2015; The SUPPORT Principal Investigators, 1995; Teno et al., 1994; Teno et al., 2011; Yokoya et al., 2018).

Although the benefits of ACP for patients, HCPs, and the healthcare system at large are lauded in the scholarly literature, the few nurse-centric research studies that were found and analyzed for this study have concluded that LTC nurses' ACP communication practices need improvement (Beck et al., 2016; Black & Emmet, 2006; Cornally et al., 2015; Jeong et al., 2009; Rietze et al., 2018; Yokoya et al., 2018). Thus, engagement of LTC nurses in ACP communication research, such as this study, had the potential to increase awareness and commitment in nurses to initiate and conduct meaningful ACP discussions with patients and families more often in their own practice. And as patient-centered care is a main tenet of ethical nursing, the effective use of ACP communication is one way that nurses can fulfill this professional duty and responsibility (CHPCA, 2012; CNA, 2017; CLPNM, 2016; CRNM, 2018).

In an effort to raise the collective consciousness surrounding ACP, this thesis sought to add to the paucity of scholarly literature that is available on the topic of LTC nurses' ACP communication perceptions and practices. The significance of this MN thesis study is that it can enhance our understanding of how nurses perceive their role in ACP communication; additionally, this study generated LTC nurse-identified barriers and facilitators to ACP communication. This qualitative study also gave LTC nurses the opportunity to think about and reflect on their ACP communication strengths and weaknesses; furthermore, this study sought to encourage LTC nurses to think about suggestions to improve upon nurses’ current ACP communication practices with the patients and families that are in their care. Especially significant is that the qualitative data gleaned from LTC nurses in this study may have the potential to guide and inform future ACP research, ACP policy, and ACP education, training, and mentoring programs for nurses in a variety of healthcare settings.

Chapter 2: Literature Review

There is a dearth of scholarly literature involving LTC nurses and ACP communication with patients and their families. A search of the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, and Scopus databases was conducted to find applicable articles published between the years 1991 and 2020. The year 1991 was chosen as a search limit due to the fact that the PSDA came into effect in the United States of America late that year (Briggs & Colvin, 2002; Prendergast, 2001; Teno et al., 1994; Teno et al., 1997; Teno et al., 2011; Weiner & Cole, 2004). The PSDA was a pivotal moment in the history of AD use in the United States, and subsequently in the emergence of ACP as a process of discussion used by HCPs to facilitate AD documentation with patients (Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Prendergast, 2001; Teno et al., 1994; Teno et al., 1997; Teno et al., 2011; Weiner & Cole, 2004). Therefore, seminal and/or historical articles from the 1990s (e.g., articles by Teno et al., 1994, and The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments [the SUPPORT study], 1995), which discussed ACP when it was in its veritable infancy, were sought out and found to be helpful in determining context for other studies and descriptive articles that came afterwards.

Primary search terms used for searches in all three databases were "advance care planning" AND "nurses" AND "long-term care" OR "nursing homes" AND "communication". Alternative wording of key terms (i.e., advance(d) care plan/planning, advance care plan/planning discussion(s), long-term/long term care facility/facilities, nursing home(s), nurse(s), registered nurse(s)) was also used to search the databases. One hundred and seven articles were retrieved, and following some scrutiny and abstract reading, forty-one articles were determined to be appropriate and were included and reviewed for the purposes of this study.

All forty-one articles were published in international peer-reviewed academic journals, with the oldest article being from the year 1994 (Teno et al., 1994) and the most recent literature source being from the year 2020 (O’Conner-Von & Bennett, 2020). Twelve different countries were represented in the ACP literature that was analyzed and synthesized for this study: Canada, Belgium, United States of America, United Kingdom, Ireland, Norway, Australia, Taiwan, Switzerland, The Netherlands, Japan, and Italy (see Table 1). The majority of the studies and descriptive articles were from the United States of America (twelve studies and eleven descriptive articles about ACP communication). Notably, only three of the total forty-one sources related to ACP communication were from Canada (two research studies and one descriptive literature review). Sixteen of the forty-one articles were either ACP literature reviews or descriptive articles about ACP communication (see Table 2). Hence, the remaining twenty-five out of forty-one articles retrieved for this thesis study were research studies conducted to explore ACP communication in a few different settings, and with a variety of healthcare participants (see Table 3).

A further breakdown of the twenty-five ACP studies by settings can be seen in Table 4. There were fourteen studies that discussed ACP in LTC/nursing home (non-acute) settings, whereas eight articles focused exclusively on ACP communication in acute care/hospital settings. Two studies looked at ACP in both acute and non-acute settings, with no further specification, and one study focused on a community setting (see Table 4).

Table 5 shows a breakdown of the twenty-five ACP studies by participants. Three studies featured nurses and social workers, two studies focused on nurses and doctors, while seven studies indicated that “healthcare teams” and/or “staff” (including nurses) were their participants. One study looked at doctors only, two studies looked only at patients, and one study focused on doctors and patients together. Two studies involved no human subjects but were ACP studies involving healthcare documents (i.e., ADs, ACP documentation, and chart reviews). Three studies were conducted with only nurse managers, and the remaining five ACP research studies (out of twenty-five studies) focused on registered nurses (RNs) and/or licensed practical nurses (LPNs) (see Table 5).

Of the twenty-five ACP research studies reviewed for this thesis study, twelve were qualitative studies, eight were quantitative studies, and five were mixed methods (qualitative and quantitative) studies. The sample sizes of the studies ranged from eleven individual participants in an American study conducted by Black (2006) to 15, 784 nursing homes in the United States that were included in one study conducted by Teno et al. (2011). The methods for data collection used in the twenty-five studies included individual interviews (7), focus groups (5), surveys/questionnaires (9), records review (1), retrospective cohort study (1), pre-test/post-test (1), and a controlled clinical trial (1). Data analysis methods, tools, and strategies varied from study to study. In the quantitative studies, validated statistical software was used to analyze data (i.e., SAS, SPSS, Intercooled Stata, & ADCPI). The qualitative studies used thematic content analysis, as well as ATLAS.ti and NVivo software programs to facilitate the analysis of the interview or focus group data that were collected.

As stated above, out of the twenty-five ACP studies that were reviewed, a total of eight studies featuring nurse participants exclusively (five focused on RNs/LPNs, and three focused on nurse managers) were found (see Table 5). Out of these eight studies, three focused on nurse managers working in LTC settings (Beck et al., 2016; Cornally et al., 2015; Yokoya et al., 2018). Of the remaining five nurse-centric studies, one study looked at the ACP communication experiences of RNs working in an acute geriatrics setting (Black & Emmet, 2006), one study looked at RNs' ACP engagement in both acute and non-acute settings (Rietze et al., 2018), one study explored the ACP practice of RNs and LPNs in skilled nursing facilities (also known as LTC settings in the United States of America) (Ludwick et al., 2018), one study explored LTC RNs' communication practices related to patients' EOL care preferences (O'Conner-Von & Bennett, 2020), and one study investigated RNs' perspectives with respect to ACP communication in LTC settings (Jeong et al., 2009).

To summarize, only six of the total twenty-five studies that were reviewed for this study conducted ACP communication research with nurses (three with RNs/LPNs as participants, and three with nurse managers as participants) working solely in LTC settings (Beck et al., 2016; Cornally et al., 2015; Jeong et al., 2009; Ludwick et al., 2018; O'Conner-Von & Bennett, 2020; Yokoya et al., 2018). It is noteworthy to point out that only three studies out of the six nurse-focused studies sampled RNs/LPNs who provided direct patient care on a "twenty-four hour/seven days a week" basis whilst working in LTC settings (Jeong et al., 2009; Ludwick et al., 2018; O'Conner-Von & Bennett, 2020). This shows that a gap exists in the scholarly literature with regards to nurses' perceptions of ACP communication with patients and families in LTC settings.

The findings and limitations of the forty-one literature sources were carefully reviewed, analyzed, critiqued, and synthesized for the purposes of this thesis. The following section will focus on and highlight the state of ACP communication in nursing practice according to the literature. Furthermore, nurses' roles in the ACP process, as described in the studies and articles retrieved for this study, will be examined and explored. Finally, ACP communication barriers and facilitators presented in the literature will be discussed.

ACP Communication in Nursing Practice

Nurses working in a number of roles within the healthcare system rely heavily on their ability to communicate effectively with patients and families at various points on the health/illness continuum (Head et al., 2018; Moore, 2005). In LTC settings, patients range from being active and participatory in their healthcare to being incapacitated or unresponsive at the EOL. LTC nurses are in a position to work closely with patients and families, build rapport with them, and discuss up-to-the-minute medical concerns or issues with them in a timely manner, as LTC nurses provide care for patients twenty-four hours a day, seven days a week (Black & Emmet, 2006; Briggs & Colvin, 2002; Head et al., 2018; Ke et al., 2015; Ludwick et al., 2018; Rietze et al., 2018). Oftentimes, patients may end up living in LTC settings for lengthy periods of time, so the nurse-patient relationship has the potential to be strengthened and nurtured under these circumstances. This type of close, evolving, and trusting relationship between the LTC nurse and the patient and their family may lay the foundation from which the nurse can initiate and build on ACP discussions (Black, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Head et al., 2018; Hebert et al., 2011; Ke et al., 2015; Ludwick et al., 2018; Rietze & Stajduhar, 2015). However, the studies reviewed for this study suggested that a nurse's confidence level, and perspectives on the question of which HCP is responsible for conducting ACP discussions, can affect the frequency and quality of nurses' ACP communication with patients, both in LTC and acute care settings.

Confidence Level

Oftentimes, nurses do not feel comfortable or confident enough to engage their patients in meaningful conversations regarding sensitive healthcare related topics such as EOL care and ACP (Beck et al., 2016; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Moore, 2005; Ottoboni et al., 2019; Rietze & Stajduhar, 2015; Weiner & Cole, 2004). Nurses that provide direct patient care need to feel confident that the EOL care that they are providing to their patients is in keeping with their patients' wishes, and that their patients' healthcare decisions are being respected by others involved in their care, including families and/or substitute decision-makers (CHPCA, 2012; CNA, 2017). In fact, the section of the code of ethics for registered nurses in Canada labelled *Promoting and Respecting Informed Decision-Making* is congruent with the overarching principles highlighted in the ACP process, such as providing education and support for informed decision-making while also respecting a patient's personal choices regarding their medical care (CHPCA, 2012; CNA, 2017).

According to the literature, nurses may struggle with both the meaning and the execution of ACP (Baughman et al., 2012; Jeong et al., 2009; Ottoboni et al., 2019). The literature points to there being an argument for the fact that a nurse's comfort and/or confidence level with respect to communicating with patients about ACP can be linked to the nurse's knowledge on the subject (Briggs & Colvin, 2002; CHPCA, 2012; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Ludwick et al., 2018; Moore, 2005; Rietze & Stajduhar, 2015; Rietze et al., 2018). Therefore, it is important to note that crucial and timely ACP and EOL discussions are not initiated by nurses because they lack ACP training, both in their educational preparation and on the job (Briggs & Colvin, 2002; CHPCA, 2012; Hebert et al., 2011; Ke et al., 2015; Ludwick et al., 2018; Rietze & Stajduhar, 2015; Rietze et al., 2018; Weiner & Cole, 2004). Perhaps if nurses were better informed and educated about ACP, they would feel more confident to discuss this information with patients and families.

Responsibility for ACP

Oftentimes, nurses may feel as though it is not their role on the healthcare team to initiate ACP discussions with patients and families (Beck et al., 2016; Briggs & Colvin, 2002; Brooke & Kirk, 2014; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Ludwick et al., 2018; Rietze & Stajduhar, 2015). In a recent American quantitative study conducted by Ludwick et al. (2018), the researchers distributed surveys to RNs (n = 136) and LPNs (n = 178) working in skilled nursing facilities (i.e., facilities that fall under the LTC umbrella of patient care in the United States). The surveys measured the differences in ACP beliefs, self-efficacy, education, and practices among and between the RN and LPN participants (Ludwick et al., 2018). Interestingly, Ludwick et al. (2018) found that, when compared to the RNs in their study, LPNs "were less likely to see ACP as part of their role" (p. 31). Additionally, Ludwick et al. (2018) went on to assert that, "Despite having more contact with residents, the LPNs in our study did not view their role in ACP to be as critical as the RNs did" (p. 32). This result illustrated that even among different nursing designations that work together in LTC settings (i.e., RNs and LPNs), nurses' perceptions of their responsibility for ACP can vary (Ludwick et al., 2018).

Furthermore, although ACP discussions fall under a nurse's scope of practice, many nurses choose to defer these important conversations with patients and families to physicians, social workers, or patient care managers in both acute care and LTC settings (Black, 2006; Hebert et al., 2011; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015; Rietze et al., 2018). According to the literature, not feeling responsible for ACP could be one explanation for why nurses feel the need to delegate the task of ACP to the other HCPs on the multi-disciplinary team instead of speaking to their patients directly (Beck et al., 2016; Black, 2006; Hebert et al., 2011; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015).

Several of the articles that were reviewed for this thesis discuss the role of the nurse (and nurses' perceptions of their role) in ACP communication in both acute care and LTC settings. The next section will take a closer look at what the literature says about the nurse’s role in ACP communication with patients and their families in a variety of care settings.

Nurses' Role Perception in ACP

The literature states that nurses view their role in ACP communication in several ways. Nurses saw themselves, and were seen by others, as advocates, team members, translators, liaisons, educators, and facilitators in the ACP literature that was reviewed for the purposes of this study (Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Cornally et al., 2015; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015; Rietze et al., 2018). The perceived and/or real roles for nurses in ACP communication that were listed above will be discussed separately and explored further below.

Advocate

Several of the articles reviewed for this thesis study commented on the role of the nurse in ACP as being a patient advocate; one of the nurse's main roles in ACP is to respect, uphold, and defend their patients' preferences for EOL care (Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Ludwick et al., 2018; Nedjat-Haiem et al., 2016; O’Conner-Von & Bennett, 2020; Oliverio & Fraulo, 1998; Rietze & Stajduhar, 2015). A significant part of the nurse advocacy role involves the trust, confidence, and rapport that make up an effective nurse-patient relationship (Black, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Hebert et al., 2011; Ke et al., 2015; O’Conner-Von & Bennett, 2020). Briggs and Colvin (2002) asserted that nurses working in LTC with chronically and terminally ill patients “frequently develop consistent and trusting relationships that place them in unique positions to assist patients and families struggling with complex information and difficult decisions" inherent to ACP (p. 303). In other words, patients in LTC oftentimes may feel that they can be more candid and open with their direct-care nurses than with their physicians, social workers, or patient care managers because of the nature of the trust-based nurse-patient relationship (Black, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Hebert et al., 2011; Ke et al., 2015). Therefore, patients and families may find it comfortable to speak with a nurse that they feel they can confide in about their true wishes for EOL care through ACP discussions.

In an Australian study by Jeong et al. (2009), the researchers focused on the experiences of registered nurses working in residential care settings with ACP and ADs. A convenience sample of thirteen registered nurses working in three residential care sites was included in a qualitative case-study design involving semi-structured interviews. Thematic content analysis identified enhancing and inhibiting factors related to the nurses' (n = 13) experiences with ACP and ADs in their LTC practice. An ACP communication enhancing factor of note for nurses in this study was that ACP helped patients achieve autonomy that was grounded within their personal values and beliefs (Jeong et al., 2009). Therefore, from an advocacy standpoint, nurses in that study expressed that "ACP is person-centered and the roles of the RNs involve identifying who the person has been, drawing out the person's end-of-life care wishes, and ensuring their wishes are upheld" (Jeong et al., 2009, p. 169).

Achievement of this important advocacy role is predicated on nurses themselves being willing and able to lead thought-provoking conversations about ACP with patients and families. This is an area of a nurse's scope of practice that can be improved upon, especially in LTC settings where palliative and EOL care is more common. Nurses working in LTC are in a special, unique, and opportune position to discuss a patient's wishes for EOL care before a medical crisis befalls that patient (Black, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Hebert et al., 2011; Ke et al., 2015; Ludwick et al., 2018; Moore, 2005; Rietze & Stajduhar, 2015; Rietze et al., 2018). Essentially, having knowledge about a patient's wishes, values, and preferences for future medical care is paramount if nurses are to advocate on that patient's behalf at the EOL.

Team Member

A few of the reviewed journal articles stated that nurses are well-positioned in the role of ACP discussion initiator with the acute care or LTC patients that are in their care (Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Ke et al., 2015; Moore, 2005; O'Conner-Von & Bennett, 2020; Rietze & Stajduhar, 2015; Rietze et al., 2018). However, several articles stated that physicians are perceived to have the responsibility to initiate ACP conversations, while nurses and the other healthcare team members are expected to support and co-manage ACP discussions that the physicians have already had with patients and families (Arnett et al., 2017; Baughman et al., 2012; Flo et al., 2016; Hebert et al., 2011; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015; Rietze et al., 2018; van Soest-Poortvliet et al., 2015; Weiner & Cole, 2004). In general, the literature indicates that nurses view themselves as being a part of a multi-disciplinary patient care team that shares the responsibility of discussing ACP with patients and their families (Arnett et al., 2017; Black, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Cornally et al., 2015; Hebert et al., 2011; Ke et al., 2015; Nedjat-Haiem et al., 2016; O'Conner-Von & Bennett, 2020; Rietze et al., 2018). Therefore, nurses oftentimes view themselves as having parallel and/or complimentary roles to physicians and social workers when discussing ACP with patients and families in their care (Arnett et al., 2017; Black, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Cornally et al., 2015; Hebert et al., 2011; Ke et al., 2015; Nedjat-Haiem et al., 2016).

A recent American qualitative study was conducted by Nedjat-Haiem et al. (2016) to explore HCPs’ views regarding initiating EOL care communication. The researchers looked at what roles healthcare team members perceived themselves to have in ACP discussions with patients. The researchers used a stratified, purposive sampling method to recruit 79 healthcare team members from various clinical settings (i.e., oncology, primary care, palliative care, and intensive care). The sample of participants included physicians (n = 25), nurses (n = 23), social workers (n = 17), and chaplains (n = 14). An inductive thematic analysis of the 79 interviews was done and revealed that 22% of nurse participants felt that EOL discussions were completely their role, 65% of the nurses felt that initiating EOL discussions was only partially their role on the healthcare team, and 13% of the nurses interviewed stated that EOL communication was not a part of their role (Nedjat-Haiem et al., 2016). According to the researchers, the 65% of nurses that took on the partial role of initiating EOL communication saw their roles “mainly as clarifying information provided by doctors to the patients and their families while being supportive and comforting patients as they grapple with bad news” (Nedjat-Haiem et al., 2016, p.4).

Translator and Liaison

Another role that nurses often assume as a member of the healthcare team, and as a part of their patient care duties, is the role of being a translator and/or clarifier of information throughout ACP communication with patients and their families (Black, 2006; Hebert et al., 2011; Ke et al., 2015; Moore, 2005; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015; Schickendanz et al., 2009). During or after ACP discussions, patients and their families may have questions related to medical jargon, procedures, and what the expected trajectory of illness progression may look like for them. Oftentimes, patients and families have questions that pop up well after an official ACP discussion has occurred, and nurses are in the perfect professional position to answer their questions as needed. As nurses are in close contact with patients twenty-four hours a day, they can more conveniently clarify information for patients in a timely fashion during times of patient care (Black, 2006; Hebert et al., 2011; Ke et al., 2015; Moore, 2005; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015; Rietze et al., 2018).

The qualitative study mentioned above that was conducted by Nedjat-Haiem et al. (2016) found that the nurse participants (n = 23) emphasized that their role in EOL communication with patients was one where they “offered explanations of medical information, clarified treatment plans, provided psychosocial support, and involved other providers through referrals” (p. 4). However, a qualitative focus group study conducted by Baughman et al. (2012) showed that some healthcare team members are not necessarily comfortable with discussing medical options and prognoses with patients as a part of ACP. In that study, sixty-two LTC care managers (60% social workers and 40% registered nurses) were recruited to participate in focus groups that met for sixty minutes (Baughman et al., 2012). Descriptive and thematic analysis of the focus group discussions revealed that while one participant felt that it was her role to engage patients in conversations regarding medical treatments and options, “Most participants expressed discomfort in discussing prognosis and medical options with consumers” because of their lack of experience in doing so (Baughman et al., 2012, p.730). The researchers did not differentiate between the care managers’ social work or nursing backgrounds when presenting these results, but Baughman et al. (2012) indicated that participants in their study were more comfortable with their roles in encouraging patients and families to discuss medical issues with their physicians.

Nurses can also serve as liaisons between patients, their families, and the rest of the healthcare team (Black, 2006; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015; van Soest-Poortvliet et al., 2015). Information that nurses gather from patients and their families can be relayed as needed to physicians, social workers, and patient care managers, and vice versa. Therefore, nurses who possess good communication skills and are familiar with conducting ACP discussions can help to unify all of the people involved in a patient's palliative and/or EOL care situation through effective liaising activities (i.e., open, honest, and timely information sharing) (Black, 2006; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015; van Soest-Poortvliet et al., 2015). Furthermore, the role of acting as a liaison for all sides of the palliative and/or EOL situation can enhance the nurse's other role of being a patient advocate.

Educator and Facilitator

Some of the scholarly ACP communication literature notes that nurses have an ethical obligation to facilitate ACP with their patients, especially as part of the delivery of holistic and person-centered care (Black, 2006; Black & Emmet, 2006; CHPCA, 2012; CNA, 2017; Hebert et al., 2011; Jeong et al., 2009; Lenherr et al., 2012). Nurses oftentimes perceive themselves as educators and facilitators in the process of ACP with patients and families (Black, 2006; Black & Emmet, 2006; CHPCA, 2012; Flo et al., 2016; Hebert et al., 2011; Ke et al., 2015; Nedjat-Haiem et al., 2016; O'Conner-Von & Bennett, 2020; Rietze & Stajduhar, 2015). Nurses possess medical knowledge, and they know how their patients relate socially to the people around them; thus, nurses can gauge the type and the amount of education and guidance that the patient and their family may need when they are tackling the difficult questions that can arise during ACP discussions (Black, 2006; Black & Emmet, 2006; CHPCA, 2012; Flo et al., 2016; Hebert et al., 2011; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015).

ACP Communication Barriers

The literature is replete with many factors and/or barriers that can lead to a nurse not taking the lead in, or initiating, ACP conversations with patients and families in acute care and LTC settings. The barriers mentioned in the literature include: the nurse's age (e.g., being a younger nurse can be a barrier); years of overall nursing experience (e.g., nurses with less years of experience participate less in ACP); lack of time; nurses' workload, inconsistent practice patterns, and work environment; perceived poor timing of ACP discussions; lack of prior ACP education and/or experience; lack of ACP role models; nurses' personal fear/apprehension regarding death and dying; nurses' low confidence in participating in ACP discussions; nurses' personal and religious beliefs; nurses' inadequate communication skills (perceived or real); the reticence of patients/families to engage in ACP; nurses' lack of a therapeutic or trusting relationship with the patient and their family; fear of causing pain/anxiety in patients and families; nurses' working relationship or perceived role in the interdisciplinary healthcare team (e.g., as a "helper" or bystander rather than a leader in ACP); nurses' perceptions that the physician (who is seen generally as the leader of the healthcare team) is responsible for ACP discussions with patients; nurses' lack of knowledge regarding team roles; and nurses' lack of familiarity with the policies, procedures, required documentation, and legalities surrounding ACP (Baughman et al., 2012; Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014;CHPCA, 2012; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Moore, 2005; Nedjat-Haiem et al., 2016; Ottoboni et al., 2019; Rietze & Stajduhar, 2015). These barriers can all impact how, if, and when a nurse will discuss ACP with a patient. After a review of the literature was conducted, five overarching themes of barriers to nurses' engagement in ACP communication were identified. The five barrier themes were: education, knowledge, and skills deficit experienced by nurses; organizational supports and team roles; nurses' personal factors; the patient and their family; and other barriers. Each of the five themes of barriers to ACP communication will be explored further to illustrate what the literature is saying about each barrier theme grouping.

Education, Knowledge, and Skills Deficit

The literature on ACP communication cited several times that the lack of education, skills, and training related to ACP, palliative care, and EOL care in entry-level educational programs and in the workplace is a major barrier to nurses initiating ACP discussions with patients and families (Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Cornally et al., 2015; Hebert et al., 2011; Ke et al., 2015; Ottoboni et al., 2019; Weiner & Cole, 2004; Yokoya et al., 2018). In their descriptive article about nurses' roles in EOL communication, Briggs and Colvin (2002) found that nurses generally report that ACP and EOL care education in nursing school curricula and in practice settings is suboptimal in both quantity and quality. Hebert et al. (2011) claimed in their descriptive article that "nurses can articulate the benefits of advance directives; however, nurses generally lack the knowledge and training to conduct such discussions" (p. 325). Weiner and Cole (2004) pointed out in their descriptive article about EOL discussions that clinicians need to be given focused instruction on conducting discussions that deal with shared decision-making (i.e., ACP discussions). Conversations about ACP can be difficult, and if nurses are not given the proper tools to initiate and carry out these discussions, they may miss opportunities to help patients and families sift through potentially overwhelming

ACP information (Baron et al., 2015; Briggs & Colvin, 2002; CHPCA, 2012; Hebert et al., 2011; Moore, 2005; Rietze & Stajduhar, 2015; Weiner & Cole, 2004).

In addition to learning about specific ACP communication activities, nurses need more education related to the general policies, procedures, required documentation, and legalities surrounding ACP at their workplaces (Baughman et al., 2012; CHPCA, 2012; Flo et al., 2016; Jeong et al., 2009; Ke et al., 2015; Rietze & Stajduhar, 2015). Nurses need to know the scope and limitations of their role in ACP by increasing their familiarity with the formal side of the process at their place of employment. In other words, nurses must be prepared to do their due diligence and research any ACP policies and documentation requirements pertaining to their acute care or LTC work setting. For instance, in the focus group study that Baughman et al. (2012) conducted with LTC care manager participants (n = 62), where 60% of the care managers were social workers (n = 37) and 40% of the care managers were registered nurses (n = 25), several participants (the exact number of participants was not specified by the authors of this study) stated that they needed more information about, as well as training related to, the legal system's impact on ACP discussions and proper ACP documentation. These participants' lack of knowledge regarding the legal documentation of ACP discussions in their workplace created a barrier to their participation in ACP discussions (Baughman et al., 2012).

Organizational Supports

Perceived suboptimal organizational supports, such as ill-defined ACP policies and procedures, inconsistent organizational definitions of ACP, and a lack of ACP role models were cited in the literature as barriers to nurses' ACP communication with patients and their families (Baughman et al., 2015; Beck et al., 2016; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012, 2020; Flo et al., 2016; Hebert et al., 2011; Ke et al., 2015; Rietze & Stajduhar, 2015). Unclear ACP policies were mentioned in the results of an American mixed-methods (quantitative and qualitative) study by Arnett et al. (2017). The researchers wanted to better understand the clinical routines and experiences of healthcare team members with ACP in a variety of healthcare settings (Arnett et al., 2017). A thirty-five-question survey, including three open-ended questions, was filled out by physicians (n = 62), advanced practice nurses (n = 21), nurses (n = 13), and other team members (n = 22). Under questions related to policies, workflow processes and clinical routines, more than half of all of the study's participants (62%) "did not have, or did not know if they had, guidelines or policies about when to review ACP documentation with patients" (Arnett et al., 2017, p. 949).

Fortunately, the CHPCA (2012) developed an ACP national framework that included sections on engagement and education of HCPs, as well as a section highlighting the importance of setting up system infrastructure to enable successful implementation of ACP programs across Canada. In 2020 the CHPCA released a newer pan-Canadian framework for ACP document that re-imagined and reframed the four basic building blocks from the 2012 ACP national framework as interconnected strands of activities that, when woven together, have the potential to normalize, support and promote ACP in Canada (CHPCA, 2020). This second ACP framework was put forth to try and provide different regions across Canada with an ACP document that can "help bridge the differences between jurisdictions by identifying a common vision, goals, guiding principles and strategies" (CHPCA, 2020, p. 6). However, each province and possibly individual health regions are in charge of developing and maintaining their own ACP programs. Moreover, if these provincial ACP programs are not aware of the newer pan-Canadian framework, it may lead to ACP definition and program confusion among individual acute care and LTC facilities across the country. For example, if each individual LTC facility in the province were to have their own ACP program that did not follow a common, agreed-upon framework or model, it would be difficult for nurses (especially novice nurses) to ascertain what their professional obligations are in ACP discussions when moving between healthcare facilities (Briggs & Colvin, 2002; CHPCA, 2012, 2020; Cornally et al., 2015; Hebert et al., 2011; Ke et al., 2015; Rietze & Stajduhar, 2015).

Role Confusion

According to the literature, nurses may also struggle with issues related to scope of practice and role definition whilst working in a multi-disciplinary environment, especially when considering what their specific nursing role is in ACP discussions (Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Hebert et al., 2011; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015). Role confusion can occur when nurses lack knowledge pertaining to specific healthcare team roles in ACP (Brooke & Kirk, 2014; CHPCA, 2012; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015). For instance, nurses may not know what the social worker's role may be in ACP discussions because of the real or perceived overlap of both roles within the ACP process (Black, 2006; CHPCA, 2012; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015).

Physician as Barrier

Interestingly, physicians themselves are sometimes the barriers that nurses come up against when trying to engage patients in ACP in an autonomous way (CHPCA, 2012; Cornally et al., 2015; Flo et al., 2016; Hebert et al, 2011; Ke et al., 2015; Lenherr et al., 2012; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015; Weiner & Cole, 2004). A recent American quantitative study conducted by Arnett et al. (2017) used an online cross-sectional questionnaire to survey healthcare team members (n = 118) about their ACP practices. Of the 118 participants, 11% were nurses (n = 13) working in a variety of healthcare settings from acute care to LTC (Arnett et al., 2017). According to Arnett et al. (2017), 31 % of nurse participants reported that they had met directly with patients and families to discuss ACP, versus 48% of nurse participants who reported that they did not initiate ACP with patients and only assisted the physician with aspects of the ACP process. Arnett et al. (2017) also found that 71% of all participants responded that physicians are responsible for conducting ACP discussions with patients and their families. In an integrative review of nine studies related to nurses’ involvement in ACP communication, Rietze and Stajduhar (2015) found that nurses “perceived that they need to gain permission from the patient's physician to engage in ACP and that physicians were reluctant to endorse nurse-initiated ACP" (p. 500). The reality is that sometimes nurses perceive that their patient advocacy role is not as important as the physician’s role in ACP discussions (Flo et al., 2016; Hebert et al, 2011; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015).

Lack of Mentorship

The real or perceived lack of role definition in ACP among healthcare team members can also lead to a lack of role models who can mentor fellow nurses in ACP communication, which is a troubling trend in nursing (Baron et al., 2015; Black & Emmet, 2006; Briggs & Colvin, 2002; CHPCA, 2012; Cornally et al., 2015; Ke et al., 2015). The literature posits that ACP education and training programs should lead to the development of peer mentoring programs for ACP; therefore, nurses with more ACP education, training, and experience would be able to teach ACP essentials to other nurses and role model ACP communication techniques for less experienced nurses (Baron et al., 2015; Black & Emmet, 2006; CHPCA, 2012; Cornally et al., 2015; Ke et al., 2015; Rietze & Stajduhar, 2015). In fact, Rietze and Stajduhar (2015) identified in their integrative review of ACP literature that "nurses' confidence in ACP communication increased with additional educational preparation and mentoring" (p. 501). Black and Emmet (2006) suggested in their study that it is essential to have more seasoned nurses with experience in ACP communication mentoring nurses with less experience, in an effort to build up their colleagues' confidence in this area. The CHPCA national/pan-Canadian frameworks for ACP recommend putting policies, core competencies, and ACP champions into practice when developing ACP programs (CHPCA, 2012, 2020); therefore, more workplace emphasis needs to be placed on encouraging more experienced nurses to take on those pivotal mentorship roles with respect to ACP communication.

Lack of Time

Also cited as an organizational barrier to nurse-led ACP communication in the literature was the sheer lack of time that nurses have to spend with patients and families to discuss ACP in a meaningful and in-depth way (Black, 2006; Brooke & Kirk, 2014; Cornally et al., 2015; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Moore, 2005; Nedjat-Haiem et al., 2016; Ottoboni et al., 2019; Rietze & Stajduhar, 2015; Weiner & Cole, 2004). In a qualitative case study conducted by Jeong et al. (2009) with LTC RN participants (n = 13), "lack of time" was cited as an inhibiting factor in ACP discussions (p. 170). The nurses in that study explained that time was needed to have a proper and in-depth ACP discussion with patients and their families in order to better elicit the patient's values and wishes in a non-rushed manner (Jeong et al., 2009).

In a recent qualitative study conducted by O'Conner-Von and Bennett (2020), focus groups were held with fourteen LTC nurses (RNs) at two LTC settings to explore these nurses' EOL care communication strategies with patients and families in their care. Interestingly, O'Conner-Von and Bennett (2020) used the phrase "EOL care communication" throughout their study to refer to communication that this particular sample of LTC nurses engaged in to ascertain their patients' EOL care goals and preferences. Others might refer to this kind of "EOL care communication" as ACP communication. These researchers found that their sample of LTC nurses (n = 14) felt that time was important in building trusting nurse-patient relationships, assessing their patients' EOL care needs, providing EOL care education to patients and families, and fostering EOL communication and collaboration with patients, families, and colleagues in their LTC settings (O'Conner-Von & Bennett, 2020). Therefore, researchers in this more recent qualitative study found that time is still a factor in determining if effective nurse-led ACP communication can and will occur in LTC settings (O'Conner-Von & Bennett, 2020).

Furthermore, the current healthcare landscape is full of instances of nurses being overworked. Heavy workloads, inconsistent practice patterns, and higher acuity within patient assignments are barriers to nurses being able to find time in their shifts to engage patients and their families in ACP discussions in a thoughtful way (Black, 2006; CHPCA, 2012, 2020; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015; Weiner & Cole, 2004). The CHPCA (2012) agrees that issues involving staffing levels and allowing staff to have adequate time to conduct ACP discussions are challenges that must be addressed at an infrastructure level. Addressing these work environment issues at an organizational level can lead to ensuring more success in ACP communication between nurses and patients on a front-line level (CHPCA, 2012, 2020; Ke et al., 2015; Rietze & Stajduhar, 2015).

Personal Factors

Quite often, nurses are skilled at projecting strength and maintaining their composure in difficult patient care situations, including palliative and/or EOL care scenarios. But nurses are also individuals who have their own set of values, beliefs, feelings, and experiences that may influence how they view ACP on the job. Some personal factors that were cited in the literature as being potential barriers to ACP and EOL communication include: the nurse having low confidence in conducting ACP discussions; feeling confronted with one’s own mortality; nurses’ personal fears/apprehensions regarding death and dying; failure to recognize one’s own emotional responses to dying patients (e.g., anxiety, denial, sadness, frustration/anger, helplessness, shame, guilt); nurses’ personal religious beliefs; and nurses’ failure to recognize the stages of grief during ACP discussions with patients and their families (Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2011; Moore, 2005; Ottoboni et al., 2019; Rietze & Stajduhar, 2015; Weiner & Cole, 2004).

For example, Jeong et al. (2009) developed a conceptual framework that depicted phases of emotions that were experienced by the nurse participants (n = 13) in their study as the nurses worked through ACP with patients. The nurses in that qualitative case study used words like “discomfort, sad, difficult, awful, cruel, confronting and resentful” to express emotions that they felt in anticipation of helping patients and families through ACP discussions in what the researchers called the “pre-transition phase” (Jeong et al., 2009, p. 168). These researchers identified that the nurses in their study were hesitant and emotionally conflicted in the “pre-transitional phase of taking part in ACP”, and that these nurses needed certain “enhancing factors” to exist or occur in order to make a transition that would help get them past their own negative feelings towards ACP communication (Jeong et al., 2009, p. 169). After a transition period that was influenced by a group of ACP communication facilitators (e.g., HCP/family agreement, promoting patient dignity and comfort, and supporting patient autonomy), these nurses were able to accept ACP as a positive activity for patients and families within their LTC setting (Jeong et al., 2009, p. 169).

Emotional Self-Awareness

A nurse's confidence in conducting ACP discussions can be linked to sufficient ACP education and experience, as well as emotional awareness (Baron et al., 2015; Briggs & Colvin, 2002; CHPCA, 2012; Cornally et al., 2015; Flo et al., 2016; Hebert et al., 2011; Ke et al., 2015; Moore, 2005; Rietze & Stajduhar, 2015; Weiner & Cole, 2004). Moore (2005) proposes that nurses need to become more self-aware in terms of their own personal feelings (and their own coping strategies) related to death, dying, and grief. However, Weiner and Cole (2004) state that "emotional self-awareness does not lead, invariably, to [the] emotional self-regulation" that is needed to carry out difficult ACP and EOL discussions with patients (p. 819). Weiner and Cole (2004) went so far as to suggest a conceptual approach to dealing with clinicians' emotional barriers during ACP and EOL discussions. Their approach included training programs directed at personal distress management, highlighting cognitive behavioral principles to minimize professionals' negative beliefs, and educational emphasis on HCPs practicing their ACP discussion skills before helping patients and families make EOL decisions (Weiner & Cole, 2004).

Religious and Professional Beliefs

Personal emotions and feelings aside, the literature also points to nurses' religious beliefs and professional expectations as possible barriers to initiating ACP discussions with their patients. If nurses believe that they must do everything in their power and ability to keep their patients alive, or that when a person dies it is God's will/plan, the likelihood that these nurses will approach their patients to discuss ACP is small (Jeong et al., 2009; Lenherr et al., 2012).

For example, nurses who believe that nature will always take its course, and that a patient's EOL and death experience is out of their hands, will most likely not be proactive in engaging in ACP activities (Jeong et al., 2009; Lenherr et al., 2012).

The Patient and Their Family

Nurses are in an advantageous position to develop good rapport and close relationships with patients and their families, so it may be challenging for nurses to engage in potentially distressful discourse with them. The literature suggests that oftentimes nurses struggle with the fear of causing patients and their families psychological harm, pain, and anxiety by bringing up EOL topics/issues that are difficult to discuss as part of ACP (Brooke & Kirk, 2014; Jeong et al., 2009; Moore, 2005; Ottoboni et al., 2019; Rietze & Stajduhar, 2015; Weiner & Cole, 2004). Furthermore, nurses do not want to decrease the patient's and family's sense of hope, even if the patient's medical situation is such that palliative and/or EOL care is the more appropriate type of care for the patient (Jeong et al., 2009; Lenherr et al., 2012; Moore, 2005; Ottoboni et al., 2019; Rietze & Stajduhar, 2015; Weiner & Cole, 2004).

Real or perceived patient and/or family reluctance to participate in ACP discussions is also a common communication barrier that is featured in the literature (Black, 2006; Brooke & Kirk, 2014; CHPCA, 2012; Cornally et al., 2015; Flo et al., 2016; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Moore, 2005; Ottoboni et al., 2019; Rietze & Stajduhar, 2015; Sudore & Fried, 2010). Although nurses are skilled at forming relationships with patients and their families, not every relationship is a good one. Some patients and families are easier to talk to, and with, than others; in fact, family dynamics can impact ACP greatly, both positively and negatively (Cornally et al., 2015; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Moore, 2005; Rietze & Stajduhar, 2015; Sudore & Fried, 2010). Hence, the process of ACP can only be initiated, and go forward to be effective and successful, if the patient and their family are willing to engage in ACP discussions with nurses and the healthcare team.

Other Barriers

There were several "other barriers" that were mentioned less often or to a lesser degree in the literature as having an impact on ACP communication. Nonetheless, these other barriers warrant some discussion because they may be important barriers in certain acute care and LTC settings. In particular, the nurse's age, years of experience, personal experiences with ACP, perceived poor timing of ACP discussions, and cultural competence were cited as barriers to ACP communication (Black, 2006; Black & Emmet, 2006; Brooke & Kirk, 2014; Cornally et al., 2015; Flo et al., 2016; Hebert et al., 2011; Ke et al., 2015; Lenherr et al., 2012; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015; van Soest-Poortvliet et al., 2015).

Age and Experience. A descriptive quantitative study was conducted by Black and Emmet (2006) to investigate the ACP communication practices of nurse participants (n = 74) working with geriatric patients on acute cardiology and respiratory units. The researchers used the Advance Directive Communication Practices Instrument (ADCPI), a thirty-nine-item self-administered questionnaire which had a high internal consistency (α = .80 to .98), to find correlations between age, experience, and ACP communication habits (Black & Emmet, 2006). According to Black and Emmet (2006), nurses who were older and/or had more years of nursing experience were generally more willing than younger, less experienced nurses to engage in ACP discussions with patients and families. Black and Emmet (2006) also found that nurses who have had personal experiences with ACP (i.e., being a substitute decision-maker for a loved one) "reported eliciting patient values less frequently than nurses without the experience" (p. 226). The process of ACP is based on identifying patients' values and wishes; therefore, it was curious to learn from this particular study that even nurses who have had personal experiences with ACP may choose not to prompt patients to express their own EOL preferences (Black & Emmet, 2006).

Timing of ACP. The perceived poor timing of ACP discussions can also be a deterrent for nurses to engage in ACP in palliative and/or EOL care situations (Brooke & Kirk, 2014; Cornally et al., 2015; Ke et al., 2015; Lenherr et al., 2012; Nedjat-Haiem et al., 2016; van Soest-Poortvliet et al., 2015). A few studies noted that caring for patients with certain diseases/conditions that lead to a patient's diminished capacity for informed decision-making and/or diminished capacity for communication (i.e., dementia) in LTC settings can make the proper timing of ACP discussions awkward and difficult (Brooke & Kirk, 2014; Cornally et al., 2015; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Ottoboni et al., 2019; van Soest-Poortvliet et al., 2015). In fact, Brooke and Kirk (2014) asserted in their descriptive article that "health professionals still lack the skills and knowledge to initiate ACP at an appropriate time prior to cognitive decline with patients with dementia and their family members" (p. 495).

Cultural Competence. Another interesting barrier that was discussed briefly in some of the literature pertaining to ACP communication was cultural competence. A language barrier is the more obvious communication barrier, but a culture that views discussions about death and dying as a cultural taboo will also make it difficult for certain patients to engage in ACP with the healthcare team (Baughman et al., 2012; Johnstone & Kanitsaki, 2009; Ke et al., 2015; Lenherr et al., 2012). Hebert et al. (2011) emphasized that “as patient advocates, nurses must ensure that patients and families of all ethnicities experience death with dignity” (p. 327). This focus on culture's impact on EOL care is important for nurses to keep in mind as a potential barrier to ACP communication, especially with culturally diverse populations (Flo et al., 2016; Hebert et al., 2011; Johnstone & Kanitsaki, 2009; Ke et al., 2015; Yokoya et al., 2018). Death and dying and healthcare in general are experienced and valued differently in different cultures; thus, nurses are expected to be culturally sensitive in delivering EOL care and in discussing ACP with patients and their families (Flo et al., 2016; Hebert et al., 2011; Johnstone & Kanitsaki, 2009; Ke et al., 2015; Yokoya et al., 2018).

ACP Communication Facilitators

The literature that was reviewed for this MN thesis study largely discussed the barriers associated with nurses' ACP communication with patients and families in acute care and LTC settings, but some facilitators of ACP communication were also highlighted. Consequently, most of the facilitators that were mentioned in the literature are direct opposites and/or remedies for the barriers that were discussed earlier in this literature review chapter. It is however important to note that quite a few of the ACP articles delineated between barriers and facilitators to ACP communication.

Change in Healthcare Culture

Some of the healthcare culture, work environment, and administrative recommendations for change that were made in the literature included hospital and/or LTC management support for ACP; clarification of healthcare team roles in ACP; and devising comprehensive and user-friendly ACP tools, policies, procedures, and documentation (Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012, 2020; Cornally et al., 2015; Counsell, 2015; Flo et al., 2016; Hebert et al., 2011; Ke et al., 2015; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015). According to the literature, these are all ways in which the healthcare system at large can help to improve ACP initiation, facilitation, and practice by nurses working in acute care and LTC settings. Additionally, a healthcare culture and work environment that promotes preference-based care will be more inclined to respect the autonomy that a patient can potentially achieve through ACP communication (Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Cornally et al., 2015; Counsell, 2015; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Ottoboni et al., 2019; Rietze & Stajduhar, 2015; van Soest-Poortvliet et al., 2015). In particular, an institutional mandate to engage in ACP discussions and to complete ACP documentation with patients and families would certainly increase the initiation and completion rates for ACP; however, the nature and quality of those ACP discussions would be difficult to measure just by considering the rates of ACP document completion (Baron et al., 2015; Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; CHPCA, 2012, 2020; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Moore, 2005; Rietze & Stajduhar, 2015; Teno et al., 1997; van Soest-Poortvliet et al., 2015). Nurses were also cited in the literature as saying that encouragement, enthusiasm, and support from direct and senior management were facilitators to improving ACP discussions with patients and their families (Flo et al., 2016; Ke et al., 2015).

An example of a positive change in the healthcare culture surrounding ACP communication with patients in LTC is the study conducted by Cornally et al. (2015). The researchers qualitatively evaluated the implementation of an ACP program called "Let Me Decide" in three LTC facilities in Southern Ireland by conducting focus groups with Clinical nurse managers (n = 15) and directors of nursing (n = 2) (Cornally et al., 2015). Content analysis of the data revealed that one of the ACP communication facilitators or benefits identified by the participants was a distinct change in the care culture seen in the LTC settings where the ACP program was introduced; in fact, the study participants indicated that the ACP program resulted in a more “composed care environment”, the promotion of “multi-disciplinary awareness” of ACP, and the enhancement of nursing “practice and profession” (Cornally et al., 2015, p. 5).

ACP Education

The most cited facilitator for ACP communication that was seen in the literature reviewed for this study was an effective ACP education program for nurses (Baron et al., 2015; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012, 2020; Cornally et al., 2015; Flo et al., 2016; Hebert et al., 2011; Ke et al., 2015; Lenherr et al., 2012; Ludwick et al., 2018; Ottoboni et al., 2019; Rietze & Stajduhar, 2015; Weiner & Cole, 2004; Yokoya et al., 2018). A recent English study by Baron et al. (2015), wherein the researchers used three longitudinal questionnaires to evaluate an ACP education program, identified that HCPs (including nurses) should be "appropriately trained, with sufficient knowledge and skills to engage in a meaningful process" of ACP discussions (p. 693). Baron et al. (2015) assessed staff knowledge of ACP, ACP practice, and the number of hospital deaths of nursing home residents before and after an ACP education program was introduced. Analysis of responses to questionnaires (n = 265) received from staff (78% health care assistants, 12% nurses, 4% managers, and less than 1% ‘other’) at twenty nursing homes revealed that the ACP education program increased the staff’s ACP knowledge, increased ACP completion in residents’ charts by 85%, and reduced resident hospital deaths by 25% (Baron et al., 2015). Therefore, in combination with such facilitators as dynamic and inclusive multi-disciplinary teamwork, systematic support of clinical ACP routines, and role-modelling of appropriate ACP practice, an ACP education program can encourage more nurses to take on the advocacy, educator, translator, and liaison jobs that are inherently part of the nurse's role in ACP (Baron et al., 2015; Black & Emmet, 2006; Briggs & Colvin, 2002;

Brooke & Kirk, 2014; CHPCA, 2012, 2020; Cornally et al., 2015; Ke et al., 2015; Hebert et al., 2011; Nedjat-Haiem et al., 2016; Rietze & Stajduhar, 2015).

Summary of the Literature Review

ACP is a process of discussion that allows patients to make decisions regarding their wishes for future EOL care; thus, ACP is an important process that can enable healthcare teams to honor a patient's autonomy and values (O’Conner-Von & Bennett, 2020). Current ACP literature illustrates that a disconnect still exists between nurses' beliefs that ACP is an important and valuable aspect of healthcare, and nurses' actual participation in ACP discussions with patients and their families in acute care and LTC settings (Black, 2006; Black & Emmet, 2006; Briggs & Colvin, 2002; Brooke & Kirk, 2014; CHPCA, 2012; Cornally et al., 2015; Flo et al., 2016; Hebert et al., 2011; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012; Moore, 2005; Rietze & Stajduhar, 2015; van Soest-Poortvliet et al., 2015; Weiner & Cole, 2004; Yokoya et al., 2018). A review of the literature helped to describe the current state of nurses' ACP communication, nurses' perceptions of their role in ACP, and the barriers and facilitators to ACP communication in nursing practice.

It is noteworthy to emphasize that only twenty-five of the total forty-one journal articles that were reviewed for this MN thesis study were quantitative, qualitative, or mixed-methods studies about ACP communication. Of those twenty-five studies, only eight studies sampled nurses exclusively for their research; moreover, of those eight studies, three studies featured nurse managers working in LTC settings (Beck et al., 2016; Cornally et al., 2015; Yokoya et al., 2018), one study focused on direct care nurses’ ACP communication practices in acute geriatric medicine settings (Black & Emmet, 2006), one study surveyed nurses working in both acute and non-acute settings (including LTC) (Rietze et al., 2018), and only three studies sampled direct care nurses working in LTC settings (Jeong et al., 2009; Ludwick et al., 2018; O'Conner-Von & Bennett, 2020). This review of the literature showed that there are very few ACP research studies done in LTC settings; in fact, the majority of ACP research has been done in acute, emergency department, or intensive care units. Additionally, the literature reviewed for this study also highlighted the lack of studies that have been done from the perspective of nurses in general, especially LTC nurses.

In summary, a knowledge gap existed in the ACP scholarly literature and in nursing communication practices with regards to ACP in LTC settings. Studies such as this MN thesis that strive to achieve a more in-depth understanding of the ACP challenges and successes that LTC nurses are encountering in their nursing practice are of great importance, especially as more and more patients are admitted to LTC facilities around the world. As mentioned earlier in this study, helping patients and families to make ACP decisions through the sharing of clear, honest, and up-to-date information is part of a nurse's professional and ethical responsibilities (Black, 2006; Black & Emmet, 2006; CHPCA, 2012; CNA, 2017; Hebert et al., 2011; Jeong et al., 2009; Lenherr et al., 2012). Ultimately, this literature review pointed to the need for more ACP research that focused on nurses' ACP communication practices with patients and families in LTC settings.

Chapter 3: Research Approach and Methods

Qualitative studies can afford researchers the opportunity to interpret, describe, understand, and generate knowledge about lived human experiences (Petty et al., 2012). The qualitative research approach that was used for this study is interpretive description, developed by Dr. Sally Thorne. According to Thorne et al. (1997), interpretive description "involves description of and interpretation about a shared health or illness phenomenon from the perspective of those who live it" (p. 171). Thorne (2006) goes on to say that “interpretive description seeks access to an important kind of knowledge about human subjective experience” (p. 221). In other words, the qualitative research method of interpretive description allowed me as the principal investigator to use a rigorous process to interpret data and describe themes that emerged from nurses' own words, via one-on-one interviews that were conducted with fifteen LTC nurses (RNs and LPNs) about their ACP communication practices with patients and families.

Interpretive description was developed by Dr. Sally Thorne as a qualitative research method starting in the early 1990s, culminating in the publishing of her book *Interpretive Description* in 2008 and subsequently the second edition of her book entitled *Interpretive Description: Qualitative Research for Applied Practice* in 2016. Her intention was to offer researchers in clinical and applied fields of work and study (e.g., healthcare, social service, education, mental health), including nursing, an alternative qualitative research method that seeks to describe people’s experiences with phenomena from their individualized contextual perspectives (Polit & Beck, 2012; St. George, 2010; Thorne, 2008, 2016). Qualitative methods like grounded theory, phenomenology, and ethnography do not necessarily meet the needs of researchers in applied disciplines who seek to answer research questions that lend themselves to a more pragmatic, contextualized, evidence-based practice sensibility (Thorne, 2006, 2008, 2016; Thorne et al., 1997). Thorne (2016) states that interpretive description as a qualitative method is not “a prescriptive, circumscribed sequence of steps” (p. 38). However, the use of interpretive description as an approach to studying, describing, and interpreting participants’ experiences with specific clinical practice issues (such as LTC nurses’ perceptions of ACP communication) offers the researcher a method of generating qualitative scholarly evidence that can potentially be used to guide and shape future nursing practice (Polit & Beck, 2012; St. George, 2010; Thorne, 2016; Thorne et al., 1997). The research questions that this qualitative study aimed to answer were:

1. What are LTC nurses' experiences with ACP communication in their practice?
2. What are LTC nurses’ perceptions (e.g., thoughts, feelings, opinions) of their roles in ACP communication with patients and families?
3. What do LTC nurses see as barriers and/or facilitators to ACP communication with patients and families in their practice settings?

In this research methods section, the setting of the study and the sample of participants are described in more detail. Furthermore, the data collection and data analysis work for this thesis are described. Additionally, ethical considerations for this study are specified and examined. Lastly, the overall research plans, goals, and merits of this study are summarized.

Setting and Sample

The focus of this study was on nurses (RNs and LPNs) working in settings such as LTC facilities, and units that identify as LTC units within a community hospital in the health regions of the province of Manitoba, Canada. The setting for this study was rather broad in an effort to include as many diverse LTC settings across the province as possible in the sampling process.

The idea was that the diversity of LTC settings would give rise to diversity in LTC nurses and LTC patient populations, which may have added to the complexity, uniqueness, and richness of any data that were collected for this study (Polit & Beck, 2012; Thorne, 2016). For example, a nurse that lives in Winnipeg may work in an LTC facility that is found in a Manitoba health region outside of the WRHA. The inclusion of Winnipeg-based nurse participants who work in LTC situations outside of the WRHA had the potential to add a different perspective to the topic of nurses' ACP communication with patients and families in LTC settings.

A convenience sampling method was used, which involved the "selection of the most readily available persons as participants in a study" (Polit & Beck, 2012, p. 724). A convenience sample is sometimes referred to as a "volunteer sample" because potential study participants are recruited via means that call for the individual to contact the researcher and identify themselves voluntarily (e.g., recruitment via a poster, email, newspaper advertisement, etc.) (Polit & Beck, 2012, p. 516). Convenience sampling can be an efficient and appropriate sampling approach when a researcher is recruiting participants who have insights, experiences, or knowledge related to a specific phenomenon within a distinct clinical setting (Polit & Beck, 2012; Thorne, 2016). The proposed sample size for this study was between ten to twenty (10-20) LTC nurse participants. The actual sample size for this study was fifteen (n = 15) LTC nurse participants.

This study focused on the population of nurses (RNs and LPNs) employed by the health regions of the province of Manitoba, Canada who self-identified as currently working in LTC settings. The College of Registered Nurses of Manitoba (CRNM) and the College of Licensed Practical Nurses of Manitoba (CLPNM) were asked to assist in identifying and contacting nurses who fit the inclusion criteria (see Appendix A and Appendix B). Nurses (RNs and LPNs, including direct-care nurses and nurses working in LTC unit management, education, and clinical nurse specialist [CNS] roles) working in full-time, part-time, and/or casual positions on LTC units within Manitoba were included in the study. Exclusion criteria for potential participants in this study were as follows:

- nurses working on any patient care units that are not identified as LTC units; and
- graduate nurses, agency nurses, and student nurses (i.e., nurses who may not be familiar with LTC patients/families, and/or with the LTC facility/unit, and/or with the ACP policies and procedures used in the facility and/or province of Manitoba in general).

As stated above, the CRNM and CLPNM were contacted to help recruit participants for this study. Recruitment was accomplished via two separate emails (sent approximately one month apart) that were sent to potential study participants who were members of either the CRNM or the CLPNM and met the inclusion criteria (see Appendix C and Appendix D). The recruitment emails laid out the particulars of the study, and what was expected of each participant during the course of the study. The emails invited potentially eligible LTC nurses to contact the principal investigator if they were interested to find out more about participating in the study. To assist in the process of obtaining informed consent from eligible participants, information about this study (i.e., the role of the researcher, the role of study participants, the potential time commitment, the nature of the interview questions, how participant confidentiality would be preserved, and how data would be confidentially protected and destroyed) was provided in recruitment email messages and informed consent forms (ICFs) that were sent to nurses who self-identified as LTC nurses in their registration with the CRNM or the CLPNM (see Appendix C, Appendix D, and Appendix E). Participation in this qualitative study was voluntary.

Data Collection

Ethics protocol approval was obtained from the Education/Nursing Research Ethics Board (ENREB) on January 20, 2020 for this study (see Appendix F). The CRNM and CLPNM were both contacted via email shortly thereafter to ask for their assistance with sending participant recruitment emails on my behalf to potential LTC nurses on their current registers (see Appendix A and Appendix B). Recruitment was delayed slightly as the COVID-19 pandemic started to unfold in Canada because staff at both the CRNM and CLPNM were relocating their individual workspaces to their homes. The CRNM was able to narrow down their membership list to a more targeted list of 870 self-identified LTC RNs as a potential sample. Of the 870 LTC RNs that received the recruitment emails on May 14 and June 12, 2020 twelve nurses contacted me and were eligible and consented to participate in this study. The CLPNM sent the two recruitment emails to all of their members, a sample of 3694 total LPN members. Of the 3694 LPNs that received the recruitment emails on March 13 and April 21, 2020 only three LTC LPNs participated in this study. As a result of the CLPNM not being able to target only LTC LPNs on their register, an amendment request was sent to ENREB to account for this change in protocol. The amendment request was approved by ENREB on March 3, 2020 to send the recruitment emails to all of the CLPNM members instead of a targeted list of LTC LPNs (see Appendix G). Moreover, due to the length of time that participant recruitment, data collection, and data analysis took in 2020 (i.e., because of COVID-19), a protocol renewal request was sent to ENREB and approved/granted on January 11, 2021 (see Appendix H).

Furthermore, due to provincial and University of Manitoba COVID-19 precautions starting in March 2020 and continuing through all of the data collection period, all participant correspondence was done via email, and all participant interviews were conducted over the telephone by me as the principal investigator. Telephone interviews were an existing option on the ICF for this study, so no changes were made to the ICF that was sent to participants (see Appendix E). Informed consent was obtained from eligible study participants using emailed and electronically/digitally signed consent forms. Interviews were scheduled individually with participants through email correspondence to adhere to COVID-19 research protocols/policies.

Data collection officially commenced at the end of April 2020 with the first telephone interview, and data collection concluded at the end of June 2020 with the fifteenth and final telephone interview. For this qualitative interpretive description study, data were collected by conducting one-on-one interviews with individual LTC nurse participants (Polit & Beck, 2012; Ryan et al., 2009; Thorne, 2016). Individual participants were interviewed by the researcher in interviews that lasted between 34 minutes (the shortest) to 1 hour and 51 minutes (the longest), or an average interview time of 55 minutes per participant. Participants were also made aware that if any questions arose in the review and analysis of the transcripts, or if clarification of their comments was needed, a second interview of shorter duration (e.g., 30 minutes) would have been requested. However, this type of second, shorter interview was not needed, nor conducted, with any of the fifteen LTC nurse participants.

The interview guide (see Appendix I) consisted of semi-structured, open-ended questions that had the potential to elicit meaningful and detailed responses from each eligible LTC nurse participant (Polit & Beck, 2012; Ryan et al., 2009; Sandelowski, 2000; Thorne, 2016). All interviews were audio recorded, transcribed verbatim, and coded line-by-line by me as the principal investigator. Transcription and coding of the interviews was done after each participant interview was completed. Moreover, a reflective journal was kept by me as the principal investigator to keep track of any personal memos related to thoughts, ideas, feelings, impressions, and contexts that may have informed the analysis of the data that were collected during the study (Braun & Clarke, 2006; Creswell, 1998; Munhall, 2012; Polit & Beck, 2012; Seers, 2012; Thorne, 2008, 2016).

In particular, the interview guide questions (see Appendix I) were shaped and influenced by the Canadian ACP national framework from 2012, which offered a basis for the development and use of current ACP policies and procedures across the country (CHPCA, 2012). The national framework for ACP was developed to provide recommendations and give "guidance to how we would operationalize advance care planning in a defined healthcare system" within Canada (CHPCA, 2012, p. 1). That particular framework for ACP in Canada put the patient/family at the center of an ACP model, with "four basic building blocks" encircling the patient/family (CHPCA, 2012, p. 11). The four blocks that worked together to lead to effective ACP communication were: "engagement; education; system infrastructure; and continuous quality improvement" (CHPCA, 2012, p.11). As such, the interview guide that was used for this study included questions that attempted to ascertain the level of ACP policy and procedure awareness and/or education that the LTC nurse participants had been exposed to in their nursing practice. The interview guide questions for this study were not based on the pan-Canadian ACP framework that was put out by the CHPCA in 2020, as the interview guide had already been written and approved by my MN thesis committee and by ENREB before the newer ACP framework was available.

The data collected from eligible study participants during the interviews, including demographic information (see Appendix J and Tables 6 and 7) and answers to interview questions, have been and will be secured in password-protected computers; also, identifying information (i.e., names of participants and names of LTC settings) was removed from any data to maintain confidentiality. Furthermore, each of the fifteen participants were given a random participant identification number (PID) to be able to keep track of the data collected and analyzed from each person, without using any direct identifying information. Data will be stored until May 2025, as per the ICF (see Appendix E), and the study data will be destroyed or wiped clean at that time, as per research ethics board regulations at the University of Manitoba. The data collected for this study were only accessed and reviewed by me as the principal investigator and by my faculty advisor/thesis committee chair. Data collection and analysis occurred concurrently as each participant interview was completed.

Data Analysis

Data analysis within the qualitative research method of interpretive description involves the "identification and exploration of commonalities and differences among and between individual experiences" (Thorne et al., 2004, p. 9). Similarly, Braun and Clarke (2006) state that "Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within data" (p. 6). Data analysis occurred concurrently with data collection, and Braun and Clarke's (2006) six-phase approach to thematic analysis guided the data analysis process for this thesis study. Essentially, this type of thematic analysis allowed me as the principal investigator to look at the entire data set of LTC nurse interviews (phase 1), generate and analyze codes from the data (e.g., interview transcripts) (phase 2), group codes into themes and subthemes that were analyzed for similarities and differences (phases 3 to 5), and finally write up a report of the findings of the thematic data analysis (phase 6) (Braun & Clarke, 2006, 2014; Maguire & Delahunt, 2017).

The one-on-one interviews that were conducted with LTC nurses for the purposes of this study were assigned a random PID, individually audio recorded, transcribed verbatim, and read thoroughly by me. All identifiable information was removed from the interview transcripts, including names of the participants, names of people that participants happened to mention during their interviews, and names of workplaces. The interview transcripts were then encrypted with passwords to help maintain confidentiality. Only files that had all potentially identifiable information removed and were encrypted were shared with my thesis advisor as data analysis progressed.

Memos were also written in a personal reflective journal after each individual participant was interviewed so that context, impressions, biases, and limitations could be identified, accounted for, and reflected on during data collection and analysis (Braun & Clarke, 2006; Connelly, 2016; Creswell, 1998; Munhall, 2012; Polit & Beck, 2012; Seers, 2012; Thorne, 2008, 2016). Some of my reflective memos highlighted commonalities and variations in what participants were saying about ACP communication. As the interviews were transcribed and read, patterns that were appearing between interviews were recorded in memos. Ideas that emerged in reflective memos as data were reviewed and included ethical versus actual nursing practice of ACP, the "what" and "why" of the nurse's role in ACP, agreement versus disagreement as positive versus negative ACP experiences, the participants' feelings of duty/responsibility to know and respect patients'/families' EOL care wishes, and the similarities and differences in nurses' ACP communication in non-acute PCH and more acute LTC settings. In fact, several of these memos helped shape my thinking around coding and categorizing data and the eventual naming and nature of the themes in this study.

Following Braun and Clarke's (2006) approach to thematic analysis, each interview was read through to get a sense of the whole and then read line-by-line, while typing words or phrases in the margin to capture key ideas from the words of the LTC nurse participants. These phrases were examined and grouped together into tentative codes. After the first three transcripts were coded in this way, I met over video chat with my advisor, who had carried out the same exercise. The phrases and tentative codes identified by the two of us were compared, and decisions were made regarding codes to be used as the analysis continued. As more and more transcripts were read through in this way and coding proceeded, the codes were grouped together into tentative categories. The categories gave way to subcategories, and finally themes and subthemes were identified through mapping out and rearranging the categories and subcategories that were identified in relation to LTC nurses' ACP communication (Braun & Clarke, 2006, 2014; Maguire & Delahunt, 2017; Saldana, 2009; Sandelowski, 2000; Seers, 2012; Thorne, 2008, 2016; Thorne et al., 2004).

To ensure consistency during the analysis of the telephone interview data, my faculty advisor also read the interview transcripts and reviewed the codes and reflective memos. As noted above, after the first three interviews were completed, we met to review the transcripts and coding and to discuss any differences in our thematic data analysis approaches. Regular meetings occurred after that to discuss the interviews, the coding of the fifteen transcripts, and thoughts on evident patterns that were noticed in the data.

Constant comparative analysis involves comparing new data with previously collected data in a study in order to see if patterns and/or anomalies are present within and between data sources (i.e., within and between individual participant interview answers and between transcripts) (Polit & Beck, 2012; Thorne, 2016). For this study, constant comparative analysis was done to compare and contrast the interview data that were collected from each LTC nurse participant (Braun & Clarke, 2006; Thorne, 2016). The themes and subthemes that were identified were derived inductively from the data analysis occurring among and between the individual interviews, and interpreted for described meaning (Braun & Clarke, 2006; Petty et al., 2012; Saldana, 2009; Seers, 2012; Thorne, 2008, 2016; Thorne et al., 1997; Thorne et al., 2004). The themes and subthemes that were derived from the data analysis were also discussed with my faculty advisor to ensure and maintain the study's rigor or trustworthiness.

Trustworthiness Criteria

Trustworthiness is described as the "degree of confidence qualitative researchers have in their data, assessed using the criteria of credibility, transferability, dependability, confirmability, and authenticity" (Polit & Beck, 2012. p. 745). These specific criteria of trustworthiness in qualitative research were outlined by Lincoln and Guba (1985) in their seminal book entitled *Naturalistic Inquiry*. The typical techniques that are used with each criterion are still seen in current studies to establish the integrity and usefulness of qualitative study findings (Connelly, 2016; Lincoln & Guba, 1985; Polit & Beck, 2012; Thorne, 2016). Each of the five criteria have several procedures associated with them, however, not all of the procedures are applicable to or used in every qualitative study, including this thesis (Connelly, 2016; Thorne, 2016).

Credibility. Credibility refers to the overall "confidence in the truth of the study" and its findings (Connelly, 2016, p. 435). Several procedures can be used to establish credibility in a qualitative study (as appropriate to the study). These include: reflexivity/reflective journaling, audiotaping and verbatim transcription, prolonged engagement, persistent observation, triangulation, peer review/debriefing, negative case analysis, referential adequacy, member-checking, and disclosure of researcher credentials/background (Connelly, 2016; Polit & Beck, 2012). In this study, reflexivity/reflective journaling (and memo writing), audiotaping and verbatim transcription of participant interviews, peer review/debriefing with my faculty advisor, and disclosure of researcher credential/background (i.e., that I worked in a LTC setting for over a decade) were the procedures used to help strengthen and maintain study credibility in this thesis (Connelly, 2016; Polit & Beck, 2012).

Transferability. Transferability is the extent to which the research findings have applicability in other situations, contexts, and/or settings (Connelly, 2016; Polit & Beck, 2012). The techniques that are used to enhance transferability of qualitative study findings include: thick/vivid description, comprehensive field notes, saturation of data, inter-coder checks, and search for confirming information (Connelly, 2016; Polit & Beck, 2012). The transferability of the findings from this study were enhanced through the rich and detailed description of the setting, sample, and context of the study (Connelly, 2016). Inter-coder checks done with my faculty advisor were also used as a procedure to reinforce this thesis study’s transferability (Connelly, 2016; Polit & Beck, 2012).

Dependability. Dependability deals with the integrity of a study in reference to how stable or consistent the data remains with the passing of time and under similar study conditions (Connelly, 2016; Polit & Beck, 2012). Dependability is strengthened with the use of procedures such as: careful documentation, decision trail, audit trail of process logs, triangulation, member-checking, peer debriefing, and inquiry audit (Connelly, 2016; Polit & Beck, 2012). For this thesis study, careful documentation of processes (i.e., all activities and/or decisions that were made during the course of the study related to setting, sample, data collection, and analysis) was done (Connelly, 2016). To that end, the process logs and data were shared with my faculty advisor for an inquiry audit and for peer debriefing at agreed-upon intervals during the course of the study as a way to achieve dependability of the findings (Connelly, 2016; Polit & Beck, 2012).

Confirmability. Confirmability is the "objectivity or neutrality of the data and interpretations" (Polit & Beck, 2012, p. 723). This criterion helps to ensure that the study findings are based on participant responses and not on researcher bias (Connelly, 2016; Polit & Beck, 2012). Procedures used to reinforce confirmability can include careful documentation, a decision trail, an audit trail of analysis and methodological memo logs, triangulation, a search for confirming evidence, peer review/debriefing, member-checking, and an inquiry audit (Connelly, 2016; Polit & Beck, 2012). Much like the procedures used to ensure the dependability of the study, all activities and decisions that were made during the study were documented. Additionally, an audit trail of the data analysis and any methodological memos were kept and shared with my faculty advisor in peer review/debriefing sessions (Connelly, 2016; Polit & Beck, 2012). These techniques were used to maintain the confirmability of this study in an effort to prevent biases that could have potentially arisen if I had been the only individual describing and interpreting the interview transcripts of study participants (Connelly, 2016; Polit & Beck, 2012). Second interviews may also be used to validate and confirm participants' answers to interview questions, in order to correctly and authentically capture their statements (Connelly, 2016; Polit & Beck, 2012; Thorne, 2016). However, no second interviews were done during the data collection and data analysis phases of this study, as they were not deemed to be necessary.

Authenticity. Authenticity refers to the "extent to which qualitative researchers fairly and faithfully show a range of different realities in the collection, analysis, and interpretation of data" (Polit & Beck, 2012, p. 720). Authenticity can be achieved by using techniques such as: study-appropriate sample selection, reflexivity/reflective journaling, prolonged engagement, persistent observation, audiotaping and verbatim transcription, inter-coder checks, thick/vivid description, and impactful/evocative writing (Connelly, 2016; Polit & Beck, 2012). For this thesis, the trustworthiness criterion of authenticity was shown in the study sample selection (i.e., LTC nurses), and in the audiotaping and verbatim transcription of the individual one-on-one interviews (Connelly, 2016). Reflective journaling by me as the principal investigator took place throughout the study, and inter-coder checks of the coded and analyzed interview transcripts were done with my faculty advisor to help maintain an authentic portrayal of the perceptions that LTC nurses shared with the me during the study (Connelly, 2016). Thick and/or vivid description of study details (i.e., sample, setting, context), as well as the inclusion of excerpts from the data to illustrate the themes when writing up the findings of this thesis, ensures that the LTC nurse participants have had their experiences with ACP communication captured and reported as authentically as possible (Connelly, 2016; Polit & Beck, 2012; Thorne, 2016).

Ethical Considerations

As part of the ethical considerations for this thesis study, and as per University of Manitoba and ENREB recommendations, a pledge of confidentiality was signed by me as the principal investigator (see Appendix K). This pledge of confidentiality was signed to indicate that the University of Manitoba *Personal Health Information Act (PHIA)* training was completed, and that any personal health information that the fifteen participants shared during this study would be kept confidential (see Appendix K). Additionally, as required by the University of Manitoba and ENREB, the *Tri-Council Policy Statement*: *Ethical Conduct for Research Involving Humans Course on Research Ethics* (TCPS 2: CORE) course that is offered by the government of Canada panel on research ethics, was completed by me as the principal investigator (Canadian Institutes of Health Research et al., 2018). My TCPS 2: CORE certificate of completion can be seen in Appendix L.

Furthermore, this MN thesis study was guided by the *Tri-council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2), as jointly agreed upon by three Canadian research agencies: Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada (Canadian Institutes of Health Research et al., 2018). The TCPS 2: CORE modules outline core principles that researchers must keep in mind when studies with human participants are conducted (Canadian Institutes of Health Research et al., 2018). Hence, this thesis took into account the following ethical considerations and principles for protecting the fifteen eligible study participants: Beneficence (which includes "The Right to Freedom from Harm and Discomfort" and "The Right to Protection from Exploitation"); Respect for Human Dignity (which includes "The Right to Self-Determination" and "The Right to Full Disclosure"); and Justice (which includes "The Right to Fair Treatment" and "The Right to Privacy") (Canadian Institutes of Health Research et al., 2018; Polit & Beck, 2012).

Beneficence

Under the ethical principle of beneficence, the right to freedom from harm and discomfort and the right to protection from exploitation are emphasized. This study was conducted in a way that maximized the benefits of research participation and attempted to minimize any potential harm that could have been reasonably expected related to study participation (Polit & Beck, 2012). The topic of ACP communication may be a sensitive subject for LTC nurse participants to talk about; therefore, the principal investigator was vigilant in anticipating negative psychological consequences of study participation. Participants were informed that they were under no obligation to answer any of the questions that they were uncomfortable with and that they could leave or withdraw from the study with no repercussions any time before the start of data analysis. Eligible participants were informed that the questions may elicit unexpected or unwanted emotional and/or psychological responses due to the nature of the topic that was studied (i.e., ACP communication). All participants were offered an opportunity to debrief during or after the interview, and participants were supplied with links on their ICFs (see Appendix E) to organizations (e.g., information related to the Manitoba Blue Cross Employee Assistance Program) that can help them with any troubling emotions that they may experience as a result of participating in this ACP communication study (Polit & Beck, 2012). None of the fifteen LTC nurse participants expressed any concerns regarding the subject matter or the interview questions before, during, or after the data collection and analysis period for this study.

Respect for Human Dignity

The right to self-determination, and the right to full disclosure are highlighted under the ethical principle of respect for human dignity. This principle calls for researchers to inform study participants that they have the right to refuse to participate in any way if they feel they cannot continue in the study. This ethical principle also compels the researcher to be as open and as forthcoming as possible with participants regarding the details of the study and what is expected of participants (Polit & Beck, 2012). For instance, the recruitment email and consent form provided potential participants in this thesis study with information related to the topic being studied (i.e., Nurses' Perceptions of Advance Care Planning Communication with Patients and Families in Long-Term Care Settings), as well as what roles the researcher and the participant were to assume during the study, and what would be done to maintain participant confidentiality. Transparency on my part as the principal investigator in regard to all aspects of this study (i.e., from informed consent to the final write-up of the report) helped eligible LTC nurse participants make well-informed decisions concerning themselves and their overall study participation (Polit & Beck, 2012; Thorne, 2016).

Justice

The final ethical research principle that guided this MN thesis study is justice. The right to fair treatment and the right to privacy were honored during every phase of the research process for this thesis. The right to fair treatment was seen in the use of a convenience sampling method to recruit the fifteen LTC nurse participants. This sampling method gave potential participants the ability to voluntarily join this study; hence, participants from diverse backgrounds were included if they met the eligibility requirements, if they chose to join the study, and if they signed and returned the ICF to me (Polit & Beck, 2012). For example, LTC nurses were the focus of this study, and each LTC nurse participant had unique characteristics and points of view that enriched the interview data that were collected. Additionally, participants who had questions about the study were treated fairly and respectfully by me as the principal investigator at every point during the study (Polit & Beck, 2012). The participants' right to privacy was and will be upheld and maintained through the storage of any data collected during the study in password-protected computer files on password-protected computers. The confidential data contained in the password-protected files and computers was only accessed by me as the principal investigator and by my faculty advisor. Confidentiality of the participants and their data was achieved with the removal of identifying information (e.g., participant names, city/town names, and workplace names) from the data, and will be maintained through the confidential storage and then destruction of study data, as per University of Manitoba protocol, after the completion of this thesis.

Summary

Using a qualitative interpretive description approach, semi-structured one-on-one telephone interviews were conducted with a sample of fifteen nurses working in LTC settings within health regions in Manitoba, Canada. The interview data collected for this thesis were coded and categorized and themes were identified (Braun & Clarke, 2006; Maguire & Delahunt, 2017; Petty et al., 2012; Saldana, 2009; St. George, 2010; Thorne, 2016). Ultimately, the qualitative research method of interpretive description "seeks to generate new insights that can help shape applications of qualitative evidence to practice" (Polit & Beck, 2012, p. 506); thus, this study was conducted with the hope of adding to the scholarly literature that is read and reviewed by those who seek to shape and improve upon ACP policies, procedures, and practices that are used by nurses in a variety of settings. The next chapter will discuss the key findings of this study in more detail.

Chapter 4: Findings

In this chapter, the findings of this MN thesis study will be discussed. The purpose of this qualitative, interpretive description study was to explore the ACP communication experiences that nurses have had with patients and families while working in LTC settings. More specifically, this qualitative study was conducted to answer the following research questions:

- What are LTC nurses' experiences with ACP communication in their practice?
- What are LTC nurses' perceptions (e.g., thoughts, feelings, opinions) of their roles in ACP communication with patients and families?
- What do LTC nurses see as barriers and/or facilitators to ACP communication with patients and families in their practice settings?

The thematic analysis approach outlined by Braun and Clark (2006) was used in the data analysis process and led to the identification of two themes:

- *A Sense of an Ethical Obligation to Engage in ACP Communication*, and
- *Sensibility of the Determinants of ACP Communication*.

These two themes will be discussed in detail in this chapter (see Appendix M and Figures 1 and 2 for the overall thematic analysis breakdown). In order to provide some context for the findings, this chapter will first feature a breakdown of the demographic information related to this study's sample of participants and a brief discussion of the participants' perspectives on the definition of ACP.

Sample Demographic Information

A total of fifteen LTC nurses met the eligibility criteria, signed informed consent forms, and voluntarily agreed to participate in this study. Each participant was assigned a random participant identification number which was used to differentiate between LTC nurses interviewed for this study. Three participants identified themselves as LPNs (1 LPN certificate and 2 LPN diploma programs) registered with the CLPNM, and the remaining twelve participants were RNs (5 diploma, 6 bachelor of nursing degree, and 1 master of nursing degree programs) registered with the CRNM at the time of this study. The ages of LTC nurse participants ranged from 26 to 72 years, with the average age being 50.33 years. There were twelve female participants (80% of the total 15 participants) and three male participants (20% of the total 15 participants). The nurses' years of overall nursing experience ranged from 3 to 43 years, with an average of 23 years of overall nursing experience among the participants. The sample's years of LTC nursing experience ranged from 7 months to 42 years, with an average of 14.9 years of LTC nursing experience. The participants' years of experience within their current facility ranged from 1 to 34 years, with an average of 12.6 years spent working in their current facility (see Table 6).

Five nurses stated that they were working within their LTC settings as a nurse manager, a nurse educator, a CNS, a clinical resource nurse (CRN), or as a combination of those job titles. The remaining ten participants all stated that they were frontline LTC nurses. Six nurses worked full-time positions, six nurses worked part-time positions, one nurse worked part-time at one location and casual at another location, one nurse worked casual hours, and one nurse was retired but was still working casual hours. Eight participants worked in facilities that were strictly LTC or PCH facilities; whereas the remaining seven nurses worked in hybrid facilities that featured a mix of LTC units and medical and/or rehabilitation units. The typical daily nurse-to-patient ratio on these LTC units, as reported by the study participants, ranged from 1:6 to 1:29, with an average of 1 nurse to 15.7 patients on a given day shift. All of the LTC nurse participants reported having around-the-clock access (i.e., 24 hours a day, 7 days a week) to a physician by telephone (i.e., on-call). However, in-person physician access varied from one, two, or three times per week for patient rounds, depending on the type of facility (i.e., strictly LTC/PCH facilities were typically once a week, and hybrid facilities were typically two or three times a week) (see Table 7).

Participant Definitions or Descriptions of ACP

Participants were asked to define or describe advance care planning at the beginning of the interviews. The participants responses are summarized as follows:

a) all 15 participants indicated that ACP was important for identifying patient wishes, decisions, or desired goals for care;

b) all 15 participants noted that the focus of ACP was on the future, with some specifying a focus on future care in emergent situations (3 participants) or at end of life (10 participants);

c) 13 participants specifically noted that ACP provides guidance or direction to the healthcare team and/or family regarding the wishes or desired goals of the patient;

d) in defining ACP, 12 participants described either the types of treatments they focus on in these discussions (e.g., cardio-pulmonary resuscitation) or the three levels of care outlined on the ACP form in their institutions that guide their discussions (i.e., resuscitation, medical, or comfort care);

e) 11 participants identified that a document or form was part of ACP and was used in their facility to capture the patient wishes or desired goals;

f) 8 participants identified that advance care plans can change and involved discussions over time or follow-up conversations post admission with the patient or family.

The following excerpt of the definition of ACP provided by one participant is a good illustration of the characteristics of ACP described above:

> The family, the resident, and the nurse, or the care team, have the same guidance when it comes to the care of this person. That is the advantage of advance care planning. It's like a road map. If you don't know where you're going, you're going to find yourself somewhere else. So, this is a, like a road map telling us, okay, this is the understanding of where we're going. However, if where we are going, we don't want to go there anymore, something happened, something changed, then we can change that road map to something else. And that's when every year at the care conference, we ask the family, "When your loved one came in as medical; this is what has happened. Do you still want to keep them medical?" And they will say, "Yeah, we want to keep them medical", and things like that. So, that road map stays the same. So, that's the advantage of that. But, when we don't have that road map, then if something happens to this resident, let's say they break a hip, and then we send them to the hospital, and the hospital says, "There's nothing we can do about them." And when we don't have this road map, we start to struggle, because we don't know what to do. (Participant 17, lines 95-110)

Participants discussed having ACP conversations both with patients, if patients were able to participate, and family members, with most participants noting that the identified wishes or goals were particularly important for the time when patients could no longer make their wishes known.

Both the participants' definitions of ACP and the sample demographic information help to set the scene in a contextual way for the themes identified in the analysis process. These themes are: 1) *A Sense of an Ethical Obligation to Engage in ACP Communication*; and 2)

Sensibility of the Determinants of ACP Communication. The themes will be described in some detail and excerpts are included to illustrate the themes.

Theme 1: A Sense of an Ethical Obligation to Engage in ACP Communication

The first theme identified through analysis of the interview data is *A Sense of an Ethical Obligation to Engage in ACP Communication*. This theme speaks to the overall sense that each of the fifteen LTC nurse participants mentioned, at one point or another during their individual interviews, of feeling that ACP communication with patients and families in their care was part of their ethical obligation, duty, and/or responsibility as nurses.

Excerpts from three of the interviews are provided here to illustrate the way participants talked about feeling ethically obligated to participate in ACP communication. One participant described this obligation as follows:

> …it's an ethical thing that I, I should make sure that I'm able to do [initiate ACP discussions with patients and families]. Um, so, I feel strongly about it, and I, and I feel like I'm pretty good at it. And I always encourage others who don't feel comfortable to acknowledge that that's pretty common. But then to maybe ask me, and we can do it together and, you know, to help support them so that they can see them and hear them and grow their skills and their capacity to have them. (Participant 18, lines 233-239)

A second participant similarly, but more philosophically, expressed her thoughts on the obligation to have ACP conversations:

> So, in my job when I'm doing this [engaging in an ACP discussion], I do it out of respect as a nurse, but I also do it out of respect because we're human beings, and I think we need to understand, everybody needs to understand what the process is. And we're not

> hiding anything, and I'm not going to be clinical about it. I'm going to be a person. (Participant 9, lines 617-621)

This participant had been witness to what she described as an ineffective ACP conversation between her father and a HCP and identified that this experience shaped how she thought about her duties in relation to ACP in her own work as a nurse.

A third participant described this sense of obligation in relation to ACP, particularly as the patient's status changes, as follows:

> Like, it's just the normal thing, like, that you just go around and ask if they want their status to be changed. I think, and especially when there's a decline, I think it should be one of our first kind of thoughts at the same time as the, as the nurse to like, "Okay, things are changing." And like, "What would you like?", and have more, I think our role needs to just be more. I think we pass the buck to the doctor on it a lot…and, um, I think we should just talk about it more because we know the patients more than anybody else. So, I don't know why we don't, but I think people get, are uncomfortable with it. (Participant 22, lines 300-311)

Note that in the first and third excerpt, the participants mention that nurses' discomfort can get in the way of fulfilling the ethical obligations related to ACP. Not fulfilling one's ethical obligation could lead to negative consequences, as outlined in this excerpt:

> And then there are some nurses who don't, so they opt to just avoid it…. which sometimes results in, I think, unnecessary transfers out, or unnecessary invasive interventions that maybe are pretty futile. Um, but just because they're so uncomfortable having that conversation, they just default to, um, not having that discussion. Like, say they're an ACP M, and something significantly changes, like they've had, you know,

> something happened, um, and we know that it's probably futile what's happened. Even sending them out is probably not going to change the outcome. The nurse may just still kind of go with it, and just send them out, and allow the acute care facility to be the ones that have that conversation and change the ACP, and then they send them back. Where I think we should be having that discussion here and avoiding sending them in the first place. But I think there are some nurses that aren't comfortable with it, but I really feel that it is our obligation to make sure we, we can have those discussions. (Participant 18, lines 206-226)

Eight participants used the language of responsibility to describe nurses' role with ACP communication. For instance, one nurse spoke of a sense of duty or obligation that nurses should feel to have ACP discussions with patients and families when she said, "it may not be your favourite part of what you do as a long-term care nurse, but you're responsible to do it as well as you're capable of doing it" (Participant 24, lines 1080-1082). Another participant who has worked in LTC for many years described ACP conversations in terms of ownership:

> Um, it is, in my mind, it's a nursing function. I believe nurses are the best equipped healthcare providers to have this discussion with most individuals. There's always exceptions to rules, but I, I really think that nursing should own the ACP conversation. (Participant 25, lines 921-928)

Two sub-themes were identified and these will be briefly described.

Sub-theme: Factors Influencing the Sense of an Ethical Obligation

It was evident from the interviews that the nurse participants' *sense of an ethical obligation to engage in ACP communication* is influenced by at least three factors: how they define ACP; how ACP is carried out in their LTC settings; and the kinds of personal and professional experiences that LTC nurses have had with ACP communication (see Appendix M and Figure 1). Each of these factors will be briefly discussed.

How LTC Nurses Define ACP. As noted earlier in the chapter, participants were asked to define or describe advance care planning at the beginning of the interviews. All participants discussed the importance in ACP of identifying patient wishes for future care and almost all (n = 13) discussed the role of ACP in guiding families and/or the healthcare team in terms of patient care. All participants acknowledged that nurses had a role to play in ACP. The language used and the sentiments expressed by the participants illustrate how ACP definitions informed or influenced the way they thought about their ethical obligations in relation to ACP. For example, participants discussed the importance in ACP of information sharing, identifying and documenting patient wishes, and respecting and honouring patient wishes or goals of care to prevent harm and preserve dignity. They also discussed their roles as healthcare team members in the ACP process (e.g., what is discussed with the patient and by whom, the timing of the conversations, the nature of the follow up over time).

Three of the participants emphasized the importance in ACP, if at all possible, of capturing the wishes of the patients while the patients were still capable of expressing those wishes. As one participant stated:

> So, advance care planning is something you would like to do before you become ill, um, before you can't make decisions for yourself. It's not a living will, um, but it does give direction as to how much medical intervention you would like from us, closer to the end of life, or, or the end of your healthy years. And what would you want done, uh, to maintain your health, to maintain your dignity. So, if you would like, "If you had a heart attack, do you want us to call 911? Um, the ambulance is coming, they will do CPR,

> they will resuscitate you all the way to acute care, you'll go to intensive care, whatever it takes to get you stabilized." (Participant 24, lines 66-74)

The participants indicated in their definitions of ACP that it was not always possible to hear directly from the patient or resident about wishes and they highlighted the role that families can play in the ACP process.

Interestingly, a difference was noted in ACP definitions in terms of how participants thought about the form used to capture some of the patient wishes. Three nurses (participants 9, 17, and 29) described the ACP form as a legal document. As with other aspects of their definitions, this informed their thinking about their obligations in completing the form as part of the ACP process.

How ACP is Done in Participants' LTC Settings. The fifteen participants in this study were asked to describe how ACP is conducted and accomplished in their LTC settings. The answers were as varied as the LTC settings themselves, but patterns emerged from the participants' comments.

It seems that how ACP is done in LTC settings depends on how the LTC setting itself is defined. For example, ACP is done differently in LTC settings that are designated as PCH units or facilities versus LTC settings that are designated as caring for long-term care patients on a more specialized, semi-acute unit, or in a hybrid-style care facility. The nurses in this study reported that the person/people responsible for ACP, when ACP discussions occur, how often ACP is reviewed, and who is responsible for reviewing ACP are all influenced by the LTC setting that they work in, as well as who makes up the staffing complement in their particular LTC settings.

In fact, eight of the fifteen participants reported that nurse-led admission and follow-up ACP discussions are the norm on their LTC/PCH units. Four nurses (participants 21, 22, 23, and 29) who work on LTC units that are not defined as PCH units stated that nurses are only engaging in admission ACP, and are very seldom involved, or not involved at all, in follow-up ACP reviews with patients and families in their LTC settings. Two nurses (participants 5 and 24) who both work in PCH facilities stated that ACP is social worker-led in their facilities. While one nurse (participant 27) who works on a LTC unit not defined as a PCH unit indicated that ACP is physician-led on their unit.

A nurse participant who works on a designated PCH unit within a hybrid-care facility described their unit’s nurse-led and nurse-driven ACP communication protocol as:

> Yeah, we kind of get a, like a quick, a quick, um, you know, at the initial visit it's often just seen as one more piece of paper that needs to be filled out. So, you get that sort of quick, um, you know, if this person stops breathing in two hours, we need to know what to do at that point. And then it’s, and then it's discussed at the initial, um, meeting, the interdisciplinary team meeting that's about, like I said, about 6-8 weeks. And then it's also reviewed annually at their annual interdisciplinary meeting. And we also review it when the patient or resident, um, has a change in their health status. (Participant 19, lines 231-238)

However, a nurse working on a non-PCH LTC unit described her ACP communication experience with patients and families quite differently by saying:

> Um, on my unit, it’s initially discussed by the nurse and the patient, and or the family, whoever’s advocating for the patient upon admission. Um, and then it gets revisited

> during family meetings with the physician and the unit manager and the patient or, and/or family. (Participant 21, lines 94-97)

Eight of the participants worked in an environment (i.e., PCH units/facilities) where nurses are the primary drivers of ACP communication from admission to yearly (and as needed) reviews. By comparison, four participants worked in LTC environments that are not labeled as PCH units, and only see nurses primarily engaging in ACP communication during patient admissions and rarely at any other point in a patient's LTC trajectory. The degree to which the participants referred to their sense of an ethical obligation to engage in ACP communication was affected by the ACP practice and protocols on their particular units.

LTC Nurses' Personal and/or Nursing Experiences with ACP. The third factor influencing participants' sense of an ethical obligation revolved around their personal and professional experiences with ACP communication. All of the participants disclosed personal and/or nursing ACP experiences during their individual interviews. For instance, two nurses (participants 5 and 9) revealed personal ACP experiences (i.e., involving themselves and/or their own family members) that impacted their current ACP communication in some way. One of these nurses recounted a story that involved a family member having ACP explained to them by a physician. The other participant spoke about completing an ACP form for herself before a procedure and remarked that it was a perspective-changing experience because, "…it was just, you know, different filling it out for myself than helping someone else fill it out for them" (Participant 5, lines 706-707). Both participants linked these personal ACP experiences to their thinking about the obligation to engage in ACP communication.

Additionally, eight of the fifteen nurses (participants 15, 18, 21, 22, 17, 27, 28, and 33) referred to remarkable and/or memorable professional nursing experiences that left an impression on them and affected their ACP practice. One nurse who is newer to LTC said:

> I just, I just really feel that ACP, um, the discussion, brings out a lot of other discussions. That it's a good discussion. Um, and that, um, it actually helps staff, not just nurses, but staff in general give better care. Um, there's no second guessing, um, there's just easier conversation between residents and staff, and that is a lovely thing. (Participant 27, lines 647-651)

Another nurse with more LTC experience spoke about how she has seen LTC nurses' ACP practice have unwanted, detrimental effects on care:

> I think we default to sending them to acute care, and then they make that discussion and those changes and then send them back. Which is a whole lot of trauma and pain to inflict on an elderly, sick resident, when maybe we could have avoided that. I see that still and it, it upsets me. I think I, I, I don't feel like it's taking the best interests of the resident to heart. And I think, so it's up to us as nurses to make sure we can have those conversations, because in doing so we're doing the best we can for the resident, and avoiding that transfer out, um, is essential. And just transferring someone because you're too scared to have the conversation, or you don't feel confident, or um, to me is, is not good nursing practice. So, I would like to see us get more competent, more clinically strong in having those conversations in long-term care. (Participant 18, lines 447-457)

The remaining five LTC nurses (participants 25, 19, 24, 23, and 29) shared stories from both their personal and professional lives that featured ACP communication, including the effect that these experiences had on their ACP practice. For example, one nurse with many years of

LTC experience shared that she struggles with translating professional comfort with ACP discussions into her own family ACP situations (participant 25). One participant reflected on an early nursing career experience where patients' EOL care wishes were unknown, stating, "I still feel to this day just a little sick about how some people suffered when they didn't have to" (Participant 19, lines 1326-1327), while another LTC nurse said that she witnessed "people suffering needlessly" (Participant 24, line 621).

An interesting point that emerged in all of the interviews was the idea of agreement versus disagreement determining whether ACP communication was seen as having gone well/positively or negatively. Two participants in particular captured this experience of ACP agreement versus disagreement. One LTC nurse stated:

> And so, the positive aspect is that it, it literally does guide you and it's something you can refer to, and, and say to the family and to the healthcare team that this is what this person wanted, this is what this person has asked for. So, it, it's something to help settle those arguments and bring everybody onto the same page, if that makes sense. (Participant 29, lines 126-130)

While a nurse working on a PCH unit gave an example of how ACP disagreement can negatively impact patients:

> The ones that I can think of that don't go well are, um, where we're at a situation where it's clear to us that the patient is not expected to recover but the family don't, um, don't agree. And we end up transferring the patient to the hospital and the patient dies in the emergency department. That is probably the, the more, um, those are the ones that are the more difficult, when at the end of the day we, we cannot, we cannot, um, help that

> family to accept the inevitable, and our residents end up in a, in a hospital dying around strangers. (Participant 19, lines 577-584)

Overall, the examples of positive and/or negative personal and professional ACP experiences presented in this category point to how these LTC nurse participants internalized these experiences and how these experiences shaped their sense of an ethical obligation to engage in ACP communication.

Sub-theme: Roles and Actions that Flow from the Ethical Obligation to Engage in ACP Communication

This subtheme is a snapshot of the roles and actions that the fifteen participants in this study saw themselves, and LTC nurses, performing and playing with respect to ACP communication with patients and families. This subtheme shows how the study participants perceived their roles in ACP, and how these role perceptions translated into actions geared towards fulfilling their overall sense of an ethical obligation to engage in ACP communication with patients and families. Four clusters of roles or actions were evident (see Appendix M and Figure 1).

Advocate, Liaison, and Mediator. These three roles were combined into one due to the similarities between them. Oftentimes, nurses act as advocates for patients and families in their care by working as liaisons and mediators, depending on what situations require. One participant gave a good example of how a nurse can be an advocate for patient care while taking the patient's ACP level into consideration:

> Um, well, the nurse's role is basically advocating for the patient. Um, usually the patient would say, uh, let's say, they're a C but they want antibiotic treatment, and stuff like that, um, we can definitely facilitate that. Um, we usually advocate with the doctors and the,

> um, with the clinical nurse specialist on how to deal with, let's say, like, the wound care and stuff like that. Um, they would use irrigation with Flagyl, or something like that. And offer for, like, C patients. So, that's, yeah, usually it's more for, like, advocating. (Participant 28, lines 178-191)

This quote from participant 28 illustrates how the nurse in the advocate role is also acting as a liaison between the patient, the physician, and the CNS to achieve a wound care goal for a patient who is ACP level C. Other participants brought this liaison role to the forefront between the patient, family, and healthcare team members. One nurse in particular described the nurse's role as a mediator in ACP communication:

> You should be a mediator. You should be somebody who, you know, because, like, again, you have your, you wear different hats. And you're, sometimes you're being a social worker, sometimes you're being a physio, sometimes you're being an OT, depending on what you need to be doing that day. So, wearing all those hats you, you need to be a mediator between the patient, the family, the healthcare team, you know, somebody. (Participant 29, lines 795-800)

The notion that nurses wear different professional hats, depending on what the patient's/family's needs are, supports the idea that nurses feel a certain sense of ethical obligation to the people that they are caring for; thus, they put this sense of ethical obligation into action through these different roles. In fact, the actions involved in the nursing roles of advocate, liaison, and mediator (e.g., conferring with healthcare team colleagues to provide appropriate nursing care regardless of a patient's ACP status) affirm that nurses are engaging in ethical practice. These three similar roles show how participants see these nursing actions (i.e., *advocate, liaison, and mediator*) as being an important part of their ACP communication work with patients and families in LTC. With that said, these were not the only roles that participants saw as LTC nurses' roles in ACP communication.

Communicator, Caregiver, and LTC Contact. These roles raised by the participants in the interviews for this study were grouped together, as they seem to go hand-in-hand in LTC nursing practice. To illustrate this point, one LTC nurse stated, "But, nurses in my mind, are the frontline caregivers and communicators with patients, and for me, ACP is a, a process and a conversation. And that's the role of nurses" (Participant 25, lines 270-272).

A second participant described the nurse's role in patient/family communication in the following terms:

> Because the nurse is the point of contact, number one, for the family. The family when they call, they want to speak to the nurse. And then the nurse is the one who is looking after the patient. Any change in the condition of the patient, the nurse will be the first to note it, to start this process of changing or revisiting the ACP. (Participant 17, lines 233-237)

All fifteen participants made comments that referred to nurses' roles of communicator, caregiver, and LTC contact for patients and families. Participants identified that LTC nurses fulfill this sense of ethical obligation to engage in ACP communication by being the primary healthcare team member that patients and families interact with on a daily basis. The participants acknowledged two more LTC nurse roles in ACP communication.

ACP Educator and Clarifier. These roles were grouped together due to the nature of information sharing that occurs in both of these nursing roles during ACP communication. All fifteen participants indicated that the nurse's role in ACP communication involves educating patients and families and clarifying ACP information to promote understanding. One nurse gave a brief explanation of how she puts these roles into action while discussing ACP with patients/families by saying, “I do read through the form, but then I reexplain it in a way that I think will help them understand it” (Participant 15, lines 375-377). While another nurse spoke about how nurses educate patients/families and clarify ACP information by tailoring their explanations and using layman’s terms to ensure understanding:

> So, and sometimes we have to, we have to be careful about, you know, there's language that we use to talk about things that is not really accessible for other people that aren't, like, in the medical field. And so, I'm comfortable with finding ways to convey that kind of information to a family or a resident, patient, um, that it’s, you know, that it’s understandable to them. (Participant 19, lines 461-469)

A third nurse participant talked about how she gauges patient comprehension of ACP levels, and how she explains what resuscitation is so that patients can make an informed decision related to choosing an ACP level for themselves:

> You know what they seem to understand better, so you use that with the next one. I, I always tried to make it, um, I don't [sigh], I mean, I'm dealing with elderly clients to begin with. Like, so, you know, when I ask whether or not they want to be resuscitated, if they say yes, I say, I always ask them if they understand what resuscitation involves. And then I explain what resuscitation is. And often after I've done that, they don't want it. (Participant 33, lines 160-165)

Although all fifteen participants asserted that the nurse’s role in ACP communication involved being an educator and clarifier of information, two LTC nurses in particular noted that these roles would ideally not be performed by nurses in their settings. For instance, one nurse pointed to the physician as being the appropriate healthcare team member who should be the prime patient/family ACP educator:

> It would be nice, um, it would be nice to have, uh, you know, ideally have the doctor go through it with them. Um, I think, you know, often the doctor knows a little bit more about what goes on with them, and could maybe have a, a better way of, of explaining things to them, if they, if they do know them and have a bit of a rapport with them. (Participant 15, lines 210-214)

A second participant noted that while nurses should share some information with patients and families, they should only be giving surface-level explanations related to ACP:

> I don't know if I should have to, really, um, as a nurse, go in and, um, go through this whole rigamarole of asking, and defining, and like, giving them all this information on death and dying, and um, what each, let's say, like, okay, what [care] is going to look like afterwards. Or, what's going to happen, like, if I do CPR on them. I don't, like, to give them some information is okay. But I don't think that we, as nurses, need to, um [pause], uh, be too invasive, because they should have already thought of this and planned this, as any human being going into a situation like this later on in life. (Participant 23, lines 297-308)

Despite these two participants' contradictory perspectives regarding the LTC nurse taking on the roles of ACP educator and clarifier, all of the nurses did say that these roles were essential to their ACP practice. Educating patients and families and clarifying ACP information in order to foster understanding are two roles central to LTC nurses' ACP communication. According to the fifteen participants in this study, educating patients/families and clarifying information for them are tenets of good and ethical nursing practice. Therefore, these roles support the main theme of *A Sense of an Ethical Obligation to Engage in ACP Communication* in a very practical and tangible way.

Acting in Ways to Respect and Promote Patient Autonomy. Eleven out of fifteen participants commented on how a nurse's role in ACP communication is respecting and promoting a patient's autonomy. This is a role that the LTC nurse participants in this study spoke about with great reverence. It is also a nursing role that is more conceptual in nature, as it is one that the participants described in more philosophical, rather than concrete, terms. The study participants claimed this was an ethically important nursing role, but they had a difficult time providing examples of how this role is realized in their practice. Nurses spoke about respecting choices or wishes, not making decisions for patients, and not judging patient choices.

One participant defined this philosophical role by simply saying that the nurse's role is to, "Not make their decision for them but help them to make the decision" (Participant 5, lines 225-226). A second participant stressed that this more supportive, and somewhat abstract, nursing role encourages patient and/or family decision-making, because as nurses, "We have to allow that person that autonomy to make those decisions, or if that person cannot there is a substitute decision-maker, etc." (Participant 9, lines 98-100).

However, a different participant admitted to disagreeing with patients' ACP decisions on occasion by commenting, "…sometimes it's not the right decision, but it's their decision." (Participant 23, lines 448-449). Similarly, another participant gave a more specific example of a situation where nurses may disagree with patients/families over ACP decisions by stating, "In, in that case where somebody is, um, a little unrealistic, like they want, they want CPR even though they're frail and fragile, um, we, we, we honor their wishes and we, we go along with that" (Participant 15, lines 318-320).

These statements from participants 23 and 15 illustrate how nurses can disagree with an ACP decision, but still feel ethically inclined to respect their patient's autonomy. This is further evidence that supports the theme of *A Sense of an Ethical Obligation to Engage in ACP Communication*, since it shows that nurses may be conflicted about patients' ACP decisions, but still fundamentally respect and promote their patients' autonomy to make these healthcare decisions.

A Sense of an Ethical Obligation to Engage in ACP Communication was only the first theme identified during data analysis for this thesis study. A second distinct, albeit related, theme was *Sensibility of the Determinants of ACP Communication*. This theme will be discussed in more detail in the next section of the chapter.

Theme 2: Sensibility of the Determinants of ACP Communication

The second theme identified through thematic analysis is focused on the nurse participants' sensibility or awareness of factors or variables that facilitate or act as a barrier to ACP communication in LTC. This theme answers the third and final research question:

- What do LTC nurses see as barriers and/or facilitators to ACP communication with patients and families in their practice settings?

A sensibility or awareness of the factors influencing ACP communication is evident in the following illustrative participant statements:

> "I find that some nurses are better at it than others" (Participant 9, line 880).
>
> "I wish more people would be at ease. I wish I knew how to fix it [laugh]. I wish I knew why, especially nurses, have a hard time with it" (Participant 27, lines 651-653).
>
> "…not everybody is a strong communicator when it comes to having those hard conversations" (Participant 29, lines 1266-1267).

> "It's gone by the wayside for nursing staff… It's been a discussion with the manager, the doctor, and social worker, and the family and the patient, um not necessarily brought nursing staff into it" (Participant 23, lines 117-123).

This theme captures what the participants felt were ACP communication hindrances or barriers and catalysts or facilitators in their LTC nursing practice settings. Interview guide questions (see Appendix I) that were asked about ACP barriers and facilitators revealed answers that showed sensitivity, awareness, and insight into what participants saw as determinants of LTC nurses' participation in ACP communication. All fifteen study participants were able to name determinants of ACP communication that they have experienced and/or seen in their LTC settings and these determinants were grouped together according to their shared qualities. Thus, the theme of *Sensibility of the Determinants of ACP Communication* was divided into two subthemes: *Communication Hindrances* and *Communication Catalysts* (see Appendix M and Figure 2). The key findings of each will be discussed below.

Communication Hindrances

This subtheme refers to the determinants of ACP communication that the study participants reported as hindering a LTC nurse's ability and/or willingness to be involved in ACP discussions with patients and families. The communication hindrances were further divided into *Personal Barriers*, both those related to the LTC nurse and those related to the patient/family, and *Structural Barriers*, both those related to education and those related to work environments (see Appendix M and Figure 2).

Personal Barriers. These communication hindrances were labelled *Personal Barriers* because of the nature of how they are shaped by personal elements displayed by the people who are involved in ACP communication. For instance, personal factors like someone's personality and/or individual lived experiences were identified by participants as potentially becoming barriers that stop people from discussing ACP. Personal barriers included barriers related to the LTC nurses and barriers related to the resident/patient/family.

LTC Nurses' Barriers. These barriers involve LTC nurses themselves. All of the nurses interviewed for this study stated that nurses' comfort levels with death and dying and confidence levels with conducting discussions about future care are the most common barriers that LTC nurses come up against in ACP communication. For instance, one participant with many years of LTC experience clearly stated that the "biggest barrier would be lack of confidence in having that discussion" (Participant 5, lines 314-315). A second participant brought up the idea that fear or discomfort with talking about death can be a barrier to ACP conversations:

> Hmm, not knowing how to bring it up. Talking about death, in general, when they have a sense that they should be, um, fixing, I guess you could call it. Even though the residents we have, have progressive disease, they don't see it that way. So, they're scared to acknowledge that to the resident, um, and the family, so they just don't want to raise any feathers [laugh], I guess. Um, I think a lot don't know, a lot of nurses just don't know what to say. (Participant 27, lines 297-309)

Similarly, another participant reflected on how a nurse's comfort level with ACP communication can ultimately affect patient care:

> I think there are some nurses who are comfortable with it and do a great job. And then there are some nurses who don't, so they opt to just avoid it, which sometimes results in, I think, unnecessary transfers out, or unnecessary invasive interventions that maybe are pretty futile. Um, but just because they're so uncomfortable having that conversation, they just default to, um, not having that discussion. (Participant 18, lines 205-213)

Other personal LTC nurse barriers to ACP communication were mentioned in the participant interviews and included culture, nurses' inexperience with ACP, nurses' beliefs that life should be extended at all costs, nurses' fear of upsetting the patient, nurses' own personal experiences in relation to health, and not making the time to have ACP discussions.

According to the fifteen study participants, low levels of comfort and confidence with ACP are common barriers to LTC nurses' engagement in ACP communication. More than that, participants mentioned other communication hurdles as noted above (e.g., nurses' culture or experience). So, it appears as though these personal communication barriers can be, both individually and in combination, hindrances to nurses' ACP communication with patients and families in LTC settings. Consideration also needs to be given to the personal barriers that hinder ACP communication and come from patients and/or the families.

Resident/Patient/Family Barriers. Some of the patient and/or family barriers that participants named in their interviews included cultural barriers, language issues, family preference to speak to the physician about ACP, religion, and family misunderstandings. At times, even if the nurse is prepared and willing to discuss ACP, the patient and/or family themselves can become barriers to effective ACP communication in LTC settings. Patient and/or family denial of the patient's condition and circumstances and avoidance of death are barriers that participants discussed. For example, one participant said, "…you often do come across a situation where somebody is in denial of life and death situations. And [pause], they just, I feel like their healthcare goals are a little unrealistic" (Participant 15, lines 313-316).

Family strife, indecisiveness, in-fighting, and disagreements amongst each other and with the patient are also patient/family personal barriers that hinder ACP communication in LTC settings. One participant, who has worked in several LTC/PCH settings over the course of his nursing career, referred to negative family dynamics and how family arguments over EOL care discourage nurses from discussing ACP because, "…it becomes this thing that you wish you never discussed with anybody, because it becomes a fight" (Participant 17, lines 137-138). Another participant, who works on a LTC unit within a hybrid-care facility, went on to point out how family disagreements over patients' wishes can leave nurses feeling unsure about ACP communication and patient care by stating, "Um, well, sometimes [laugh] the family are not on board with what the patient wants, for sure. And then you are kind of torn between, like, where do we go from here?" (Participant 23, lines 101-106).

An interesting barrier that was highlighted in the analysis of the participant interviews was the reality that sometimes the LTC patient and/or their family distrust HCPs, including nurses. Two LTC nurse participant interviews in particular spoke about this distrust. One of these LTC nurses reflected on how this poor nurse-patient/family relationship can affect ACP communication:

> Um, because sometimes you'll have, you know, established, um, patterns are kind of set with some families where there might be, uh, some mistrust. Um, where maybe something has happened through the course of that, that patient or resident's stay with us that has caused the family to not have a lot of trust in the care givers. And so, in that point sometimes follow-up conversations can be a little bit more difficult. (Participant 19, lines 508-517)

As reported by the fifteen participants in this study, a variety of patient and/or family barriers can essentially block nurses from discussing ACP in LTC settings. Similar to the LTC nurses' barriers that were previously discussed, many of these patient/family barriers can be hindrances to nurses' ACP communication in LTC settings, both as individual barriers and in combination with each other. However, personal barriers were not the only barriers that the participants brought up in this study. Structural barriers also came to the forefront when participants thought about LTC nurses' ACP communication hindrances.

Structural Barriers. These barriers refer to those which are part of a larger, non-personal structure that can be communication hindrances that impact LTC nurses' ACP practice. For example, structural factors like policies, training, and LTC unit staffing are things that can have a negative effect on ACP communication, regardless of a person's internal issues or struggles with ACP. The structural barriers in this category were split into two groups: *Educational Barriers* and *Work Environment Barriers* (see Appendix M and Figure 2).

Educational Barriers. Structural barriers dealing with aspects of ACP education were specifically cited by 14 of the 15 participants as communication hindrances. A participant who has worked on a LTC unit within a hybrid-care facility for several years clearly asserted that, "There's no training. I don't even remember learning it in school. I mean, maybe we did, but it was a while ago" (Participant 22, lines 253-258). Another participant who is newer to LTC, and newer to nursing in general, echoed the same sentiments of experiencing a lack of ACP education by saying, "Because, yeah, like, really it's one of the, the, one of the aspects of long-term care that's very essential, but at the same time, I feel like there's not enough guidelines or training for us" (Participant 28, lines 632-634). The same newer nurse also described how he was eventually educated in ACP communication with on-the-job training, which is an ACP education trajectory shared by two thirds of the LTC nurses interviewed for this study (10 of 15 participants):

> Um, really, it's more of, like, an on-the-job training. Like, I usually just listen to family conferences and, um, watched a charge nurse explain how the ACP levels go. But as for formal training, I don't think I've received any. (Participant 28, lines 172-174)

Again, it is apparent that the nurses who were interviewed for this study have a sense that ACP education is important in encouraging nurses to participate in these discussions. The participants in this study reflected on the fact that they and their colleagues have encountered educational barriers (i.e., no formal ACP training) that may have negatively impacted ACP practice amongst LTC nurses in general. Having said that, educational barriers were not the only structural barriers that were identified as communication hindrances by the participants in this study.

Work Environment Barriers. ACP communication hindrances that are structural barriers covering the larger, organizational, and systemic issues that participants have encountered while working within their LTC settings were grouped together. For example, relevant work environment barriers that were described by participants included staffing, workload, the time required to have ACP conversations, infrequent admissions, concerns regarding legal liability, lack of peer support, and poor team communication.

A work environment barrier that was brought up by just over half of the LTC nurses in this study (8 of 15 participants) was confusion about responsibility for ACP communication. One nurse participant, who has worked her whole career in LTC settings, spoke about some of the negative aspects of ACP and mentioned, "I think one of the biggest ones is that, because it's everyone's responsibility, it's no one's responsibility, so it often doesn't get done" (Participant 25, lines 87-88). A second participant who works on a LTC unit in a hybrid facility stated:

> I think in a way it's, like, everyone's role as a team to make sure we know what their wishes are, but roles get, like, overstepped, where maybe we think we're, like, higher than social workers but under doctors. So, it gets kind of, like, muddled as whose role is it really? (Participant 22, lines 555-562)

Furthermore, ACP role confusion was compounded by nurses reporting that they had been excluded from ACP discussions because in their LTC settings ACP is within the physician's purview. One participant described how physicians can be an ACP communication work environment barrier for nurses by stating, "…the doctors ask us to leave the room when they're having the ACP discussion in the family meeting, so it's never something I've had to do" (Participant 21, lines 207-209).

On top of that, the ACP form itself was brought up by several participants (6 of 15 participants) as a work environment communication barrier. One participant elaborated on why the ACP form can be frustrating to nurses in LTC settings:

> Um, negative aspects would be, um, it's [the form] sort of vague, especially in defining, like, the difference between an M and a C, kind of thing. Because, even in M, there are levels. Let's say, for where I work right now, they can be ACP M with transfer or with no transfer and, um, like, there's a lot of, um, I feel like there's a lot of gray areas in between, and it's not specific enough. Um [pause], so, yeah, I think that's mainly, like, the negative thing. (Participant 28, lines 89-101)

More work environment barriers that participants named as being potential ACP communication hindrances in LTC settings were nursing staffing and continuity of care. These work environment ACP communication barriers were best described by a nurse who now works on a LTC unit, after having spent years on a different unit with more stable staffing of nurses:

> Um, but now being on [the LTC unit], where you've got the nurses are changing a lot of times, you've got a lot of part-time staff, and so there's not as much continuity with the nursing staff. So, I've often found that the conversations tend to be initiated more by either the physician or social worker. (Participant 29, lines 420-427)

Finally, an interesting work environment barrier that was only directly discussed by one participant is that of racism. While almost half of the participants in this study (7 of 15 participants) did make indirect references to certain biases or prejudices as possible barriers to ACP communication (i.e., the nurse's and/or the patient's/family's language, accent, culture, religion, traditions, etc.), this one participant gave all of those allusions an unambiguous name: racism. The participant was very clear in stating that racism can be a communication hindrance, in general and including ACP discussions. For instance, this particular LTC nurse participant, who has worked many years on a LTC/PCH unit, referred to families who request to speak to only native English-speaking nurses and doctors:

> I'm just going to come right out and say that there's racism involved. So, that sometimes can be a little bit of a problem. Where people can get impatient with people who are not, like, English as their first language. And it can cause situations where there's miscommunication and mistrust, um, you know, because there isn't a good effort made to try to, you know, make sure that the communication is happening. (Participant 19, lines 655-668)

Racism, either from nurses towards patients/families or from patients/families towards nurses, can certainly impact if and when ACP communication takes place, both in LTC settings and beyond. And, even though only one participant mentioned racism by name, over half of the study participants (8 of 15 participants) implied in some way or another that discrimination can act as a barrier to effective ACP communication.

Although this section focused on a variety of communication hindrances that can stop nurses from engaging in ACP communication in LTC settings, the fifteen participants in this study were also able to name communication catalysts. These positive determinants of LTC nurses' ACP communication will be discussed in the next section of this chapter.

Communication Catalysts

The second subtheme that underlies the theme of *Sensibility of the Determinants of ACP Communication* is *Communication Catalysts*. This subtheme features the determinants of ACP communication that the study participants reported as being facilitators that may assist a nurse to improve their skillset and increase their inclination to take part in ACP with patients and families in LTC settings. The communication catalysts that were described by the LTC nurse participants in this study included *Personal Facilitators* and *Structural Facilitators* (see Appendix M and Figure 2).

Personal Facilitators. Personal facilitators like positive personal and professional ACP experiences and high comfort level with difficult discussions can be catalysts that encourage nurses and patients/families to partake in ACP discussions. Two types of personal facilitators were identified by participants: those related to the LTC nurses and those related to residents/patients and/or families. These facilitators will be reviewed below.

LTC Nurses' Facilitators. These facilitators described by participants focused on the LTC nurses themselves. Past personal and professional experience with EOL care, death, and dying seemed to encourage participants to conduct ACP discussions with patients and families in LTC settings. This included previous palliative care experience and expressed comfort discussing end of life. One participant thought about her nursing career and what helps her to engage in ACP communication by simply stating, "Um, I guess that I've just had a, a, a broad experience with, with end-of-life circumstances. And, um, I u-, I guess I draw on that experience" (Participant 15, lines 264-265). Another participant reflected on how his personal philosophy about death carries over into his role as a nurse:

> Um, I, I don't have a problem talking about death. I don't have a problem discussing, you know, people's thoughts about what happens when you die. And I'm, and I'm always, you know, I'm fascinated by different belief systems and stuff like that, you know? So, it's not like I have a very rigid belief system that, that I'm bringing to my role as a nurse. (Participant 29, lines 990-994)

Another facilitator presented by participants as a communication catalyst was rapport building and overall familiarity with the patients and families. A LTC nurse who has worked many years in the same PCH facility linked familiarity with the resident and family and nurses' ACP confidence by expressing:

> Um, what helps them to discuss is how well they know the family. Um, and how well they know their resident. If it's, uh, possibly say a nurse, an agent nurse, agency nurse might come in and not know the family well enough, so wouldn't have confidence to approach that family. But I think in knowing the family and the resident well, you have greater confidence because, well you, you just, they trust you so, they will listen to you and, um, you know, and as I said, you can just help them make the best decision and what, you know, for what they want. (Participant 5, lines 326-337)

Two other participants (participants 19 and 28) also talked about the importance of rapport building or familiarity with residents/patients and/or families as being an ACP communication catalyst.

Not only were past EOL experiences and rapport building seen as ACP communication facilitators, but participants also talked about nurses' hands-on and practical experiences with ACP as a communication facilitator. In fact, almost all of the LTC nurses in this study (13 of 15 participants) attributed their comfort with ACP communication to their years of ACP experience as part of their nursing practice. Perhaps not so coincidentally, the two remaining nurses who did not claim that they are fully comfortable with ACP also happen to be the participants with the least years of nursing experience. Participants described a progression over time to the development of their own ACP styles and scripts. One participant with well over a decade of nursing experience summed up how experience begets ACP discussions:

> So, there was a lot of admissions and discharges going on. So, I, I admitted a lot of patients over those years, and so I had to have that conversation every single time I admitted somebody. Basically, I got to a point where I pretty much had my own little spiel [laugh]. (Participant 29, lines 886-889)

Interestingly, a facilitator that was mentioned by two study participants was good assessment skills and clinical knowledge. This facilitator was highlighted as a tool that empowers nurses to discuss ACP with patients and families in LTC settings. For instance, one of the two LTC nurse participants succinctly stated:

> I find that clinically strong nurses have an easier time with the ACP discussions than the nurses that aren't very strong clinically. And I think that's a big part that we're missing, is being able to recognize clinically what's happening, what's going on, what's

> changing, um, and understanding it. It plays a big role. And I, I find the nurses that aren’t very clinically strong default to the physician. (Participant 18, lines 409-414)

Although this facilitator was directly named by only two participants, every participant in this study brought up the idea that years of nursing and/or ACP practice experience is a communication facilitator. Nursing experience may be connected to clinical knowledge and assessment skills. However, it is important to distinguish between these personal facilitators because clinical knowledge and assessment skills can vary greatly between individual nurses, regardless of years of nursing experience.

Resident/Patient/Family Facilitators. LTC nurses’ facilitators are not the only personal facilitators and ACP communication catalysts that participants mentioned in their interviews. There were also facilitators that were viewed as patient or family fueled and driven, regardless of nursing and/or healthcare team actions. One of the more cited facilitators in this group was the openness of the patient or family to discuss ACP with nurses. A LTC nurse participant captured this ACP communication facilitator best by stating:

> Well, I guess it’s, if the, if the patient seems interested in it, then it’s, like, if they ask questions and they want to know more, I mean, that's also, that’s very encouraging, and it makes you want to give them all the information you can. (Participant 33, lines 362-365)

The second most referenced patient/family facilitator in this subcategory was the family’s presence, understanding, and acceptance of the patient’s ACP decision. One participant explained how having a trusted family member with the patient can help encourage better ACP communication:

> Uh, it’s, it’s definitely helps to have somebody they trust with them. Uh, so their family member, their loved one with them to help them decide. Um, and explain things to them

> if, if we're not explaining it effectively. Um, just yeah. Especially, especially that, that connection. So, family trust. (Participant 15, line 355-359)

Another participant talked about how family acceptance and support of a patient's ACP translates into timely nursing care in EOL situations:

> Um, so, I think it went well, because the family understood, um, you know, the patient's wants, kind of thing, and the patient's needs. And as a healthcare team we were able to get there on time, wherein we made sure that the patient is comfortable, even at end of life, so, yeah. (Participant 28, lines 284-288)

Additionally, an interesting communication facilitator that emerged from data analysis was patients'/families' earlier ACP experiences. Four participants, who all happen to work on LTC/PCH units within hybrid-care facilities, mentioned that patients/families who had prior experiences with ACP while in hospital were more open to discussing ACP during their admissions to LTC settings. In fact, these study participants felt that ACP should not be a new concept to patients/families entering LTC settings; thus, the patient's/family's pre-existing ACP exposure can act as an ACP communication facilitator.

Structural Facilitators. ACP communication catalysts that pertain to *Structural Facilitators* in this study included ones that looked at larger, unit-centered and/or institutional determinants of ACP discussions in LTC settings. For example, besides a person's internal motivations and commitment to ACP, structural facilitators like education, mentors, and workplace standards are things that can have a positive effect on ACP communication. Two types of structural facilitators were discussed by participants: *Educational Facilitators* and *Work Environment Facilitators* (see Appendix M and Figure 2).

Educational Facilitators. All fifteen study participants commented on educational facilitators that they saw as ACP communication catalysts for LTC nurses. Participants see education as a major determinant of ACP communication among LTC nurses. In fact, the participants in this study elaborated on where and how ACP education for LTC nurses should occur to help facilitate ACP communication with patients and families in their care.

ACP education in nursing school was mentioned by several participants as an important, foundational facilitator for LTC nurses' ACP communication in their nursing practice. A participant who has worked many years in a LTC/PCH facility proposed that ACP education in nursing school should generally cover potential patient/family issues that nurses may come across:

> Um, first of all, I think in, in gerontology in their course at University or college, or wherever it is, there should be ACP education at that point in time. A general instruction to advance care planning. Um, what it means. Um, how, how it affects family dynamics, and how it affects the resident. (Participant 24, lines 1046-1050)

A few of the study participants named mandatory ACP education for nurses as a structural and educational facilitator of ACP communication. To illustrate this idea, one participant who attended an optional EOL/ACP educational seminar that their employer offered to nurses, emphasized that it should be a required session for all nurses by stating:

> It's, it's actually, every nurse should go through that. But I, I find that, um, it's not mandatory. For example, it should, it should be, it should be as mandatory as the code red, code white, and all the other codes that we, we do every year. How come advance care planning, or end-of-life, is not mandatory for nurses to take? When do nurses get

> comfortable and get education about it? I don't know. But that's where I got mine. (Participant 17, lines 865-877)

Study participants also referenced ACP educational materials as structural facilitators and ACP communication catalysts. There were several examples of educational resources and materials that participants mentioned in their interviews as being educational facilitators and determinants of nurses' ACP communication in LTC settings, including ACP videos, workshops, the WRHA ACP discussion tool, an ACP booklet, WRHA palliative care physician videos, online ACP learning modules, and the palliative care program ACP conversation examples. Additionally, a couple of participants referred to the Digital Health, Shared Health Learning Management System (LMS) which is "a software application that can be used to administer, document, track and report on instructor-led and online courses" (Shared Health Manitoba, 2020, para 1). The LMS is used by healthcare workers in Manitoba, including nurses, to conduct learning activities that impact practice and patient care, and these participants talked about its potential use in facilitating ACP communication. In particular, one participant expressed, "But, um, should we have, um, just like everything else, instead of doing hand hygiene and, um, fire safety on LMS, why are we not doing something like advance care planning on LMS?" (Participant 23, lines 522-524). Still, according to the fifteen study participants, educational materials do not work alone as educational facilitators that help LTC nurses discuss ACP with patients and families.

Some of the participants in this study focused on educational facilitators that emphasize how LTC nurses can learn to effectively partake in ACP conversations with patients and families. For example, one participant equated ACP communication education to learning other practical nursing skills:

> …it's a skill, it's definitely a skill you have to learn, and you have to, like starting an IV. You know, if you've never done one before, you know, you're not that great, you're nervous, you're not sure of yourself. But the more you do it, the better you get. And I think ACP conversations are the same way. (Participant 18, lines 368-375)

This particular LTC nurse reiterated that ACP communication may be affected by nurses' clinical knowledge base by stating, "And then I also think we really need to ensure in long-term care the clinical knowledge of our nurses is kept up" (Participant 18, lines 404-405). Participants identified that ACP education has an equally important hands-on, experiential side that is essential to facilitating nurses' ACP communication competence with patients and families in LTC settings.

Nevertheless, the educational facilitators that were discussed are not the only structural ACP communication facilitators that participants talked about. The fifteen LTC nurses who were interviewed for this study also talked about ACP communication catalysts that come from their work settings.

Work Environment Facilitators. Participants discussed structural facilitators that can have a motivating and/or supportive effect on LTC nurses' ACP practice. Six of the fifteen LTC nurse participants talked about how raising ACP's profile through public education campaigns was important in normalizing ACP for patients/families, before nurses discuss it with them in LTC settings. One participant who has worked many years in a variety of LTC settings pointed out, "Like, I [pause] [sigh], most [sigh], you know what, when I talk to my clients, most of them don't know what it is" (Participant 33, lines 42-43). However, a different participant thought about his own personal and professional ACP awareness and experience and shared:

> And I know that, and I'm, I know that when I was younger, like, before I became a nurse, that from my own personal experiences it was, it wasn't really the sort of thing that got discussed a lot. It didn't usually come up. And it's become far more normal. People, a lot more people, nowadays, when you start talking about advance care planning, they know what you're talking about. Or they've had some kind of a conversation already, so it's not brand new. (Participant 29, lines 1063-1072)

Even though ACP has been a topic of healthcare conversation since the 1990s (since the early 2000s in Manitoba), these contradictory views show that nurses are seeing inconsistencies in patients' and/or families' ACP awareness. Moreover, nurses reported that more public awareness of ACP would help encourage nurses to discuss ACP with patients/families who are in the LTC system; because nurses would feel more at ease discussing such a difficult topic with patients/families who have some prior knowledge of, or familiarity with, the subject of ACP.

Another six out of fifteen study participants stated that health region and workplace standards, including the ACP form itself, are a communication catalyst for LTC nurses' ACP communication. In particular, a LTC nurse who works on a LTC/PCH unit within a hybrid-care facility clearly expressed:

> Um, and I mean, it certainly helps that we have, we have a Manitoba Health standard that it has to be done. So, having a structural plan, their program, whatever, that this does need to be discussed on a regular basis. That this, um, piece of paper has to be filled out within, you know whatever, 24 hours of admission. So, you know, having those kinds of, uh, you know, standards are, makes it helpful. (Participant 19, lines 762-767)

In addition to the WRHA/MB Health LTC ACP standards that were discussed, a contradiction arose between several of the participants when it came to comments about the ACP form itself. In fact, four participants made comments about whether or not the ACP form was an ACP communication facilitator or a barrier. Two of the four study participants claimed that the ACP form works as a bit of a barrier to effective communication, and that it should be improved to help facilitate better communication between nurses and patients/families. Whereas the other two participants made comments about being satisfied with the ACP form as is, and that it helps them discuss ACP with patients/families. Although this contradiction regarding the ACP form exists, many participants still said that WRHA/MB Health LTC standards, including the standardized ACP form, are work environment facilitators that help LTC nurses discuss ACP with patients/families.

Six participants referred to scope of practice and ACP role clarity as work environment communication catalysts. LTC nurse participants felt that ownership of ACP discussions among nurses can be facilitated by knowing that it is part of a nurse's job (i.e., scope of practice). Participants also stated that if nurses are aware that ACP is part of their role within the healthcare team (i.e., ACP role clarity), this role clarity could be a catalyst for nurse-led ACP communication in LTC settings.

A more practical facilitator that emerged from the data analysis looked at nurses supporting each other through ACP communication. Seven participants mentioned peers or colleagues as a facilitator. A participant who works in an educational role in a PCH elaborated on the idea of nursing peer/colleague mentorship by stating:

> So, I think the best thing is for them to watch them, and to listen to people that are good at it. People that are comfortable at it. And to not, and it's not just reading on paper what to do. I think they really, like the videos, or in like, participating and just listening to a real conversation. And being able to practice that, so, multiple times, maybe, until they

> feel comfortable having that person do the conversation. They watch them and then maybe that person is there with them as they're having them for the first time, or until they feel comfortable having them. I think having someone there to support, and jump in, and help out with the conversation. Almost like kind of a mentor. (Participant 18, lines 347-363)

A few nurse participants went on to say that a facilitator that goes hand-in-hand with nurse mentorship of ACP is the need for continuity of care by more full-time, experienced nurses. LTC nurse participants in this study emphasized the impact of nurse staffing on the quality of nurse mentors who may work as ACP communication facilitators for other nurses. This relationship between continuity of nursing staff and ACP peer mentorship was described well by one participant:

> Um, and I, and I think that's true of a lot of things in nursing, where you need strong mentors. You need, uh, and again [laugh], it comes back to having continuity of care. Having full-time nurses. Having people who have that experience and get to know the situations well and can guide someone who is part-time or new, or you know [pause], be a mentor. (Participant 29, lines 1367-1371)

The final work environment facilitator that various LTC nurses in this study (5 out of 15 total participants) claimed was a communication catalyst was the idea of gathering the healthcare team together to discuss ACP. One participant described how ACP is discussed at her PCH facility through an ethical lens:

> Um, one thing that you just said triggered something for me. And that is about the ethical end of this. Um, one of the things that we have at our facility is a very active Clinical Ethics Committee, uh, with frontline representatives…. What are the things that you have

> to deal with every day in your job that are causing ethical issues? So, we've talked about advance care planning. (Participant 25, lines 1361-1367 and lines 1374-1375)

Another study participant shared how they hope to improve ACP communication for nurses (and other healthcare team members) on her LTC unit within a hybrid facility through an interdisciplinary team approach:

> Um, we've actually just made a committee last week about how to, um, start the discussion on the ACP, um, on admission. And, um, we've all kind of come, but a bunch of different, like, social work, respiratory, the manager, myself, and I've brought in one of the nurses that actually has a difficult time, um, to do that, to come on that committee and just try to improve how it's done. (Participant 27, lines 433-442)

A healthcare team approach to ACP, both before and after discussing it with patients and families, was a work environment facilitator that several LTC nurse participants agreed would support them and their colleagues to engage in ACP communication with patients and families in their care. Perhaps this facilitator was mentioned by study participants because LTC nurses try to cultivate a work environment where they focus on wholistic patient care; so, they need the support of their healthcare team colleagues to achieve and maintain optimal nursing practice, including ACP communication with patients and families.

Summary

The two themes and subthemes identified through the data analysis process have been described. A visual representation of the themes and subthemes can be seen in Figures 1 and 2 and an itemized list of the themes and subthemes (in the order that they appear in this chapter) can be found in Appendix M. The two themes that developed from the thematic analysis of individual, telephone interviews with fifteen LTC nurses are *A Sense of an Ethical Obligation to Engage in ACP Communication* and *Sensibility of the Determinants of ACP Communication*.

Theme 1: A Sense of an Ethical Obligation to Engage in ACP Communication

The first theme, *A Sense of an Ethical Obligation to Engage in ACP Communication*, answers the first two research questions of this study:

- What are LTC nurses' experiences with ACP communication in their practice?
- What are LTC nurses' perceptions (e.g., thoughts, feelings, opinions) of their roles in ACP communication with patients and families?

The fifteen nurses in this study all spoke about a sense of duty, responsibility, or obligation to engage in ACP communication with patients and families. The way they thought about this obligation was influenced by their definitions of ACP, the way ACP was carried out in their workplaces, and their past experiences with ACP both personally and professionally. This sense of an ethical obligation in relation to ACP was enacted through roles and actions identified by the participants. These roles were: advocate, liaison, and mediator; communicator, caregiver, and LTC contact; and ACP educator and clarifier. The participants also described acting in ways to respect and promote patient autonomy.

Theme 2: Sensibility of the Determinants of ACP Communication

The second theme, *Sensibility of the Determinants of ACP Communication*, answers the third and final research question of this study:

- What do LTC nurses see as barriers and/or facilitators to ACP communication with patients and families in their practice settings?

The participants identified *Communication Hindrances* and *Communication Catalysts*. Two types of communication hindrances were described: *Personal Barriers*, including barriers related to the LTC nurses themselves and to patients and families, and *Structural Barriers*, including barriers related to education and work environments. The subtheme called *Communication Catalysts* described *Personal Facilitators*, those related to the LTC nurses and those related to patients and families, and *Structural Facilitators*, those related to education and those related to work environments. In the final chapter of this thesis, the implications of these findings will be discussed.

Chapter 5: Discussion

The purpose of this qualitative interpretive description study was to explore nurses' perceptions of ACP communication with patients and families in LTC settings. Careful, extensive reading and consideration of the scholarly literature pertaining to nurses' ACP practice showed that a gap existed in the area of ACP communication research that focused on nurses working in LTC settings. In this chapter, the findings of this study are discussed in relation to the ACP communication literature that was analyzed and synthesized for the literature review chapter (i.e., Chapter 2) of this thesis. Additionally, the limitations of this study are identified. Finally, recommendations for nursing practice, ACP education, and future research are discussed.

Thematic Findings

Fifteen nurses participated in this study and shared their perceptions of ACP communication with patients and families in their LTC settings. The findings of this study illustrated that these LTC nurses felt a sense of an ethical obligation to engage in ACP communication and demonstrated a sensibility or awareness of the determinants (e.g., the facilitators and barriers) of ACP communication that influence whether and/or how nurse-led ACP discussions occur. The two main themes were then examined in comparison to the ACP literature reviewed for this thesis.

Theme 1: A Sense of an Ethical Obligation to Engage in ACP Communication

The findings under this first overarching theme, which answered the first two research questions in this study, are consistent with what other researchers and scholarly writers have noted in their ACP communication studies and descriptive articles. The ethical nature of nursing and the nurses' duties to patients therein are laid out by the CNA (2017) in the code of ethics for registered nurses and by the CLPNM (2014) in their code of ethics. As ACP is an ethically motivated communication activity that falls under a nurse's scope of practice, it makes sense that the findings in this study reflect the links between ethics, nursing practice, and ACP communication that were seen in the ACP literature (CNA, 2017; Hebert et al., 2011; Jeong et al., 2009; Lenherr et al., 2012). The findings in this study were generally in line with the scholarly ACP literature (e.g., the roles identified for nurses were similar, many of the barriers and facilitators to nurses' ACP communication were similar). However, the findings of this study demonstrate a clearer sense of an ethical obligation to engage in ACP communication as expressed by this sample of fifteen LTC nurses than was evident in some of the literature reviewed for this thesis.

There may be a few reasons why the participants in this study articulated a clearer sense of nurses' ethical obligation to engage in ACP communication with patients than seen in earlier studies. This may have been due to the types of questions that were asked from the interview guide (see Appendix I) that attempted to delve into the nurses' perceptions of their overall experiences with ACP communication. It may also be related to how LTC nurses develop rapport with their patients and families over time and how they view their patient care duties and responsibilities. LTC settings are different from other settings in terms of the opportunities provided to nurses to come to know the patients in their care. The experiences that some of the participants described of feeling as though they had failed patients by sending them out for care they deemed as inappropriate also shaped their sense of obligation or responsibility to residents in their care. It is also possible that over time, and as ethics has been integrated into nursing education in a more deliberate way, that nurses have a heightened awareness of their ethical responsibilities in general, and more particularly related to ACP. Regardless, a sense of an ethical obligation to engage in ACP communication was explicitly expressed by participants in this study.

Factors Identified as Influencing Nurses' Sense of an Ethical Obligation. One of the factors identified as influencing nurses' sense of an ethical obligation was how they defined ACP. This is in keeping with findings from other studies. It was noted in a seminal article by Teno et al. (1994), and in a more recent scoping literature review by Flo et al. (2016), that differing opinions about the definition of ACP exist and could impact how HCPs view ACP (e.g., as a form to fill out as part of the documentation requirements for patient care or as an ongoing series of conversations). It is noted that the process to develop a more current definition of ACP, involving a 52-person, international, multi-disciplinary Delphi panel, was complicated by tensions and disagreements over several issues, including written forms versus discussions, before a consensus was finally reached (Sudore et al., 2016). Similarly, participants in this study expressed differences in how they understand and define ACP. A small number of participants in this study defined ACP as a form that needs to be filled out at patient admission, while most of the participants viewed ACP as involving ongoing discussions with their LTC patients. While all felt an obligation to engage in the ACP process, their understanding of the process varied.

A second factor identified as influencing participants' sense of an ethical obligation to engage in ACP communication was the way in which ACP is currently done in their LTC settings. The literature demonstrates how characteristics of a patient care setting (i.e., staffing, resources, training, leadership, and evaluation practices) may affect nurse involvement in ACP communication (Baughman et al., 2015; Rietze et al., 2018). Interestingly, the findings of this study showed that how LTC settings are classified (e.g., as PCH units/facilities versus non-PCH

LTC units within hybrid-care facilities) may impact when and how nurses are involved in ACP discussions.

The participants in this study who worked on PCH units reported being very involved in ACP from admission to EOL. Some participants in this study who worked on LTC units within hybrid-care facilities, at times with more of an acute care patient population and focus, revealed that their ACP involvement was limited to only admission ACP. These findings somewhat contrast with an ACP engagement study done by Rietze et al. (2018) comparing acute care nurses with nonacute care (including LTC) nurses where researchers found that acute care nurses engaged in ACP discussions more often than nonacute care nurses. These researchers found that 59% of their acute care RN participants and 27% of their nonacute care RN participants "reported ever engaging their patients in ACP" (Rietze et al., 2018, p. 234). In contrast, participants in this study who worked on LTC units where the patient care focus had more acute tendencies reported lower instances of ACP involvement (especially after admission), while nurse participants working on nonacute PCH units asserted that they were consistently and frequently involved in ACP communication.

A number of the participants in this study who worked on LTC units with higher patient acuity stated that physicians and social workers were more responsible for ACP communication with patients because they were present on the units more consistently (i.e., three to five times a week) than the individual nurses. The participants in this study who worked in PCH settings identified that physician and social worker accessibility and availability was limited (i.e., once a week), and that the LTC nurses were the most consistent HCP on the units. These study findings indicate that nurse staffing and physician and/or social worker availability on different LTC units may impact continuity of care and ACP communication with patients and families.

Findings from this study also showed that nurse participants' personal and/or professional ACP experiences shaped their sense of an ethical obligation to engage in ACP with patients and families. For instance, the participants in this study linked positive and negative ACP experiences with ACP agreement and disagreement between HCPs and patients or families. Participants in this study shared personal and professional examples of consensus between the healthcare team and patients and families with regard to the patients' ACP and EOL care goals. Study participants also revealed that they dealt with ethical dilemmas and distress in relation to situations where the healthcare team and patients and families disagreed on the patients' ACP goals of care (CNA, 2017).

These LTC nurses' experiences are supported by literature that found that nurses' experiences with families related to patients' ACP choices influenced how nurses approached ACP in their practice (Cornally et al., 2015; Jeong et al., 2009; Moore, 2005; Teno et al., 1994). Both the literature and participants in this study stated that nurses felt that they could fulfill their ethical obligation to engage in ACP when the healthcare team and patients/families were in agreement about patients' ACP goals of care (Cornally et al., 2015; Jeong et al., 2009). But when faced with patient/family strife and disagreement related to patients' ACP goals of care, nurses in this study and in the literature felt that full engagement in ACP communication with those patients/families was difficult for them (Cornally et al., 2015; Jeong et al., 2009). And as a result, LTC nurses in this study and in the literature experienced some distress in providing care that did not necessarily reflect what their patients wanted, especially in EOL situations (Cornally et al., 2015; Jeong et al., 2009).

Also referencing personal ACP experiences, participants in this study shared that reflecting on ACP and filling out the ACP form for themselves and/or for their own loved ones inspired them to embrace their professional nursing role in ACP and take part in ACP communication with LTC patients and families. In contrast, a study conducted with nurses working in acute geriatrics settings reported that nurses who had personal experiences in serving as substitute decision makers for family members were less inclined to engage in ACP communication with patients in their care (Black & Emmet, 2006). Perhaps the dissonance in these findings is due to the timing of each study: Black and Emmet's study is from 2006, and this study is from 2021. It can also be argued that perhaps ACP has become more accepted by nurses over time as a positive activity, and that nurses' personal and professional ACP experiences may influence their overall sense of an ethical obligation to engage in ACP discussions with patients that are in their care.

Roles and Actions in ACP. A number of roles and actions related to ACP were identified in this study flowing or arising from the nurses' sense of an ethical obligation to engage in ACP communication. Existing ACP research reflected many of the same roles that were named in this study by LTC nurse participants: *advocate, liaison, and mediator* (Baughman et al., 2012; Black, 2006; Jeong et al., 2009; Nedjat-Haiem et al., 2016); *communicator, caregiver, and LTC contact* (Baughman et al., 2012; Black, 2006; Nedjat-Haiem et al., 2016; van Soest-Poortvliet et al., 2015); and *ACP educator and clarifier* (Baughman et al., 2012; Black, 2006; Nedjat-Haiem et al., 2016). Similarly, the nursing role of *acting in ways to respect and promote patient autonomy* that was found in this study was also mentioned in previous ACP communication research as both a nursing role and as an enhancing factor that encourages ACP discussions between nurses, patients, and families (Black, 2006; Black & Emmet, 2006; Cornally et al., 2015; Jeong et al., 2009). It is likely that the roles described by study participants in this study were influenced by an underlying feeling of ownership of ACP that was expressed by over half of the LTC nurse participants in this study.

Some of the literature reviewed for this study found that nurses working in a variety of settings and under various job titles claimed that ACP discussions were not necessarily their responsibility (Baughman et al., 2012; Beck et al., 2016; Ke et al., 2015; Rietze & Stajduhar, 2015). But it has also been well documented that nurses are the main caregiver that patients and families have continued and sustained interactions with, both in acute care and LTC settings (Head et al., 2018; Rietze & Stajduhar, 2015; Rietze et al., 2018). This prolonged professional interaction between nurses and patients, especially in LTC settings, seems to foster an environment that encourages and/or enhances nurses' self-proclaimed role of being responsible for ACP communication, as evidenced by what several participants asserted in this study. This sense of responsibility has not been well described in the literature. This may be due to the lack of studies to date that have been done with LTC nurses as the main focus of ACP research.

Theme 2: Sensibility of the Determinants of ACP Communication

The fifteen LTC nurses who were interviewed for this study demonstrated a sensibility of the determinants of ACP communication by sharing their perceptions of hindrances and catalysts to ACP discussions encountered in their nursing practice. In addition to naming barriers and facilitators, participants in this study conveyed in their interviews that this sensibility and awareness of communication hindrances and catalysts affected their ACP practice. For example, participants in this study reported that in the absence of formal ACP education they sought out self-education activities like reading ACP information packages before engaging in ACP discussions with patients or families. Participants in this study also talked about receiving and providing ACP peer support and mentorship as catalysts for their involvement in ACP communication. And several LTC nurses interviewed for this study shared that they actively participated in interdisciplinary committees where ACP practice and the improvement of ACP communication between HCPs and patients/families were topics of discussion. Similarly, researchers that previously studied LTC nurses' ACP communication indicated that nurses were able to identify barriers and facilitators (e.g., education, peer mentorship, and interdisciplinary approaches to ACP), and that nurses were able to apply their awareness of these determinants of communication to influence and/or improve their actual ACP practice (Beck et al., 2016; Cornally et al., 2015; Ludwick et al., 2018; O'Conner-Von & Bennett, 2020; Yokoya et al., 2018).

Participants named a variety of individually nuanced, yet interconnected and/or interrelated, barriers and facilitators to ACP communication, which served as answers to the third and final research question in this study. Additionally, the findings of this research that focused on communication hindrances and catalysts were separated into LTC nurse, resident/patient/family, educational, and work environment barriers and facilitators. The findings under this second overarching theme are broadly in line with findings from prior studies where ACP communication barriers and facilitators were examined.

Communication Hindrances. Several researchers and scholars have concluded that lack of comfort with death/dying (Brooke & Kirk, 2014; Ke et al., 2015; Lenherr et al., 2017; Moore, 2005; Rietze & Stajduhar, 2015; Rietze et al., 2018), lack of confidence with engaging in ACP discussions (Ampe et al., 2017; Briggs & Colvin, 2002; Brooke & Kirk, 2014; Rietze & Stajduhar, 2015; Weiner & Cole, 2004), patient/family conflict (Beck et al., 2016; Cornally et al., 2015; Jeong et al., 2009; Ke et al., 2015; Lenherr et al., 2012), education gaps (Beck et al., 2016; Ke et al., 2015; Rietze & Stajduhar, 2015; Rietze et al., 2018; Yokoya et al., 2018), and unclear healthcare staff roles (Beck et al., 2016; Rietze & Stajduhar, 2015; Rietze et al., 2018) are significant and common ACP communication barriers. Based on the findings of this study, these hindrances to ACP communication that were highlighted in the ACP literature appear to still be present in LTC settings today. However, this study found two ACP communication barriers that were less explicitly, or less straightforwardly, mentioned in the ACP literature: the ACP form and racism.

Some studies and descriptive articles named ill-defined and inadequate ACP policies and documentation requirements as barriers to ACP communication (Baughman et al., 2012; Beck et al., 2016; Flo et al., 2016; Rietze & Stajduhar, 2015; Rietze et al., 2018), but none directly referenced the ACP form as a barrier. Participants in this study specifically elaborated on how the standardized ACP form that is currently used in Manitoba is basic, dry, and vague, making it a barrier to ACP communication in their opinion. This is an interesting contextual and/or regional communication barrier highlighted in this study, as the documentation of ACP likely differs across different geographical areas (CHPCA, 2020).

Moreover, both the ACP literature and participants in this study claimed that HCPs' and patients'/families' cultural backgrounds, language, and religious beliefs can be ACP communication barriers (Baughman et al., 2012; Flo et al., 2016; Hebert et al., 2011; Johnstone & Kanitsaki, 2009; Ke et al., 2015; Lenherr et al., 2012; Ottoboni et al., 2019; Yokoya et al., 2018). An important finding that was explicitly mentioned in this study was the ACP communication barrier of racism. Direct references to racism as an ACP communication barrier were not seen in the literature reviewed for this study. But by only making general references to cultural and language barriers, it is possible that the underlying, nuanced, and insidious effect that ignorance, prejudice, and discrimination may have on ACP communication may be missed

(Johnstone & Kanitsaki, 2009). Therefore, having racism, both from patients/families towards nurses and from nurses towards patients/families, emerge as a specific ACP communication barrier in this study appears to make it a new or different finding compared to barriers mentioned in previous studies. Highlighting racism as a barrier in healthcare communication, including ACP, may be especially important when one considers the vast, culturally diverse population of Manitoba and of Canada at large.

Communication Catalysts. Many of the communication catalysts that were found in this thesis study are direct opposites of the communication hindrances that participants shared in their interviews. Several studies and descriptive articles also found that communication facilitators often mirror barriers, and that facilitators are oftentimes seen as solutions to the impediments to ACP communication. In fact, ACP communication facilitators that were common findings, both in this study and in previous ACP research, included: comfort with death/dying (Lenherr et al., 2012; Moore, 2005); ACP discussion experience and confidence (Ampe et al., 2017; Rietze & Stajduhar, 2015); patient/family agreement (Beck et al., 2016; Cornally et al., 2015; Jeong et al., 2009; van Soest-Poortvliet et al., 2015); ACP education (Ampe et al., 2017; Arnett et al., 2017; Baron et al., 2015; Beck et al., 2016; Cornally et al., 2015; Ke et al., 2015; Rietze & Stajduhar, 2015; Rietze et al., 2018; Yokoya et al., 2018); and HCP role clarity (Beck et al., 2016; Cornally et al., 2015; Rietze & Stajduhar, 2015). Other notable ACP communication facilitators that were mentioned by participants in this study, and were supported by the scholarly ACP literature, included peer support/mentorship (Ampe et al., 2017; Beck et al., 2016; Cornally et al., 2015; Ke et al., 2015; Rietze & Stajduhar, 2015) and ACP teamwork among HCPs (i.e., frontline nurses, physicians, social workers, and nurse managers working together to discuss ACP with patients and families) (Ampe et al., 2017; Arnett et al., 2017; Beck et al., 2016; Black, 2006; Cornally et al., 2015; Ke et al., 2015; Nedjat-Haiem et al., 2016).

Participants in this study interestingly connected the facilitator of ACP peer support/mentors to the facilitators of nursing staffing and continuity of care. The nurses interviewed in this study claimed that ACP communication can be bolstered by experienced, full-time nurses, and that these nurses can then serve as ACP mentors for less experienced nurses in LTC settings. This study finding is only indirectly seen in the literature as references to such facilitators as manageable patient assignments/workloads (Ampe et al., 2017; Arnett et al., 2017; Beck et al., 2016; Black, 2006; Head et al., 2018; Ke et al., 2015) and having more time to conduct ACP discussions (Ampe et al., 2017; Arnett et al., 2017; Beck et al., 2016; Black, 2006; Head et al., 2018; Ke et al., 2015; Oliverio & Fraulo, 1998). Several participants in this study asserted that a link exists between the amount and quality of ACP mentorship and nursing staffing issues in LTC settings. The literature does not seem to directly link these facilitators and only mentions a possible link between mentorship and staffing in passing. For example, in a study looking at the differences and similarities between nurses' and social workers' roles in ACP, it was revealed that their participants were able to engage in ACP due to having "patient assignments that allowed for continuity of providers" (Black, 2006, p. 183). Most ACP studies done to date involved nurses working in acute care settings; so, perhaps this is a finding that may speak to the specific nature of nursing staffing levels, turnover, and continuity of care that currently exists in LTC settings.

Another fascinating communication catalyst that participants in this study posited was that patients'/families' previous ACP experience (e.g., while in hospital and/or in the community) can be an ACP communication facilitator for LTC nurses. This study's participants felt that individuals who are being admitted into LTC settings should have already done ACP at one point or another along their healthcare system trajectory. Participants in this study also felt that this prior ACP experience may make the patient/family more easily approachable from the nurse's perspective. The studies and descriptive articles that were reviewed for this thesis did not feature patient/family past ACP experiences as an ACP communication facilitator.

However, a facilitator that was mentioned in both the ACP literature and by the participants in this study is the idea of raising public awareness regarding ACP in general. It can be argued that there may be a relationship between raising the public's collective consciousness related to ACP and how ACP is received or processed by patients/families in community, hospital, and/or LTC settings, but no such connection is currently evident in the scholarly literature. According to participants in this study and in the ACP literature, public education about ACP and changing societal norms and/or expectations related to death/dying (i.e., normalizing death/dying as a natural and inevitable process, and recognizing promoting patient autonomy and expression of EOL care wishes as advisable and prudent) are fundamental facilitators to ACP communication (Arnett et al., 2017; Beck et al., 2016; Brooke & Kirk, 2014; CHPCA, 2012; CHPCA, 2020; Head et al., 2018; Ke et al., 2015; Oliverio & Fraulo, 1998; Ottoboni et al., 2019). The finding in this study that a catalyst for LTC nurses' ACP communication is patients'/families' pre-existing familiarity with ACP discussions before their LTC admissions is interesting. It emphasizes the importance of ACP communication across the healthcare spectrum, from the community to acute care to LTC settings.

Limitations of the Study

All studies have limitations, and a few were highlighted during and after this qualitative interpretive description study. Participant recruitment, data collection, and data analysis for this study took place during the COVID-19 global pandemic in 2020. The pandemic affected all healthcare settings in Manitoba, including LTC settings, and this may have negatively impacted the overall willingness and/or ability of LTC nurses to participate in this study.

The pandemic may have also affected informed consent protocols for this study, because meeting with potential participants and having them read and sign the consent form in-person was prohibited by the University of Manitoba during the pandemic. In fact, study recruitment may have been negatively affected by the use of electronically signed and returned ICFs, as evidenced by having had a total of thirty-five LTC nurses who initially responded positively to the recruitment email, but only fifteen LTC nurses responded with an electronically signed and emailed ICF. This electronic ICF activity may have been too labor intensive and/or too technical for some of the potential LTC nurse participants to deal with.

This study aimed to recruit 10-20 participants and ended up with fifteen LTC nurses as interviewees. The recruitment period for this study started on March 13, 2020 (i.e., close to the start of the first pandemic lockdown in Manitoba), continued until there were two weeks of no more emails of interest from potential participants, and was closed on July 3, 2020. It is possible that the study sample number could have been closer to, or over, twenty participants if the recruitment period had been longer, or if a third recruitment email had been sent out to LTC nurses.

Although a sample size of fifteen LTC nurses was right in the middle of the participant number that was proposed, this study was still a small study with a small sample size. Additionally, the majority of participants were RNs (12 out of 15 participants), so LPNs were not as well represented as RNs were in this study's sample and the transferability of findings to LPNs working in LTC may be limited. Furthermore, the vast majority of participants were working in Winnipeg, Manitoba, so the transferability of the findings of this study to other LTC settings within Manitoba, and/or in other regions across the country and around the world, is therefore uncertain. This study also had many participants who admitted that they had a passion for ACP; therefore, LTC nurses' willingness to participate in this study, and their answers to the interview guide questions, may have been skewed in a particular way.

Due to the COVID-19 precautions that were laid out by the province and by the University of Manitoba, in-person interviews were prohibited. Thus, individual interviews for this study were conducted over the telephone. Consequently, it was difficult to gauge participant engagement with interview questions visually, so some participant answers may have been prematurely and unintentionally cutoff or less descriptive, leading to a potential loss of rich data. The use of video calls may have provided additional data not evident from a telephone conversation. Furthermore, the length of interviews (60 to 90 minutes) could have also acted as a deterrent for potential participants, as it may have been hard for them to find time to be interviewed for this study. The interview guide was not shared with participants prior to each interview; thus, providing participants with the interview guide questions prior to the individual interviews may have resulted in more thorough and/or thoughtful answers.

Moreover, I (the principal investigator) had worked with five of the fifteen participants at one point or another in my nursing career, which may have influenced their willingness to participate and the overall candor of their responses to questions in this study. Additionally, the possibility of unintended bias may have existed in this study, as I worked on a LTC unit within a hybrid-care facility for most of my nursing career; therefore, my nursing experiences with ACP and with LTC patients and families may have impacted the lens through which I analyzed the data and ultimately came to my thematic conclusions. But my experience as a LTC nurse may have helped me to understand, interpret, and describe the nuances and deeper meanings that emerged from the interview data that were collected for this study. In any case, I was transparent with participants when they asked me about my nursing background, my motivations, and my intentions for conducting this ACP study for my MN thesis. And my faculty advisor checked all of my data analysis procedures and findings in order to strengthen the overall trustworthiness of this study and its findings.

Implications for Practice and Education

The purpose of this qualitative interpretive description study was to explore nurses' perceptions of ACP communication with patients and families in LTC settings. Despite declaring that they felt passionate about ACP communication in their LTC nursing practice, participants in this study shared that nurse-led ACP communication in LTC settings is still inconsistently and/or intermittently done. In fact, two participants from this study touched on the current state of LTC nurses' ACP practice by claiming, "I think it's still a long area for growth for long-term care" (Participant 24, lines 1121-1122) and "I feel like in long-term care we don't do it as well as we should" (Participant 18, lines 442-443). This study was conducted to get a better understanding of LTC nurses' experiences with ACP, their thoughts about the role of the nurse in ACP, and what they saw as barriers and facilitators to nurses' ACP communication. Key findings from this study highlighted the participants' sense of an ethical obligation to engage in ACP communication and their sensibility of the determinants of ACP communication. The insights that were gained from study participants have the potential to affect nurses' ACP practice and education.

Nursing Practice

This study showed that the participants believed that ACP communication should be part of a nurse's job, yet LTC nurses' involvement in ACP beyond patient admission remains inconsistent at times. Reasons for limited and intermittent ACP engagement among LTC nurses are multifaceted. This study was conducted to try to shed light on this issue and to hopefully improve nurses' ACP practice.

First, this study highlighted the idea that LTC units labeled as PCH units differ from LTC units that are not specifically labeled as PCH units. Participants in this study reported working in one or the other type of LTC setting, and it was found that the differences between a PCH unit and a non-PCH LTC unit within a hybrid-care facility may result in different ACP practice for nurses. Although participants who work in PCH or non-PCH LTC settings stated that nurses are the patients'/families' main healthcare contacts, caregivers, and communicators, the two LTC settings are seemingly set up in a way that either encourages or discourages LTC nurses from participating in ACP conversations on a consistent basis. This difference in ACP practice among nurses who work in different LTC settings may be due to work environment factors like nurse staffing, physician availability/presence, and social worker involvement (Arnett et al., 2017; Black, 2006; Cornally et al., 2015; Nedjat-Haiem et al., 2016; Rietze et al., 2018).

For instance, nurse participants who worked in a PCH setting where physician access may be limited shared that they have more ownership of their role in ACP communication than their nursing colleagues who work on non-PCH LTC units. Participants in this study who worked on non-PCH LTC units where the physician is present several times a week shared that their engagement in ACP communication with patients and families is limited, and that it is not necessarily their role within the healthcare team to do ACP beyond brief admission discussions.

According to participants in this study, ACP ownership appears to lead to more nurse-led ACP communication with patients and families on PCH units.

As stated in the literature, and by participants in this study, LTC nurses often develop trusting and caring relationships with patients/families over long periods of time (Head et al., 2018; Ke et al., 2015; Ludwick et al., 2018; O'Conner-Von & Bennett, 2020; Rietze & Stajduhar, 2015). As such, nurses in the literature and in this study have expressed that they want and need to know and understand their patients' healthcare wishes so that they can provide appropriate patient-centered care, especially in EOL care situations (Jeong et al., 2009; Ludwick et al., 2018; O'Conner-Von & Bennett, 2020; Yokoya et al., 2018). Thus, it is important that LTC nurses, regardless of LTC setting/workplace, are involved in ACP communication with patients and families as much as possible. Where nursing practice is concerned, this study may inspire nurses who currently have limited ACP engagement in their LTC settings to question their current ACP communication role and to invest more time and effort into discussing ACP with patients and families henceforth.

Additionally, findings from this study indicated that nurses need to reflect on their past personal and/or professional ACP experiences in order to use these reflections to more positively inform their current and future ACP practice. When looking at the barriers and facilitators to ACP communication, this study found that nurses need to increase their self-awareness related to how they feel about death/dying and what personal factors influence their current ACP practice. This type of self-reflection done by LTC nurses has the potential to get nurses to confront their feelings, deal with their trepidation, increase their confidence, and ultimately be more involved in ACP communication with patients and families in their care (CHPCA, 2020; Moore, 2005; Weiner & Cole, 2004). Self-reflection could also give LTC nurses the opportunity to think about any positives that exist in their current ACP practice (e.g., building rapport with patients/families, knowing their patients' EOL care wishes, being a liaison between patients/families and the healthcare team) and they could apply those positives in future ACP discussions (Black, 2006; Cornally et al., 2015; Moore, 2005; O'Conner-Von & Bennett, 2020). Perhaps this type of reflective education related to self-awareness could be offered starting in nursing school and continue in healthcare settings.

Awareness and ownership of the different ACP roles that LTC nurses occupy and reported in this study may affect how they see themselves in the context of patient and family communication. If LTC nurses feel responsible for ACP, they will most likely engage in the advocate, mediator, and liaison roles that support the promotion and respect of patients' autonomy. They also need to link their roles of being key communicators, caregivers, and LTC contacts with their roles of educator and clarifier to ensure more effective ACP communication with patients and families. Oftentimes, observation of nurse colleagues engaging in these ACP communication roles, including the nursing roles that were found in this study, can spark belief in and ownership of these ACP roles in other nurses.

Furthermore, this study showed that LTC nurses felt that ACP role clarification is needed within their work settings. Because ACP communication is generally seen as a healthcare team activity, perhaps role clarification on LTC units could be achieved via interdisciplinary ACP committees. In fact, a few participants in this study shared that they have participated in interdisciplinary committees on their LTC units and that they discuss ACP communication exclusively or discuss ACP communication as an ethical topic. These participants also shared that interdisciplinary committees were helpful in keeping their LTC healthcare team, including nurses, informed and engaged with ACP communication. Forming interdisciplinary committees to highlight and discuss personal and structural ACP barriers and facilitators, and to clarify ACP communication roles on individual units, could be a catalyst for nurse-led ACP discussions.

Investment in ACP mentors and making ACP mentorship a common practice is also an important take-away from this study. Increased nurse mentorship of ACP on LTC units may help increase nurses' good discussion habits, help with nurses' uptake of their ACP role, and may lead to more effective communication practices between LTC nurses and patients/families (Ampe et al., 2017; Beck et al., 2016; Cornally et al., 2015; Ke et al., 2015; Rietze & Stajduhar, 2015). Nurse managers have the potential to be useful leaders in this ACP mentorship endeavor, because they could find and encourage frontline nurses who are naturally gifted mentors to take up the ACP mentorship role with their fellow nurses. Also, to make more nurse ACP mentorship a reality, this sample of LTC nurses stated that there is a need for more nurses overall to alleviate workload and to leave more time for nurse-led ACP. Participants also stressed that more full-time nurses are needed to ensure more continuity of care for patients and to serve as ACP mentors for other nurse colleagues. In addition to this, maybe each LTC unit or facility could have ACP champions, or an ACP team, that can assist and mentor nurses through ACP communication struggles (Ke et al., 2015; Oliverio & Fraulo, 1998).

Finally, as previously mentioned and established, LTC nurses are the HCPs that are frequently and consistently in contact with and caring for patients/families on a daily basis; thus, LTC nurses are in a unique professional position to be actively engaged in culturally sensitive and appropriate ACP communication with patients and families (CHPCA, 2020; Ludwick et al., 2018; O'Conner-Von & Bennett, 2020; Rietze et al., 2018). Work with Indigenous populations is an area of nursing ACP communication practice that should also be addressed and evaluated. Nurses working in different LTC settings in Manitoba are likely to encounter and care for

Indigenous patients/families. The CHPCA pan-Canadian ACP framework has set “Reach out to underserved communities” (e.g., First Nations, Inuit, and Metis communities) as a priority action for ACP engagement and consultation activities (2020, p. 25). In light of the therapeutic relationships that LTC nurses often develop with their patients, nurses should be involved in initiatives within their LTC settings that focus on working with Indigenous patients/families to improve ACP communication practices. In fact, the advocacy role that was highlighted in the ACP literature, and was echoed by the LTC nurse participants in this study, is a nursing role that involves work “to improve systems and societal structures to create greater equity and better health for all” (CNA, 2017, p. 5). Therefore, nurses should be at the forefront of connecting with Indigenous communities to discuss and address issues related to healthcare inequity and systemic biases, and to explore how these issues specifically affect ACP communication between nurses and Indigenous patients/families in their care (CHPCA, 2020; CNA, 2017).

ACP Education

This study's LTC nurse participants stated that more ACP education is needed overall, both in nursing school and in healthcare workplaces alike. This study highlighted a sample of LTC nurses' thoughts about hindrances and catalysts to ACP communication; and, perhaps these personal and structural barriers and facilitators can potentially be used to inform ACP educational programs for a variety of healthcare settings. Changes to the quality and quantity of ACP education needs to occur to help bridge the gap that exists between nurses believing that ACP is part of their role and their actual ACP practice. Based on this study, educational programs for nurses and nursing students should include personal and situational awareness (i.e., awareness of one's surroundings/environment and the potential impact of those surroundings on

ACP discussions), how to understand and explain the ACP form and policy, a variety of ACP scenarios, and role-playing of ACP discussions in an encouraging environment with colleagues.

Additionally, participants in this study called attention to the definition of ACP and to the ACP form itself as being possible areas of confusion and frustration for LTC nurses when they are trying to have ACP discussions with patients and families. Nursing education, both in school and in the workplace, should focus on the foundational definition of ACP as being an ongoing process of communication and not just filling out a chart form (CHPCA, 2020). Participants in this study also reported that the current ACP form is too vague and basic and does not necessarily help them in ACP discussions. The current ACP form, along with the WRHA ACP policy, have both been in use since 2011 and may benefit from another round of re-evaluation and possible revision (WRHA, 2011). ACP form and policy education, including the definition of the different ACP levels, should begin in nursing school, be included in orientation education for new nurses in different healthcare settings, and it should also occur yearly for nurses.

According to participants in this study, yearly ACP education could potentially be achieved by using the Digital Health, Shared Health LMS. Some of the instructor-led and online courses that are currently on LMS and are available to nurses and other healthcare workers in Manitoba, include hand hygiene, personal protective equipment (PPE), the *Personal Health Information Act (PHIA)*, Indigenous health, respectful workplace, and wound care workshops, just to name a few (Shared Health Manitoba, 2020; WRHA, 2020). Due to non-traditional work schedules, nurses could in all likelihood benefit from a flexible, “learn on your own time”, online approach to ACP education, if a comprehensive ACP learning package or module was offered on LMS and effectively advertised to nurses. LMS may offer LTC nurses a convenient way to keep ACP communication skills up to date, especially if these skills are not used often. And, when new items are added to the ACP form or policy, yearly LMS education may help nurses stay up to date with the ACP practice expectations that are laid out by the WRHA. Perhaps an ACP learning module on LMS would be a way to introduce, continue, and refresh ACP education on a yearly basis for all nurses in Manitoba.

ACP education could also be focused on the interprofessional teams that work together in LTC settings. Individual HCPs (e.g., nurses, physicians, social workers, managers, etc.) do not work in silos when providing care to patients in LTC settings. For instance, ACP communication is often conducted by combinations of HCPs working together (e.g., nurses and social workers, physicians and managers, etc.) to ascertain and document patients'/families' care wishes and goals of care. Therefore, ACP education packages should be created for interdisciplinary teams to be able to work through different ACP scenarios together. This type of interprofessional ACP education should also teach HCPs about each other's roles in ACP and about how to approach ACP discussions with patients/families as a healthcare team.

Furthermore, ACP education could possibly be done using simulation-based education, both in nursing school and in healthcare workplace settings. According to Al-Elq (2010), "Simulation is a generic term that refers to an artificial representation of a real world process to achieve educational goals through experiential learning" (p. 35). In fact, experiential education through simulation-based clinical scenarios may create a safe, interactive environment where students, nurses, and other HCPs could apply ACP communication training and techniques (Al-Elq, 2010; Ellis, 2018; Pereira-Salgado et al., 2019). Simulation-based ACP education also has the potential to increase HCPs' knowledge and confidence in relation to these types of discussions (Al-Elq, 2010; Ellis, 2018; Pereira-Salgado et al., 2019).

Findings from this study also suggest that education related to the effects of racism on ACP is needed. Racism is an especially important issue that deserves educational attention in a province like Manitoba, where the healthcare workforce and the general population are both significantly culturally diverse. As indicated in this study, racism against nurses can lead to real-life practice issues if patients and families are unwilling to communicate with them. Equally, if nurses harbor concealed or overt prejudicial biases against certain patients and families, it can plausibly lead to situations where communication may break down and patient care may suffer. Not only should ACP education address potential cultural, language, and religious barriers that may affect nurses' ACP communication with patients and families (Baughman et al., 2012; Flo et al., 2016; Hebert et al., 2011; Johnstone & Kanitsaki, 2009; Ke et al., 2015; Lenherr et al., 2012; Yokoya et al., 2018), it should also include the consequences and ramifications that discrimination, prejudice, and racism may ultimately have on patient care.

Finally, an area of ACP education that was highlighted in this study was raising ACP's profile with the general public. In two recent national polls conducted by the CHPCA in 2013 and 2019, where Canadians were asked about their ACP attitudes and behaviors, it was found that 80% of respondents in 2019, compared to 51% in 2013, indicated that it was important to talk to HCPs about their ACP goals of care (CHPCA, 2020). The significant difference in responses to the CHPCA polls may point to the success that they have had with public education related to ACP communication over that last few years. Participants in this study stated that more public education campaigns (e.g., perhaps by using informational pamphlets at doctors' offices/clinics, television, internet, public transportation, and billboard advertisements) could help to normalize ACP communication, which in turn could eventually normalize ACP discussions for patients/families who are entering the healthcare system in acute care and LTC settings (Arnett et al., 2017; Beck et al., 2016; Brooke & Kirk, 2014; CHPCA, 2012; CHPCA, 2020; Head et al., 2018; Ke et al., 2015; Oliverio & Fraulo, 1998).

Recommendations for Future Research

The CHPCA (2020) has set priority actions to help ensure continuous quality improvement for the use of the 2019 Pan-Canadian Framework for Advance Care Planning in Canada. One of these priority actions is focused on ACP research and using that research data to change and improve ACP communication practices across the country (CHPCA, 2020). The CHPCA (2020) also asserted that, "For ACP research to have an impact, the questions, process, results, and recommendations must be developed in partnership with relevant stakeholders" (p. 29). Keeping this in mind, and considering the particular sample, setting, and findings of this MN thesis study, six recommendations for future research are identified.

As previously discussed, a gap was seen in ACP research conducted with LTC nurses. As such, a similar qualitative, quantitative, or mixed methods ACP communication study could be done with a sample of LTC nurses working in healthcare settings across Canada. This would likely increase the sample size, and it may make the findings/results more transferable or generalizable (depending on the research approach used) to nurses working in other healthcare settings and geographical regions (Connelly, 2016; Polit & Beck, 2012). Moreover, a quantitative survey of LTC nurses that investigates their thoughts about nurses' roles in ACP and barriers and facilitators to ACP communication could be useful and may build upon the findings of this study. Additionally, qualitative, quantitative, or mixed methods research related to factors that affect LTC nurses' "comfort and confidence" with ACP communication, and the ethical dilemmas and "moral distress" contained therein, could help elucidate issues that can potentially be addressed in future ACP practice, education, and research (CHPCA, 2020, p. 29).

Second, quantitative or mixed methods research investigating the effectiveness of an ACP education package or learning module (e.g., offered on LMS or otherwise) for nurses in a few PCH/LTC settings, or across Manitoba, could help with future ACP education efforts. For instance, mixing Likert-style surveys and one-on-one interviews to ask LTC nurses questions about what they have learned, if the education was helpful/useful, and what they would include and/or change about the ACP education package/module could be helpful in understanding what relevant stakeholders (i.e., LTC nurses, nurse educators, nurse managers, physicians, social workers, and patients/families) see as being important ACP educational issues (CHPCA, 2020). This type of research could have an impact on the quality and quantity of ACP education that nurses may receive in the future (Ampe et al., 2017; CHPCA, 2020).

Third, findings from this study showed that some LTC nurses see value in ACP committees and ACP teamwork. Therefore, research is also needed to help understand the role of LTC nurses and other members of the interdisciplinary team in LTC ACP communication. Perhaps qualitative, quantitative, or mixed methods ACP communication studies involving existing interdisciplinary committees in LTC settings could shed light on role clarity, communication, and teamwork issues that may influence ACP communication practice with patients and families (Black, 2006).

Based on the findings of this study, a fourth avenue for further study would be research into nurses' impressions of the standardized WRHA ACP form that is currently used. A qualitative, quantitative, or mixed methods ACP form study could be undertaken by the WRHA to explore HCPs' (including nurses) feelings about, and understanding of, the current ACP form and ACP policy. A study could also focus on the ACP form's ease of use, the effectiveness of the ACP form in discussions with patients and families, and suggestions that HCPs may have for the improvement of the current ACP form.

A barrier to ACP communication that was highlighted in the findings of this study was the issue of racism. Therefore, a fifth area of research is the need for studies that investigate how racism may affect LTC nurses' ACP communication with patients and families. Qualitative, quantitative, or mixed methods ACP research that examines nurses' experiences and perceptions of the impacts of racism on ACP communication could potentially inform future healthcare education, practice, and research.

Finally, a sixth possible area for further research and investigation would be the impact of COVID-19 on LTC nurses' ACP communication with patients and families. The coronavirus global pandemic has had a devastating effect on LTC settings, as many COVID-19 infections and deaths across Canada, and the world, have been among LTC patients (Canadian Institute for Health Information [CIHI], 2020). The majority of activities for this thesis study (i.e., participant recruitment, data collection, and data analysis) occurred during the pandemic; consequently, this study took place during the provincial lockdowns, and when there was increased stress put upon nurses and the healthcare system. Thus, the findings of this study may have been affected by the impact of COVID-19 on the LTC nurse participants and on the patients/families that were in their care. For this reason, more research is needed to understand the effects that the pandemic may have had on ACP communication, particularly from a LTC nurse perspective.

Conclusion

ACP is characterized by ongoing discussions between HCPs, including nurses, and patients and families about preferred future medical care. As the population in Canada continues to age and use more healthcare resources, it is increasingly important for HCPs to have conversations with their patients (and the patients’ families) about their values and wishes for EOL care, especially in LTC settings. Although it has long been established that ACP communication falls within a nurse’s scope of practice, many LTC nurses still do not fully and effectively undertake these types of discussions with their patients.

This MN thesis study aimed to explore nurses’ perceptions of ACP communication with patients and families in LTC settings. By using a qualitative interpretive description research method and a thematic analysis approach, this thesis answered three research questions related to LTC nurses’ ACP experiences, their roles in ACP, and the barriers and facilitators to ACP communication that are seen in their work settings. This study found that a sample of LTC nurses had a sense of an ethical obligation to engage in ACP communication, which was influenced by their definitions of ACP, the practice of ACP in their facilities, and their experiences with ACP and enacted through a variety of roles. Furthermore, the findings of this study showed that the LTC nurse participants had a sensibility or awareness of the determinants of ACP communication in their practice, which was supported by the communication hindrances and communication catalysts that they were able to describe in their individual interviews.

The findings of this study generally complemented, and were compatible with, the existing ACP research that has been done with nurses, especially in terms of highlighting nurses’ roles in ACP and in identifying barriers and facilitators (i.e., both personal and structural barriers and facilitators) to ACP communication. Notably, this thesis study took a more in-depth look at LTC nurses’ ACP practice, which was a contextual angle that was seldom seen in the ACP communication literature featuring samples of nurses. In fact, the findings in this study shed light on what ACP knowledge and experiences LTC nurse participants have had and how these experiences influence their ACP practice. These findings are important in determining what a sample of LTC nurses already knew about ACP, and according to them, how they applied their ACP knowledge in real-life situations with patients and families within their LTC settings. Comparing and contrasting the lived ACP experiences of the LTC nurses who were interviewed for this study led to findings that can be used to inform future nurse-focused ACP communication practice, education, and research.

In light of the findings of this study, the implications for nursing practice and education included having LTC nurses reflect on how ACP is done in their LTC settings and to engage in self-reflection to overcome their personal barriers to ACP communication. Additionally, the findings of this study included the roles in ACP that LTC nurses assumed, and that further ACP role clarification could be achieved through an interdisciplinary approach to ACP communication. Furthermore, it was found that ACP mentors, yearly ACP education, and raising ACP awareness among the general public could be substantial and effective ACP communication catalysts, according to the LTC nurse participants in this study.

To better understand the implications of this study's findings, LTC nurses' ACP communication experiences and practice should be researched on a national level. LTC nurses' perceptions of ACP communication should be studied in other regions in Canada, so as to compare and contrast findings from studies, like this thesis, with those from other provinces. Indeed, future work in the area of LTC nurses' ACP communication should also try to further investigate the personal and/or professional reasons why some LTC nurses do not fully engage in ACP discussions with their patients. Additionally, more research could be conducted to study the content of current ACP education, the implementation of an ACP educational program/package/module, and the evaluation and outcomes of ACP education from a nursing perspective. Lastly, the findings of this study pointed to a few more avenues of future inquiry: how racism may affect ACP communication among LTC nurses; how interdisciplinary teams influence ACP; and what effects the COVID-19 pandemic has had on ACP communication in LTC settings.

In conclusion, this study adds to the dearth of ACP communication research that currently exists, especially in terms of studies that have been done to date with LTC nurses as the focal participants. This study found that this sample of LTC nurses had a sense that they and their colleagues have an ethical obligation to engage in ACP as part of their roles as nurses, and that they were sensitive to and aware of barriers and facilitators that either hinder or catalyze nurses’ ACP communication in LTC settings. However, this sample of LTC nurses also expressed that they, and their nursing colleagues, may not be as involved in ACP communication with patients and families as they ought to be. This inconsistency between LTC nurses’ sense of an ethical obligation to do ACP and their actual ACP practice was also seen in the literature reviewed for this study. Thus, the findings of this study show that a disconnect still exists between nurses’ perceptions of ACP communication and their actual ACP practice. This thesis study hopefully provided LTC nurse participants with an opportunity to think about, change, and improve their overall ACP communication with patients and families. Ultimately, and in practical terms, the findings of this qualitative interpretive description study could potentially be used in future research, development, and evaluation of ACP communication policies, procedures, practice, and education for nurses and other healthcare professionals.

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Appendices

Appendix A: Letter to the College of Registered Nurses of Manitoba (CRNM)

XXXXXXXX
Communications Specialist
College of Registered Nurses of Manitoba
890 Pembina Hwy
Winnipeg, Manitoba
R3M 2M8

Dear Sir/Madam:

This is a letter formally requesting the assistance of the College of Registered Nurses of Manitoba (CRNM) with a study that I am carrying out. The title of my research study is "Nurses' Perceptions of Advance Care Planning Communication with Patients and Families in Long-Term Care Settings". My name is Ivone Vieira. I am the principal investigator for this study, and I am a graduate student in the Master of Nursing Program in the College of Nursing at the University of Manitoba. Dr. Marie Edwards is my academic/faculty advisor and research supervisor. The proposed study has been reviewed and approved by the Education/Nursing Research Ethics Board at the University of Manitoba.

If possible, I would like the CRNM's assistance in sending out an email message inviting people to participate in this study. The population of interest is nurses registered with the College of Registered Nurses of Manitoba (CRNM), or with the College of Licensed Practical Nurses of Manitoba (CLPNM), who self-identify as working in long-term care (LTC) facilities or units that are designated as LTC units within a tertiary-care facility within the province of Manitoba, Canada. I am requesting that the attached recruitment email message be sent by your organization to potential study participants. The email outlines the purpose of the study, what is required of participants, and how their confidentiality will be protected. We also request that one month following the initial email distribution that a follow-up email notice be sent to these nurses in an attempt to increase recruitment/response rates.

It is anticipated that the data collected for this study has the potential to guide and add to future Advance Care Planning research, policy, education, training, and mentoring programs for nurses in a variety of healthcare settings.

If you have any questions about this request, please feel free to contact me (Ivone Vieira at XXXXXXX) or my advisor (Dr. Marie Edwards at XXXXXXX).

This research has been approved by the Education/Nursing Research Ethics Board (ENREB). If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-xxx-xxxx or humanethics@umanitoba.ca.

Thank you for your time and consideration of this request.

Sincerely,

Ivone Vieira, RN, BN
MN Student

Appendix B: Letter to the College of Licensed Practical Nurses of Manitoba (CLPNM)

XXXXXXX
Practice Consultant
College of Licensed Practical Nurses of Manitoba
463 St. Anne's Road
Winnipeg, Manitoba
R2M 3C9

Dear XXXXX:

This is a letter formally requesting the assistance of the College of Licensed Practical Nurses of Manitoba (CLPNM) with a study that I am carrying out. The title of my research study is "Nurses' Perceptions of Advance Care Planning Communication with Patients and Families in Long-Term Care Settings". My name is Ivone Vieira. I am the principal investigator for this study, and I am a graduate student in the Master of Nursing Program in the College of Nursing at the University of Manitoba. Dr. Marie Edwards is my academic/faculty advisor and research supervisor. The study has been reviewed and approved by the Education/Nursing Research Ethics Board at the University of Manitoba.

If possible, I would like CLPNM's assistance in sending out an email message inviting people to participate in this study. The population of interest is nurses registered with the College of Licensed Practical Nurses of Manitoba (CLPNM), or with the College of Registered Nurses of Manitoba (CRNM), who self-identify as working in long-term care (LTC) facilities or units that are designated as LTC units within a tertiary-care facility in the province of Manitoba, Canada. The attached recruitment email message that is to be sent by your organization to potential study participants outlines the purpose of the study, what is required of participants, and how their confidentiality will be protected. We also request that one month following the initial email distribution that a follow-up email notice be sent to these nurses in an attempt to increase recruitment/response rates.

It is anticipated that the data collected for this study has the potential to guide and add to future Advance Care Planning research, policy, education, training, and mentoring programs for nurses in a variety of healthcare settings.

If you have any questions about this request, please feel free to contact me (Ivone Vieira at XXXXX) or my advisor (Dr. Marie Edwards at XXXXX).

This research has been approved by the Education/Nursing Research Ethics Board (ENREB). If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-xxx-xxxx or humanethics@umanitoba.ca.

Thank you for your time and consideration of this request.

Sincerely,

Ivone Vieira, RN, BN
MN Student

Appendix C: Recruitment Email Message (1st email)

Dear Registered Nurse (or Licensed Practical Nurse),

This is an invitation to participate in a study entitled "Nurses' Perceptions of Advance Care Planning Communication with Patients and Families in Long-Term Care Settings".

Nurses registered with the College of Registered Nurses of Manitoba (CRNM) or with the College of Licensed Practical Nurses of Manitoba (CLPNM) who self-identify as working in long-term care (LTC) facilities or units that are designated as LTC units within a tertiary-care facility in the province of Manitoba, Canada are invited to participate in this study. The CRNM and the CLPNM are contacting you on behalf of the principal investigator (Ivone Vieira), a graduate student in the Master of Nursing Program at the University of Manitoba, advised by research supervisor Dr. Marie Edwards.

This study's purpose is to explore and describe the thoughts, feelings, opinions, and overall experiences that full-time and part-time LTC nurses have had with Advance Care Planning (ACP) communication with patients and families in their nursing practice. Each LTC nurse participant will be interviewed by the principal investigator (Ivone Vieira), at an agreed-upon date, time, and location of the participant's choosing where an interview can take place comfortably (e.g., your home, your workplace, a quiet coffee shop, at the University of Manitoba, over the telephone). Each individual, one-on-one interview will be audio-recorded and will take approximately one to one-and-a-half hours (1 to 1½ hours) to complete. If after reviewing the interview the principal investigator has any additional questions or would like to clarify any of your responses in the interview, you may be contacted for a second, short (15 to 30 minute) interview. This second interview may take place over the phone. Interviews are voluntary and you may refuse to answer any question you do not wish to answer. It is anticipated that the data collected for this study, from a nurse's perspective, has the potential to guide and add to future Advance Care Planning research, policy, education, training, and mentoring programs for nurses in a variety of healthcare settings.

Your confidentiality and the confidentiality of the data collected from you during the interviews, including demographic information and your answers to interview questions, will be protected. Identifying information will be removed and all data will be stored on a password-protected computer in my home or in the locked office of my supervisor. Participation in this study is voluntary, and you may decline consent or withdraw from the study if you so choose.

If you are interested in participating in this ACP communication study, please contact the principal investigator (Ivone Vieira) or the research supervisor (Dr. Marie Edwards) at the email addresses or phone numbers below to set up an interview date, time, and location.

If you have any general questions about this study, please contact the principal investigator (Ivone Vieira) or the research supervisor (Dr. Marie Edwards) at the email addresses or phone numbers below.

This research has been approved by the Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the below-named persons or the Human Ethics Coordinator (HEC) at humanethics@umanitoba.ca. or at 204-xxx-xxxx.

Sincerely,

Ivone Vieira, RN, BN
MN Student
XXXXX

Dr. Marie Edwards, RN, PhD
XXXXX

Appendix D: Follow-up Recruitment Email Message (2nd email, one month later)

Dear Registered Nurse (or Licensed Practical Nurse),

Recently you received an email inviting you to take part in a study entitled "Nurses' Perceptions of Advance Care Planning Communication with Patients and Families in Long-Term Care Settings".

If you have already been interviewed as a participant in this study, thank you. If you have not, and you are a nurse registered with the College of Registered Nurses of Manitoba (CRNM) or with the College of Licensed Practical Nurses of Manitoba (CLPNM) who self-identifies as working in a long-term care (LTC) facility or a unit that is designated as a LTC unit within a tertiary-care facility in the province of Manitoba, Canada, you are invited to participate in this study. The CRNM and the CLPNM are contacting you on behalf of the principal investigator (Ivone Vieira), a graduate student in the Master of Nursing Program at the University of Manitoba, advised by research supervisor Dr. Marie Edwards. This study has been approved by the Education/Nursing Research Ethics Board.

This study's purpose is to explore and describe the thoughts, feelings, opinions, and overall experiences that full-time and part-time LTC nurses have had with Advance Care Planning (ACP) communication with patients and families in their nursing practice. Each LTC nurse participant will be interviewed by the principal investigator (Ivone Vieira), at an agreed-upon date, time, and location of the participant's choosing where an interview can take place comfortably (e.g., your home, your workplace, a quiet coffee shop, at the University of Manitoba, over the telephone). Each individual, one-on-one interview will be audio-recorded and will take approximately one to one and half hours (1 to 1½ hours) to complete. If after reviewing the interview the principal investigator has any additional questions or would like to clarify any of your responses in the interview, you may be contacted for a second, short (15 to 30 minute) interview. This second interview may take place over the phone. Interviews are voluntary and you may refuse to answer any question you do not wish to answer. It is anticipated that the data collected for this study, from a nurse's perspective, has the potential to guide and add to future Advance Care Planning research, policy, education, training, and mentoring programs for nurses in a variety of healthcare settings.

Your confidentiality and the confidentiality of the data collected from you during the interviews, including demographic information and your answers to interview questions, will be protected. Identifying information will be removed and all data will be stored on a password-protected computer in my home or in the locked office of my supervisor. Participation in this study is voluntary, and you may decline consent or withdraw from the study if you so choose.

If you have already been interviewed as a participant in this study, thank you. If you have not, and you are interested in participating in this ACP communication study, please contact the principal investigator (Ivone Vieira) or the research supervisor (Dr. Marie Edwards) at the email addresses or phone numbers below to set up an interview date, time, and location.

If you have any general questions about this study, please contact the principal investigator (Ivone Vieira) or the research supervisor (Dr. Marie Edwards) at the email addresses or phone numbers below.

This research has been approved by the Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the below-named persons or the Human Ethics Coordinator (HEC) at humanethics@umanitoba.ca. or at 204-xxx-xxxx.

Sincerely,

Ivone Vieira, RN, BN
MN Student
XXXX

Dr. Marie Edwards, RN, PhD
XXXXX

College of Nursing
Helen Glass Centre for Nursing
Winnipeg, Manitoba
Canada R3T 2N2
Telephone 204-474-7452
Fax 204-474-7682

University of Manitoba
Rady Faculty of
Health Sciences

Appendix E: Informed Consent Form

Research Project Title: Nurses' Perceptions of Advance Care Planning Communication with Patients and Families in Long-Term Care Settings.

Principal Investigator and Contact Information: Ivone Vieira, RN, BN
Master of Nursing Student
College of Nursing, Rady Faculty of Health Sciences, University of Manitoba

Research Supervisor and Contact Information: Dr. Marie Edwards, RN, PhD
College of Nursing, Rady Faculty of Health Sciences, University of Manitoba

Sponsor: Non-funded

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of the Study:

The purpose of this study is to describe the thoughts, feelings, opinions, and overall experiences that full-time and part-time long-term care nurses have or have had with Advance Care Planning communication with patients and families in their nursing practice.

What You Will Be Asked to Do:

Each long-term care nurse participant will be interviewed one-on-one by the principal investigator (Ivone Vieira), at an agreed-upon date, time, and location of the participant's choosing where an interview can take place comfortably (e.g., your home, your workplace, a quiet coffee shop, at the University of Manitoba, over the telephone). The initial interview will take approximately one to one-and-a-half hours (1 to 1½ hours) to complete. If, after reading the transcript from the interview, the principal investigator has any additional questions or requires clarification of something you have said, you may be asked to participate in a second shorter interview (15 to 30 minutes). The second interview may occur by phone. Participation in the study and the interview or interviews is voluntary and you may refuse to answer any questions you do not wish to answer.

Recording Devices:

Audio recorders (two of them) supplied by the Manitoba Centre for Nursing and Health Research (MCNHR) will be used to audio record each interview. Two audio recorders will be used for each interview as a back-up in case one audio recorder stops working properly.

Potential Benefits:

There are no immediate benefits to you for taking part in the study. However, a direct benefit of participating in this study will be the ability of each long-term care nurse to openly express their thoughts related to Advance Care Planning communication. An indirect benefit of study participation is that the findings of this study, from the perspective of long-term care nurses, have the potential to guide and add to future Advance Care Planning research, policy, education, training, and mentoring programs for nurses in a variety of healthcare settings.

Potential Risks:

The potential risks of participating in this study are minimal. Interview questions cover a topic that you might encounter in your everyday work life. However, some participants may experience negative emotions (e.g., bad memories, sadness, frustration, mild anxiety, etc.), due to the nature of the study topic: Advance Care Planning communication (i.e., discussions that help prepare patients and families for future care, including end-of-life situations). Participants may want to seek professional assistance if they feel the need to talk about any discomfort that the interview topic has brought up for them. Access free counselling services through:

Manitoba Blue Cross Employee Assistance Program by calling 204-786-8880, toll free at 1-800-590-5553, or TTY at 204-775-0586, or via their website:
https://www.mb.bluecross.ca/products/group/wellness/employeeassistance

Klinic Drop-In Counselling Service by calling 204-784-4067, or via their website at:
http://klinic.mb.ca/in-person-counselling/klinic-drop-in-counselling/

The Canadian Mental Health Association (CMHA) Service Navigation Hub by calling 204-775-6442, e-mailing hub@cmhawpg.mb.ca , visiting them in-person at 930 Portage Ave, Winnipeg MB, or via their website at:
https://mbwpg.cmha.ca/cmha-service-navigation-hub/

Confidentiality:

Your confidentiality and the confidentiality of the data collected from you during the interviews, including demographic information and your answers to interview questions, will be protected through a variety of strategies. Study data will be secured in locked, password-protected computers and in password-protected computer files that will only be accessed by the principal investigator (Ivone Vieira – located in my home) and the research supervisor (Dr. Marie Edwards – located in her private office in xxxx building). Any hard copies of data will be stored in locked filing cabinets in the above offices or homes. Any identifying information (e.g., names of participants, work site) will be removed from the data to maintain confidentiality. We will collect demographic information (e.g., age, gender, type of workplace, educational level, job title, employment status, etc.), making it potentially possible to identify you. All of the demographic information collected for this study will be kept confidential by coding each demographic form with a participant identification number. Data will be confidentially destroyed and wiped clean by my advisor at the completion of the study. Data will be stored on my password-protected computer until five years after the Master of Nursing thesis has been completed (until May 2025), at which point the data will be destroyed and wiped clean, as per research ethics board regulations at the University of Manitoba.

The findings of this study will be presented as part of an oral thesis defence in front of the principal investigator's research supervisor (Dr. Marie Edwards), the two thesis committee members (Dr. Genevieve Thompson and Dr. Bruce Martin), and any members of the public who wish to attend the thesis defence presentation on a future, agreed-upon date. Participants will not be identified in the oral thesis defence presentation and no identifying information will be presented. The researchers may also publish the findings of the study in a journal or present the findings at a conference, but participants will not be identified in any publication or presentation. Information about participants will be presented in the form of summary statistics for the whole group and direct quotations from interviews, with any identifying information removed. Reference to any individual participant's responses will be limited to general descriptors (e.g., one Registered Nurse working in a long-term care facility).

Incentives:

There are no incentives offered for your participation in this study.

Voluntary Participation and Withdrawal:

Your participation in this study is voluntary. There is no penalty for refusing to participate in the study, and refusal to participate will have no effect on you personally or professionally. If you withdraw from the study before data analysis begins, your data will not be used and will be destroyed. However, once data analysis has begun, removal and destruction of your data will not be possible. You may decline consent or withdraw from the study at any time before the data analysis stage of the study without reprisal by contacting the principal investigator (Ivone Vieira) or the research supervisor (Dr. Marie Edwards).

Debriefing Procedures:

The principal investigator (Ivone Vieira) and participants will debrief following each interview, to discuss the interview topic and questions as a whole. The participant can discuss their overall feelings about the study, and/or they can amend, add to, or omit any interview answers if they so choose during this debriefing session.

Dissemination of Results:

Research findings will be shared with the principal investigator's research supervisor (Dr. Marie Edwards) as data are being analyzed, as well as with the principal investigator's two thesis committee members (Dr. Genevieve Thompson and Dr. Bruce Martin). After the study findings have been compiled, summarized, and written into a final thesis document, they will also be presented as part of an oral thesis defence in front of the principal investigator's research supervisor, the two thesis committee members, and any members of the public who wish to attend the thesis defence presentation after the thesis document is complete. It is also anticipated that the results of this study will be published in a scholarly journal and may be presented at a conference. Upon completion of the thesis document, the principal investigator (Ivone Vieira) will post the thesis document (as an e-thesis) on the University of Manitoba's MSpace website, as per University of Manitoba Graduate Studies requirements for graduation. MSpace is an open access site, which provides free and unrestricted access to University of Manitoba documents to the public online. A study summary will also be made available to study participants who request one.

Questions About the Study and Summary:

If you have any questions about the study, you can contact the researchers using the contact information located at the top of this informed consent form. If you are interested in receiving more information regarding the results of this study, a brief summary of this Master of Nursing thesis study (1-3 pages) can be provided to participants by either mail or email (participants' choice) in approximately May 2020. Please provide the principal investigator (Ivone Vieira) with either a standard mailing address or an electronic (email) address in the space provided at the bottom of this informed consent form, if you wish to receive a brief summary of this thesis study.

Destruction of Confidential Data:

All confidential participant data that is collected during the study will be destroyed five years after the principal investigator's anticipated graduation date of May 2020; therefore, confidential data will be destroyed in May 2025.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Education/Nursing Research Ethics Board (ENREB). If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-xxx-xxxx or

humanethics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature ________________________ Date ____________

Researcher and/or Delegate's Signature ___________________ Date __________

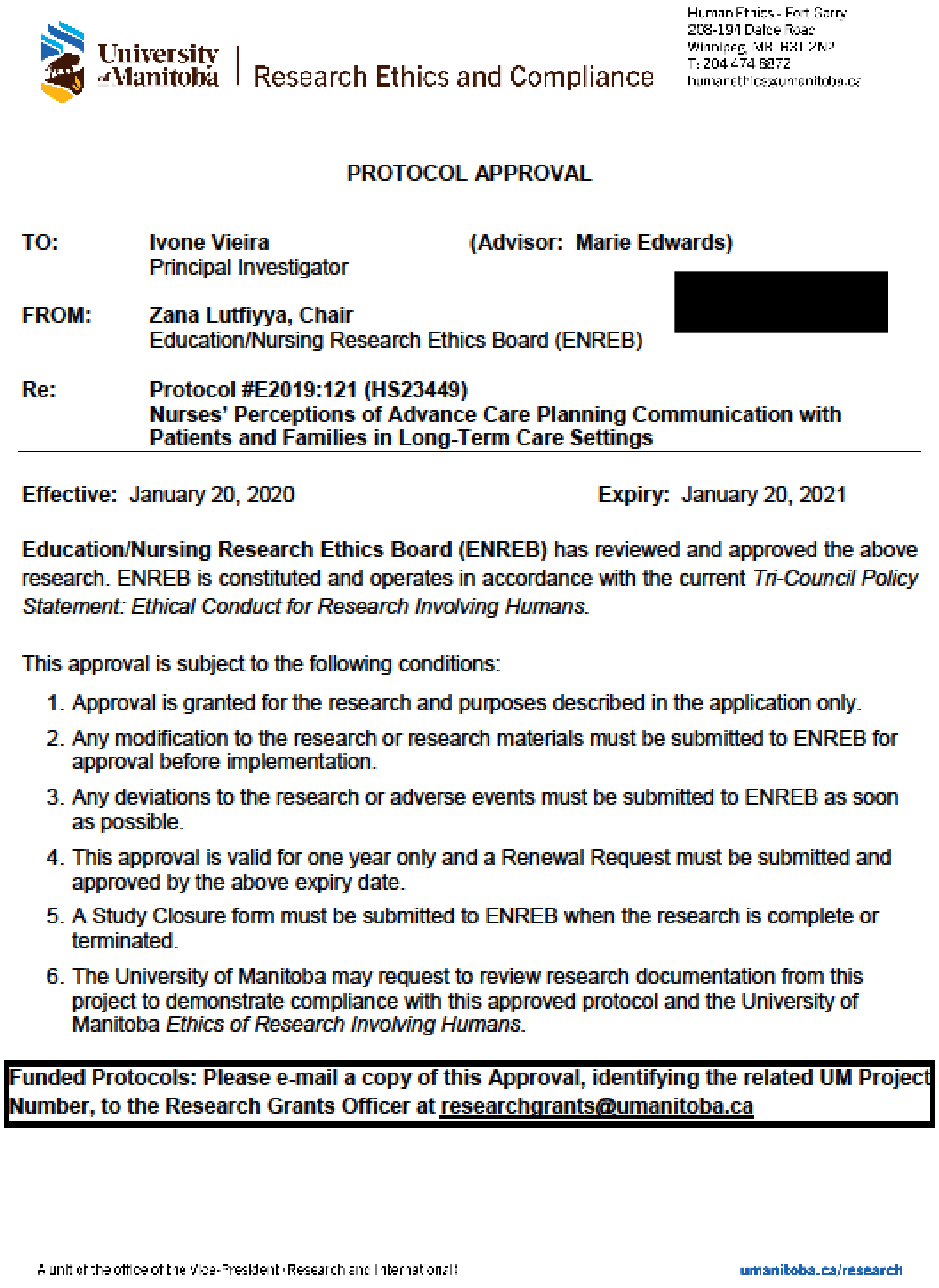
If you would like to receive a brief summary of this Master of Nursing thesis study (1-3 pages) in approximately May 2020, please provide the principal investigator (Ivone Vieira) with either a standard mailing address OR an electronic email address in the space provided below.

Participant's standard mailing address: _________________________

____

Participant's electronic (email) address: _________________________

Appendix F: Education/Nursing Research Ethics Board (ENREB) Protocol Approval



University of Manitoba | Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

PROTOCOL APPROVAL

TO: **Ivone Vieira** **(Advisor: Marie Edwards)**
Principal Investigator

FROM: **Zana Lutfiyya, Chair**
Education/Nursing Research Ethics Board (ENREB)

[redacted]

Re: **Protocol #E2019:121 (HS23449)**
Nurses’ Perceptions of Advance Care Planning Communication with Patients and Families in Long-Term Care Settings

---

Effective: January 20, 2020 **Expiry:** January 20, 2021

Education/Nursing Research Ethics Board (ENREB) has reviewed and approved the above research. ENREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

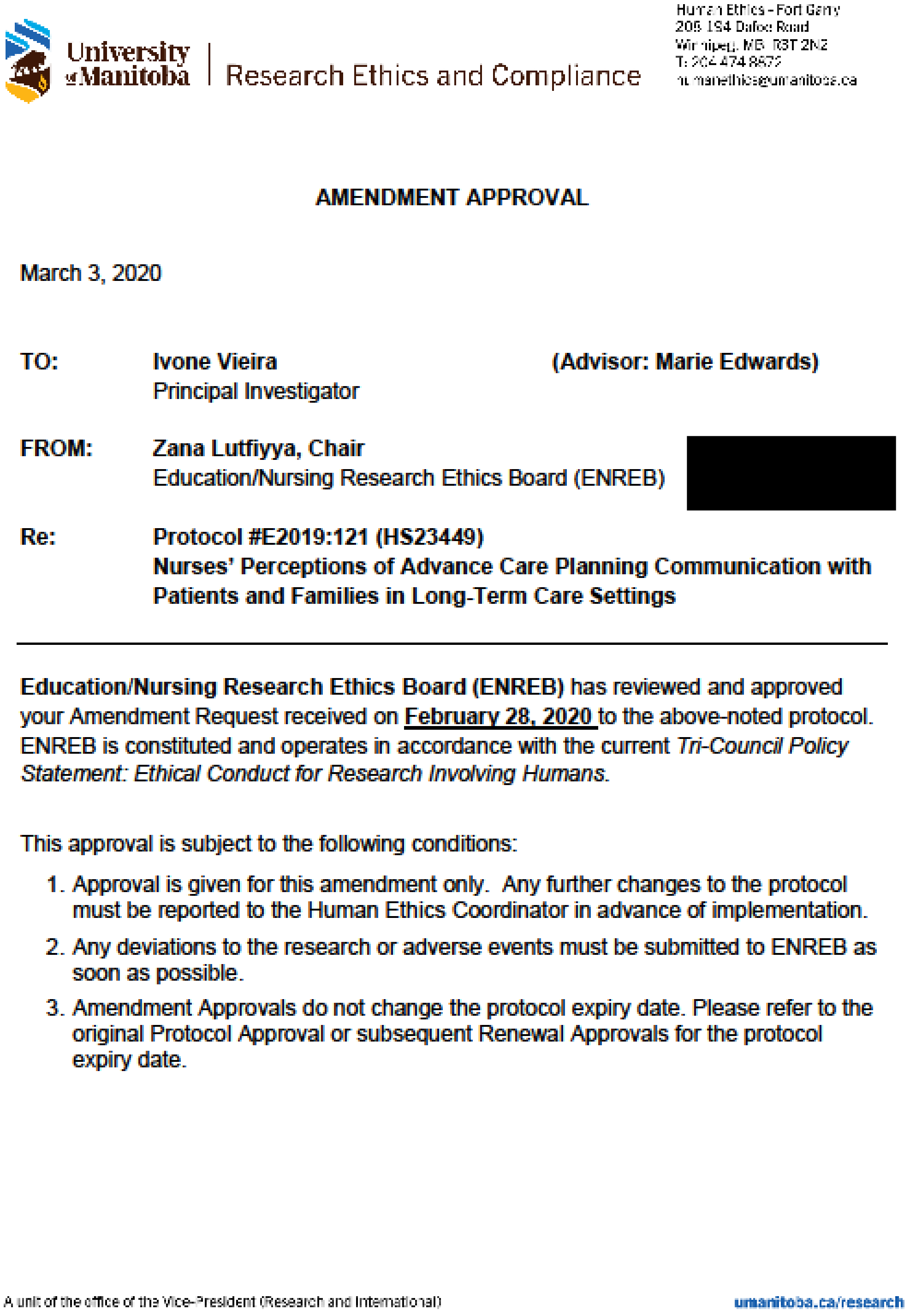
This approval is subject to the following conditions:

1. Approval is granted for the research and purposes described in the application only.
2. Any modification to the research or research materials must be submitted to ENREB for approval before implementation.
3. Any deviations to the research or adverse events must be submitted to ENREB as soon as possible.
4. This approval is valid for one year only and a Renewal Request must be submitted and approved by the above expiry date.
5. A Study Closure form must be submitted to ENREB when the research is complete or terminated.
6. The University of Manitoba may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

Funded Protocols: Please e-mail a copy of this Approval, identifying the related UM Project Number, to the Research Grants Officer at researchgrants@umanitoba.ca

A unit of the office of the Vice-President (Research and International) umanitoba.ca/research

Appendix G: Education/Nursing Research Ethics Board (ENREB) Amendment Approval



University of Manitoba | Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

AMENDMENT APPROVAL

March 3, 2020

TO: **Ivone Vieira** **(Advisor: Marie Edwards)**
Principal Investigator

FROM: **Zana Lutfiyya, Chair**
Education/Nursing Research Ethics Board (ENREB) [redacted]

Re: **Protocol #E2019:121 (HS23449)**
Nurses’ Perceptions of Advance Care Planning Communication with Patients and Families in Long-Term Care Settings

---

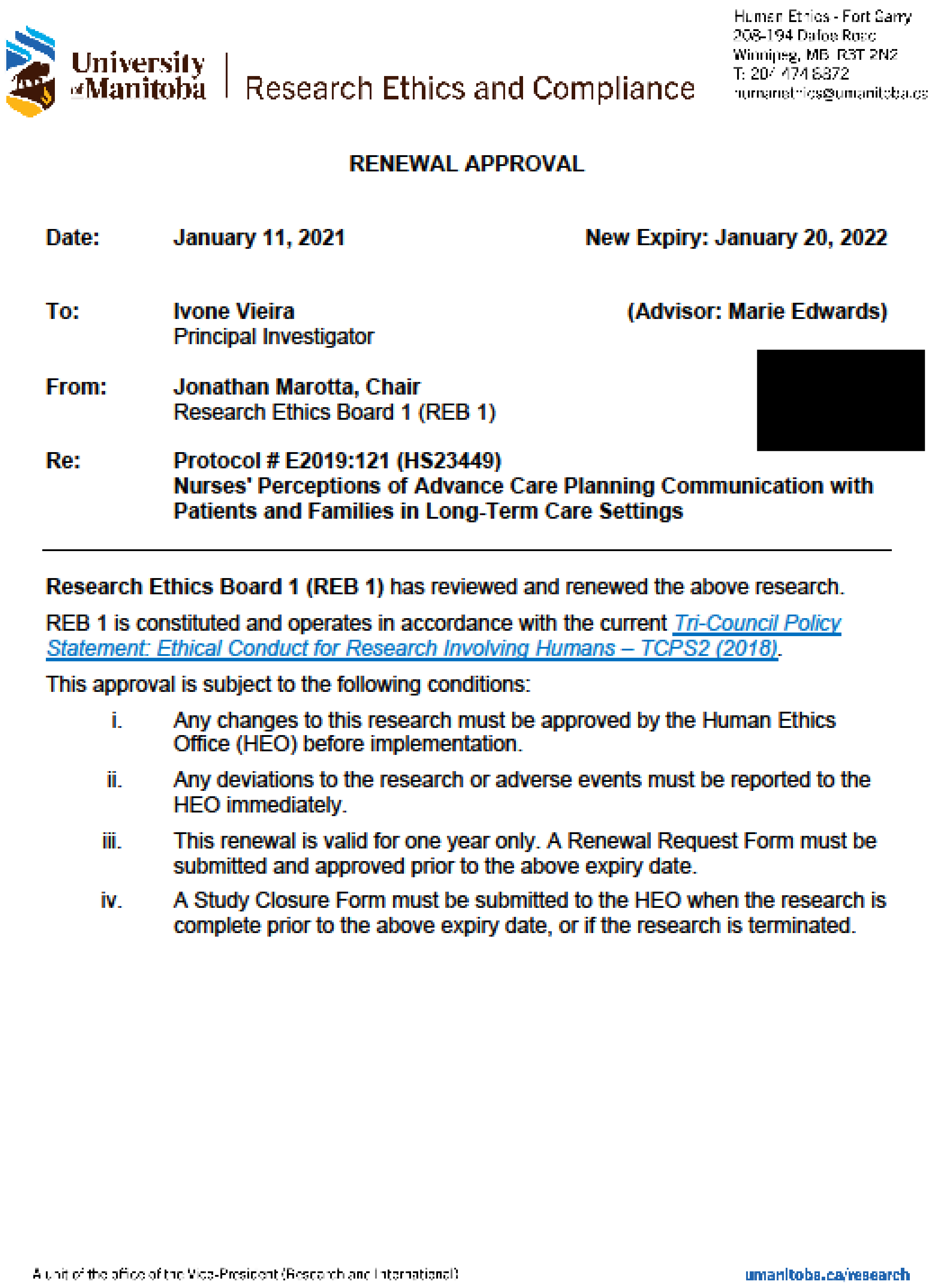
Education/Nursing Research Ethics Board (ENREB) has reviewed and approved your Amendment Request received on **February 28, 2020** to the above-noted protocol. ENREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

This approval is subject to the following conditions:

1. Approval is given for this amendment only. Any further changes to the protocol must be reported to the Human Ethics Coordinator in advance of implementation.
2. Any deviations to the research or adverse events must be submitted to ENREB as soon as possible.
3. Amendment Approvals do not change the protocol expiry date. Please refer to the original Protocol Approval or subsequent Renewal Approvals for the protocol expiry date.

A unit of the office of the Vice-President (Research and International) umanitoba.ca/research

Appendix H: Education/Nursing Research Ethics Board (ENREB) Renewal Approval



University of Manitoba | Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

RENEWAL APPROVAL

Date: **January 11, 2021** **New Expiry: January 20, 2022**

To: **Ivone Vieira** **(Advisor: Marie Edwards)**
Principal Investigator

From: **Jonathan Marotta, Chair**
Research Ethics Board 1 (REB 1)

[redacted]

Re: **Protocol # E2019:121 (HS23449)**
Nurses' Perceptions of Advance Care Planning Communication with Patients and Families in Long-Term Care Settings

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Research Ethics Board 1 (REB 1) has reviewed and renewed the above research.

REB 1 is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS2 (2018)*.

This approval is subject to the following conditions:

i. Any changes to this research must be approved by the Human Ethics Office (HEO) before implementation.

ii. Any deviations to the research or adverse events must be reported to the HEO immediately.

iii. This renewal is valid for one year only. A Renewal Request Form must be submitted and approved prior to the above expiry date.

iv. A Study Closure Form must be submitted to the HEO when the research is complete prior to the above expiry date, or if the research is terminated.

A unit of the office of the Vice-President (Research and International) umanitoba.ca/research

Appendix I: Interview Guide Questions

- When I say the phrase “Advance Care Planning”, what comes to mind?
- What is Advance Care Planning (ACP)? (Please define/describe ACP as best as you can).
- How would you describe ACP to a colleague, family member, or friend?
- In your opinion, what are some positive aspects of ACP?
- Conversely, please describe any negative aspects of ACP.
- How is ACP conducted in your facility or on your unit?
- Who is responsible for initiating and conducting ACP discussions with patients and families in your LTC setting?
- Why is (insert their answer(s) here) responsible for ACP in LTC settings?
- What ACP education/training have you received as a nurse?
- What is the nurse’s role in ACP communication where you work?
- What do you think the nurse’s role in ACP should be?
- How comfortable are you with initiating ACP discussions with patients and families?
- What makes you comfortable to initiate ACP discussions?
- How comfortable are you conducting ACP discussions with patients and families?
- Please describe a situation you were involved in or witnessed where ACP communication went well.
- Please describe a situation you were involved in or witnessed where ACP communication did not go well.
- What do you think gets in the way or stops nurses from discussing ACP with patients and families? (communication barriers)

- What do you think helps/encourages nurses to discuss ACP with patients and families? (communication facilitators)
- Please share your suggestions for improving nurses' ACP communication with patients and families in LTC?
- Is there anything else related to ACP communication in your nursing practice that you would like to share?

Appendix J: Demographic Information

Age:

Gender:

Female

Male

Other

Highest Nursing Education Level Achieved:

Diploma

Bachelor's Degree

Master's Degree

Doctorate Degree

Category of Nurse:

RN

LPN

Are you an Advanced Practice Nurse? Please specify whether you are a Nurse Manager, Nurse Educator, or a Clinical Nurse Specialist.

Yes

No

Employment Status:

Full-time

Part-time

Casual

Type of healthcare facility you currently work in:

Long-term Care (LTC) Facility

Tertiary Care Facility

Other

Years of overall nursing experience?

Years of LTC nursing experience?

Years of experience in your current facility?

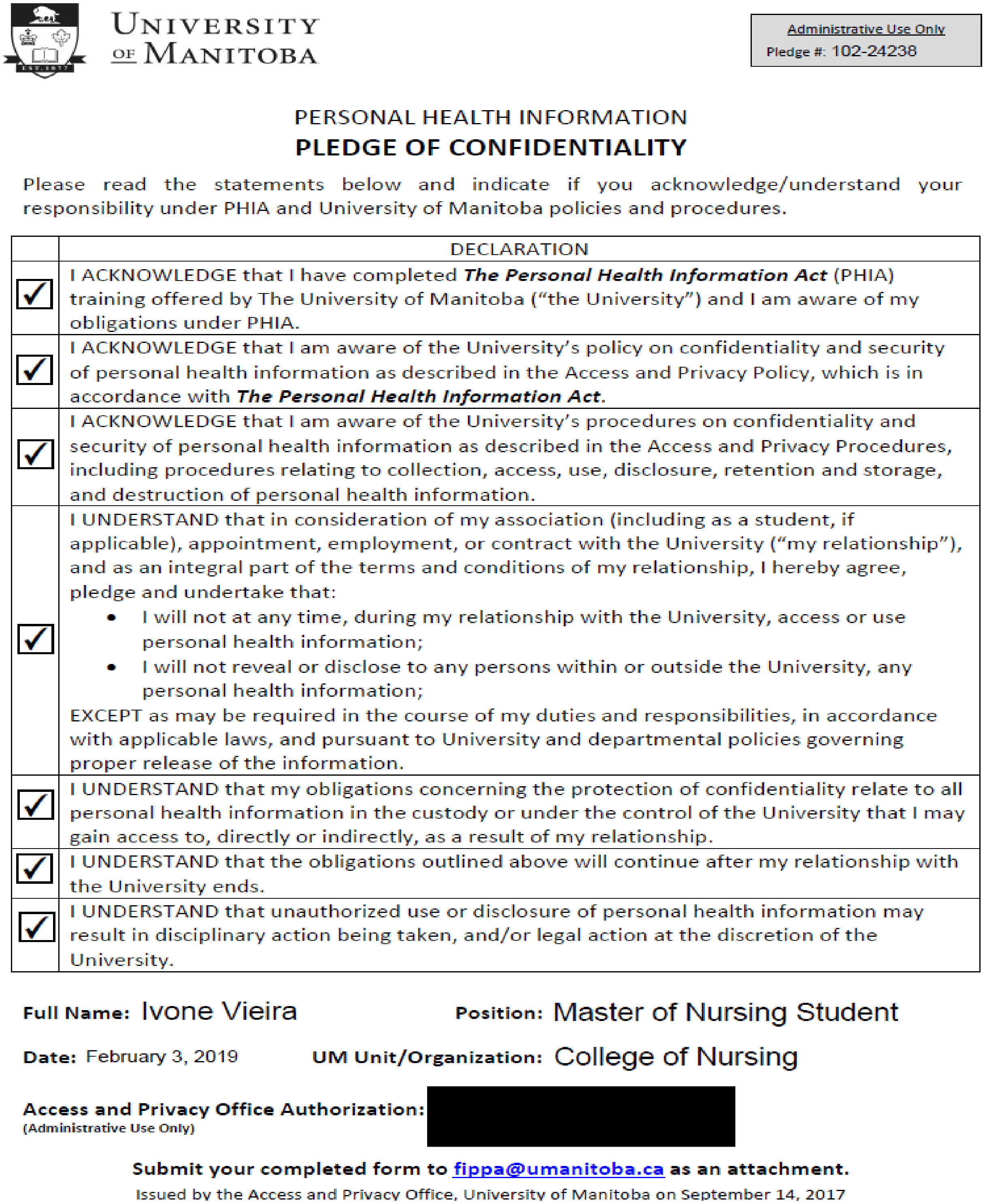
Number of beds on your unit?

What is the typical daily nurse to patient ratio on your unit?

Who makes up the healthcare team on your unit? (i.e., Nurses, healthcare aides, Social Work, Occupational Therapy, Physiotherapy, Patient Care Manager, Physician, etc.)

What kind of access do you have to Physicians on your unit? (e.g., a Physician is always available on the premises, or only available on-call/over the telephone, or only available certain days of the week, etc.)

Appendix K: Pledge of Confidentiality



UNIVERSITY OF MANITOBA

Administrative Use Only
Pledge #: 102-24238

PERSONAL HEALTH INFORMATION
PLEDGE OF CONFIDENTIALITY

Please read the statements below and indicate if you acknowledge/understand your responsibility under PHIA and University of Manitoba policies and procedures.

	DECLARATION
☑	I ACKNOWLEDGE that I have completed ***The Personal Health Information Act*** (PHIA) training offered by The University of Manitoba ("the University") and I am aware of my obligations under PHIA.
☑	I ACKNOWLEDGE that I am aware of the University's policy on confidentiality and security of personal health information as described in the Access and Privacy Policy, which is in accordance with ***The Personal Health Information Act***.
☑	I ACKNOWLEDGE that I am aware of the University's procedures on confidentiality and security of personal health information as described in the Access and Privacy Procedures, including procedures relating to collection, access, use, disclosure, retention and storage, and destruction of personal health information.
☑	I UNDERSTAND that in consideration of my association (including as a student, if applicable), appointment, employment, or contract with the University ("my relationship"), and as an integral part of the terms and conditions of my relationship, I hereby agree, pledge and undertake that: • I will not at any time, during my relationship with the University, access or use personal health information; • I will not reveal or disclose to any persons within or outside the University, any personal health information; EXCEPT as may be required in the course of my duties and responsibilities, in accordance with applicable laws, and pursuant to University and departmental policies governing proper release of the information.
☑	I UNDERSTAND that my obligations concerning the protection of confidentiality relate to all personal health information in the custody or under the control of the University that I may gain access to, directly or indirectly, as a result of my relationship.
☑	I UNDERSTAND that the obligations outlined above will continue after my relationship with the University ends.
☑	I UNDERSTAND that unauthorized use or disclosure of personal health information may result in disciplinary action being taken, and/or legal action at the discretion of the University.

Full Name: Ivone Vieira **Position:** Master of Nursing Student

Date: February 3, 2019 **UM Unit/Organization:** College of Nursing

Access and Privacy Office Authorization: [redacted]
(Administrative Use Only)

Submit your completed form to fippa@umanitoba.ca as an attachment.

Issued by the Access and Privacy Office, University of Manitoba on September 14, 2017

Appendix L: TCPS 2: CORE Completion Certificate

PANEL ON
RESEARCH ETHICS
Navigating the ethics of human research

TCPS 2: CORE

Certificate of Completion

This document certifies that

Ivone Vieira

has completed the Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans
Course on Research Ethics (TCPS 2: CORE)

Date of Issue: **11 February, 2017**

Appendix M: List of Themes and Subthemes

Themes
Subthemes

Theme 1: A Sense of an Ethical Obligation to Engage in ACP Communication

Subtheme: ***Factors Influencing the Sense of an Ethical Obligation***

- **a) How LTC Nurses Define ACP**
- **b) How ACP is Done in Participants' LTC Settings**
- **c) LTC Nurses' Personal and/or Nursing Experiences with ACP**

Subtheme: ***Roles and Actions that Flow from the Ethical Obligation to Engage in ACP Communication***

- **a) Advocate, Liaison, and Mediator**
- **b) Communicator, Caregiver, and LTC Contact**
- **c) ACP Educator and Clarifier**
- **d) Acting in Ways to Respect and Promote Patient Autonomy**

Theme 2: Sensibility of the Determinants of ACP Communication

Subtheme: Communication Hindrances

- **a) Personal Barriers**
    - ***LTC Nurses' Barriers***
    - ***Resident/Patient/Family Barriers***
- **b) Structural Barriers**
    - ***Educational Barriers***
    - ***Work Environment Barriers***

Subtheme: Communication Catalysts

- **a) Personal Facilitators**

LTC Nurses' Facilitators

Resident/Patient/Family Facilitators

b) Structural Facilitators

Educational Facilitators

Work Environment Facilitators

Tables

Table 1

ACP Literature Source Breakdown by Country

Country	**ACP Research Studies**	**Descriptive Articles**
1. Canada	2	1
2. Belgium	1	0
3. United States of America	12	11
4. United Kingdom	4	1
5. Ireland	1	0
6. Norway	0	1
7. Australia	1	1
8. Taiwan	0	1
9. Switzerland	1	0
10. The Netherlands	1	0
11. Japan	1	0
12. Italy	1	0
Total	**25**	**16**

Note. 12 different countries featured in the ACP literature that was reviewed for this MN thesis study.

Table 2

Descriptive ACP Articles Reviewed

Authors, Year, & Country	**Purpose**	**Methods**	**Sample**	**Findings**	**Other (e.g., Limitations, Recommendations)**
1) Briggs, L., & Colvin, E. (2002), USA.*	Discuss cultural changes for organizations to increase effective ACP with RN role as pt advocate.	Descriptive article.	None.	Shift of AD to ACP clarification of RN's role in ACP.	Barriers incl. lack of ACP educ., poor comm., & inconsistent practice patterns.
2) Brooke, J., & Kirk, M. (2014), UK.*	Lit review re: barriers on healthcare professionals' engagement with ACP for pts with dementia.	Literature review.	4 empirical articles and 2 lit reviews.	Family unwilling to participate in ACP, HCPs lacked knowledge and skills to do ACP, poor timing.	Focused on primary and community health care professionals.
3) Counsell, S. (2015), USA.*	To report on Medicare funding billing of ACP discussions.	Descriptive article.	None.	New billing codes incl. ACP discussions and AD completion (30 mins each).	Ability of physicians to bill for ACP services will increase HCP engagement in ACP with pts.
4) Flo, E., Husebo, B., Bruusgaard, P., Gjerberg, E., Thoresen, L., Lillemoen, L., & Pedersen, R. (2016), Norway.*	Investigation of methods, designs, outcomes & implementation of ACP in nursing homes.	Scoping review of literature.	16 papers r/t NHs.	Large variations in ACP programs in the papers.	ACP intervention studies in NHs are few and heterogeneous. Difficult to compare results.
5) Head, B. A., Song, M., Wiencek, C., Nevidjon, B., Fraser, D.,	Exploration of nurse's role in communication & ACP, and pt	Descriptive Report from the Palliative Nursing Summit.	# of attendees or participants in the summit not specified in the report.	Areas addressed incl: education, clinical care, research, and policy/regulation. As well as honoring pt/fam preferences & inclusion of ACP discussions	Education, mentoring, competency development and assessment of ACP communication are important in nursing role.

Mazanec, P. (2018), USA.*	outcomes in palliative care.			during routine care and across lifespan.	
6) Hebert, K., Moore, H., & Rooney, J. (2011), USA.*	Describe the nurse advocate in EOL care.	Descriptive article.	None.	Nurse advocated are essential in quality EOL care especially ACP.	Barriers= the physician, pt.'s family, and fear.
7) Johnstone, M., Kanitsaki, O. (2009), Australia.*	Review of the literature involving cross-cultural considerations in ACP in multicultural countries.	Descriptive article.	Critical cross-cultural examination of mainstream bioethical underpinning of ACP.	Cross-cultural and culture care r/t ACP incl broadening mainstream conceptualization and understanding of autonomy, informed consent, truth telling, cultural liberty, and family roles in EOL care.	ACP in an ethnically diverse setting can be very complex and layered. Need more cross-cultural EOL research to inform future policy & evidence-based practice.
8) Ke, L., Huang, X., O'Connor, M., & Lee, S. (2015), Taiwan.*	To explore RNs views re: implementing ACP for older people.	Meta-synthesis. Systematic review and synthesis of qualitative studies.	18 articles.	4 themes identified re: ACP, advantages/disadvantages of ADs, RN's role/responsibility, facilitators/barriers, RN needs recommendations.	Barriers r/t work environment, teamwork, time, knowledge re: team roles.
9) Moore, C. D. (2005), USA.*	To provide practical strategies to enhance communication in palliative and EOL medical care settings.	Descriptive article.	None.	Effective communication and EOL is important but few HCPs are formally trained in communication skills.	RNs who possess self-awareness and effective communication practices are important for EOL care.
10) Oliverio, R., & Fraulo, B. (1998), USA.*	The nurse clinician's perspective regarding SUPPORT (the Study to Understand Prognoses and	Descriptive article from a nursing perspective.	None. Narrative examples used to highlight lessons learned from pts and families in SUPPORT.	The SUPPORT nurse clinician's role included being present for pts and families during times of decision, times of grief, and times of loss. A role akin to the SUPPORT nurse clinician needs to be instituted in hospital settings to promote mentoring	Death needs to be understood as a natural and inevitable part of all our lives and should be normalized on a community level. Preferences and decisions for end-of-life treatment

	Preferences for Outcomes and Risks of Treatment).			and education of healthcare staff to work with pts and families in end-of-life situations.	need to be discussed with pts and families in outpatient settings, and then carried over to the hospital setting.
11) Prendergast, T. J. (2001), USA.*	Exploring the pitfalls, progress, and promise of ACP in the ICU.	Descriptive article.	Not a sample. But focused on ICU physicians only.	AD's don't work, but ACP is successful if it is seen as a process of discussion about values and preferences.	Conversations by physicians with pts & families are key to EOL decisions in the ICU.
12) Rietze, L., & Stajduhar, K. (2015), Canada.*	RNs involvement in ACP with pts in acute care settings.	Integrative review of the literature.	9 articles.	4 patterns: RNs involvement, RNs perceptions of roles, barriers and facilitators.	More ACP education needed for RNs.
13) Sudore, R. L., Fried, T. R. (2010), USA.*	To provide practical steps for clinicians to help pts and surrogates prepare to make in-the-moment medical decisions in the outpatient setting.	Descriptive article.	None.	ACP should prepare pts and surrogates to work with their clinicians to make the best possible in-the-moment medical decisions.	
14) Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., Matlock, D. D., Rietjens, J. A. C., Korfage, I. J., Ritchie, C. S., Kutner, J. S., Teno, J. M., Thomas, J., McMahan, R. D., Heyland, D. K. (2016), USA.*	To develop a consensus definition of ACP for adults.	52-person Delphi Panel.	Multidisciplinary panel of international ACP experts consisting of 52 clinicians, researchers and policy leaders from 4 countries, and a pt/surrogate advisory committee.	ACP "is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness" (p. 26).	This definition can be used to inform implementation and measurement of ACP clinical, research, and policy initiatives.

15) Teno, J. M., Nelson, H. L., Lynn, J. (1994), USA. **Seminal work in the field of ACP.***	To outline ACP research priorities (from 1994 on).	Descriptive article.	None.	ACP offers an appealing possibility of maintaining control over medical treatment decisions even at a time when one has become incapacitated.	
16) Weiner, J. S., Cole, S. A. (2004), USA.*	Description of clinician' emotional, cognitive, and skills barriers to ACP with pts.	Thematic literature review.	None.	3 principles to address communication barriers dealing with emotional, cognitive, and skills r/t ACP.	Barriers must be overcome before deficiencies in EOL care can be improved.

Note. 16 ACP articles in total**:** 10 descriptive articles (*), 5 literature reviews (*), and 1 Delphi panel consensus document (*).

Table 3

ACP Research Studies Reviewed

Authors, Year, & Country	**Purpose**	**Methods**	**Sample**	**Findings**	**Other (e.g., Limitations, Recommendations)**
1) Abdul-Razzak, A., You, J., Sherifali, D., Simon, J., Brazil, K. (2014), Canada.*	To understand **patient's** preferences for **physician** behaviours during end-of-life communication.	Qualitative Interpretive Description to analyze data from semi-structured, one-on-one interviews with patients.	16 participants total. Patients 55 + with a high risk of mortality within 6-12 months of admission to general medical wards at 3 Canadian tertiary care hospitals.	2 major concepts: 1) "knowing me" (influence of family roles and life hx on values and priorities during EOL communication), & 2) "conditional candour" (process of info exchange incl an assessment of patient's readiness, being invited to the conversation, and sensitive delivery of info.	Nuanced approach to truth telling preferred when talking to dr. about end-of-life.
2) Ampe, S., Sevenants, A., Smets, T., Declercq, A., & Van Audenhove, C. (2016), Belgium.*	To pilot "we DECide" in terms of influence on ACP policy & practice in nursing home dementia units, and to investigate barriers & facilitators for implementing "we DECide".	Quasi-experimental Pre-test – Post-test study with an intervention and a control group. Mixed methods evaluation of "we DECide" policy compliance and the actual practice by staff.	Nursing home staff (90 total; healthcare team including nurses (n=30 out of 90 participants) from both management and clinical levels working on 18 dementia care units from 18 different nursing homes in Belgium.	For the dementia care units that participated in "we DECide", the policy of ACP was more compliant with best practice after the intervention; however, the actual practice of having ACP discussions with dementia patients and their families did not improve.	Only a small number of conversation recordings were obtained by the researchers for analysis. No recordings of informal ACP discussions were available for analysis. The study ran for six months, and if it was longer could have possibly yielded more results to be studied.

3) Arnett, K., Sudore, R. L., Nowels, D., Feng, C. X., Levy, C. R., Lum, H. D. (2017), USA.*	To understand clinical routines & experiences (related to ACP) of interprofessional team members.	(Qualitative & Quantitative) 35 question cross-sectional online survey, mixed methods approach at analysis.	118 healthcare team members (doctors., advance practice nurses, nurses, administration, chaplains, & social workers.	Drs, SW, nurses play a role in ACP. Not sure of policies regarding ACP documentation. ACP is a high priority, and training is needed.	Clinical settings lack systematic clinical routines to support ACP.
4) Baron, K., Hodgson, A., & Walshe, C. (2015), UK.*	ACP education program effect on staff knowledge, ACP practice and EOL hospital admission rates.	Quantitative longitudinal Study. 3 longitudinal questionnaires, pre and post ACP education program.	16 nursing homes in Greater Manchester area, U.K.	Program is successful in improving the purpose of study.	Does not look at the quality of ACP or whether pt.'s preferences were achieved. Staff turnover affected questionnaire answer quantity/quality.
5) Baughman, K. R., Aultman, J., Hazelett, S., Palmisano, B., O'Neill, A., Ludwick, R., Sanders, M. (2012), USA.*	Better understand how community based LTC managers (SW & RN's) define ACP and their role in the process.	Qualitative study/thematic analysis. Focus Groups (8).	62 LTC care managers (60% SW and 40% RN). Convenience sample.	Care managers struggled with the definition, terminology, and meaning of ACP and their perceptions of how pts & families understood ACP.	Care manager perceived roles: social & legal, medical, and educational. Limited generalizability of results d/t volunteer recruitment.
6) Baughman, K. R., Ludwick, R., Palmisano, B., Hazelett, S., & Sanders, M. (2015), USA.*	To explore how the organizational characteristics of agencies, a necessary component of ACP implementation, may influence the use of ACP by community-based long-term care providers.	Qualitative descriptive cross-sectional study to examine how the attitudes, experiences, and characteristics of care managers and organizational characteristics of the Area Agencies on Aging (AAA) in which they work influence ACP practice. (Telephone interviews with site directors and care	433 care managers (RNs & SWs) working for 9 agencies.	ACP was not consistent across agencies or across care managers. 2 out of 9 agencies were more likely to discuss ACP with greater than 50% of their caseload (31% of the total 433 care managers). Agencies A and B had ACP resources (e.g., info packets) available to care managers, a leader advocating for greater use	A cultural shift in beliefs about ACP, strong advocacy from leadership, and training is needed to increase the frequency of ACP discussions. Causal relationships between variables could not be determined (e.g., did additional training lead to more ACP or did these 2 agencies see

		manager surveys were conducted).		of ACP best practices, and training for ACP.	a need for training because more of their care managers were stepping up to do more ACP?). No measurements of ACP knowledge & skills was done, key beliefs or other organizational factors could have been missed, and respondents may have given socially desirable answers.
7) Beck, E., McIlfatrick, S., Hasson, F., & Leavey, G. (2016), UK.*****	To examine nursing home managers' knowledge, attitudes, beliefs and current practice regarding ACP for people with dementia in LTC settings, informed by the theory of planned behavior.	A cross-sectional quantitative postal survey was carried out as part of a larger scale sequential explanatory mixed-methods study between January-March 2015.	178 nursing home managers (nurse managers) in a region in the UK (response rate of 66% (n = 116).	Nursing home managers showed a lack of knowledge of ACP with negative attitudes underpinned by concerns regarding the capacity and lack of perceived benefits for the person with dementia. They also do not view ACP as part of their role.	Nursing home managers recognize the potential benefits of ACP; however, barriers and challenges create a reluctance to facilitate ACP. Training & role clarification are needed. System, organizational, and individual examination must take place before implementation of ACP can occur. The study was limited to one region in the UK and may not be applicable to other international settings. The quantitative methods restricted further

					exploration/probing of answers. There is potential for response bias and challenges with self-reporting methods used.
8) Black, K. (2006), USA.*	Comparing AD communication by RNs & SWs.	Qualitative Study. Focus group interviews.	6 RNs & 5 SWs in acute care.	5 themes. RNs & SWs perceive having educator roles, advocacy roles, parallel & complimentary ACP practices.	Data may not reflect others' perspectives, small sample size, not enough role and pt pop. variety.
9) Black, K., & Emmet, C. (2006), USA.*	Descriptive study re: RN's AD communication practices with hospitalized pts.	Quantitative analysis. Self-administered questionnaire with 7 subscales.	74 RNs in 2 Hospitals (cardiology and respiratory units).	RNs communication re: AD reflects ACP process and age and experience with AD affect communication practices.	Convenience sample, social desirability error/bias, low response rate.
10) Cornally, N., McGlade, C., Weathers, E., Daly, E., Fitzgerald, C., O'Caoimh, R.,… Molloy, D. (2015), Ireland.*	Evaluation of ACP program implementation in 3 LTC homes.	Qualitative content analysis. Focus groups, semi-structured topic guide.	15 nurse managers and 2 directors of nursing in LTC.	Benefits = enhancing comm., changing care culture, promoting preference-based care, avoiding crisis decision-making.	Recommendations from participant including education and multi-disciplinary teamwork.
11) Jeong, S. Y., Higgins, I., & McMillan, M. (2009), Australia.*	Experiences of RNs with ACP and AD in residential care.	Qualitative thematic content analysis. Case-study design, participant observation, field notes, semi-structured interviews, document analysis.	3 NHs, 13 RNs.	Enhancing/inhibiting factors identified.	Evidence of positive experiences by pts, families, RNs with ACP.
12) Lenherr, G., Meyer-Zehnder, B., Kressig, R. W., Reiter-Theil, S.	To review the willingness and difficulties of Dr. & RNs to speak about death and	Qualitative descriptive semi-structured interviews and systematic content analysis.	14 Doctors, 17 RNs.	Majority of participants reported considerable willingness to speak about dying and death with EOL pts.	Ethical obligation on the part of the HCPs to facilitate ACP in **acute geriatrics.**

(2012), Switzerland.*	dying with geriatric pts.				
13) Ludwick, R., Baughman, K. R., Jarjoura, D., & Kropp, D. J. (2018), USA.*	To compare the similarities and differences in ACP-related beliefs, sense of self-efficacy, education, and practices of RNs & LPNs working in skilled nursing facilities.	Quantitative multipart survey instrument (self-administered written questionnaire with a 9-point scale measuring 11 items). Multivariate mixed-model analysis was done. Data were extrapolated from a larger multisite study conducted in one midwestern state.	136 RNs and 178 LPNs from 29 participating skilled nursing facilities (i.e., LTC facilities).	Two main outcome variables: % of residents with whom a nurse discussed ACP & the timing of the most recent ACP discussion. Negative beliefs not significantly associated with timing of most recent ACP. Higher levels of ACP self-efficacy & education significantly/positively associated with both outcome variables. RNs & LPNs did not differ significantly in their ACP-related beliefs, but RNs reported significantly higher levels of self-efficacy & education than LPNs did.	Included two measures of ACP-related professional practice that asked respondents for quantifiable answers but could not verify those amounts in actual ACP practice, due to the nature of the self-report limitation. Despite more contact with patients, LPNs in the study did not view their role in ACP to be as important as the RNs did. ACP education is central to RN/LPN ACP practice.
14) Nedjat-Haiem, F. R., Carrion, I. V., Gonzalez, K., Ell, K., Thompson, B., & Mishra, S. I. (2016), USA.*	Exploring perspectives of Doctors, RNs, SW and chaplains on engaging pts in EOL communication.	Qualitative study and analysis of Semi-structured interviews.	79 medical and non-medical providers at 2 medical centres.	Themes: providers' roles, responsibility of doctors for initiating EOL conversations, need for team co-management.	Physicians are a vital part of leading EOL comm. But the team is important.
15) O'Conner-Von, S., & Bennett, F. (2020), USA. *	Exploring the communication strategies used by LTC nurses to clarify patients'	Qualitative study done using two focus groups and a phenomenological framework to elucidate	14 LTC RNs from two LTC facilities (one rural and one urban) in	Two themes grounded in time: a) nurses use time to assess patients' EOL situations & assist patients to discern care options;	Nurses shared that EOL communication is never "done", and that time frames to assess,

	EOL care preferences.	RNs' EOL communication experiences.	Midwestern USA.	and b) nurses educate patients re: EOL care, adjust care plans, and develop trusting relationships. Two themes grounded in clinical experience: a) nurses become persistent advocates & educators to initiate and sustain EOL communication; and b) nurses learn consistency in communication, including awareness of patients' nonverbal communication.	educate, & clarify are continuous.
16) Ottoboni, G., Chattat, R., Camedda, C., Galletti, M., Macripo, S., Mariani, E., & Ingravallo, F. (2019), Italy.*	To investigate knowledge of, attitudes towards, and experience with ACP of nursing home staff members in Italy.	Quantitative cross-sectional survey. Statistical analyses done to investigate interactions between participants' characteristics, knowledge, attitudes and frequency of ACP discussion with residents.	185 HCPs working in 12 Italian nursing homes. Nurses (n = 23) made up 12.4% of total 185 participants.	HCPs' knowledge & training in ACP, and the knowledge & awareness of ACP in pts./families & the general population were considered either main barriers or facilitators. Only 16% of participants discussed ACP at least sometimes, usually at the request of pt. and/or family.	ACP knowledge & practice are still in the early stages in Italy (i.e., Law 219/2017 about informed consent and ADs was approved in December 2017 in Italy). Nursing home HCPs' concerns re: ACP seemed to be r/t a misconception about pt./family willingness to discuss ACP.
17) Rietze, L., Heale, R., Roles, S., & Hill, L. (2018), Canada.*	Identifying factors associated with Canadian RNs' engagement in ACP.	Mixed methods, Qualitative/Quantitative cross-sectional descriptive study.	125 RNs participated. A survey consisting of demographic questions, yes/no, Likert scale, multiple choice,	Although RNs value ACP implementation and view it as part of their role, RNs' engagement is not consistent.	Acute care RNs engaged in ACP more than non-acute care RNs. Barriers to RN ACP practice: limited organizational policy, limited expectations of other on healthcare

			and short-answer questions.		team to engage in ACP, and lack of ACP educational opportunities.
18) Schickendanz, A. D., Schillinger, D., Landefeld, S., Knight, S. J., Williams, B. A., Sudore, R. L. (2009), USA.*	To explore barriers to ACP steps with older adults.	(qual & quant analysis). Descriptive Study. Mixed methods.	Telephone interviews with 205 general med patients. 6 months after enrolment in an AD study 143 remained for analysis.	6 Barrier themes: ACP is irrelevant, personal, relationship concerns, info needs, health encounter time constraints, and probs with ADs.	This builds on prior work describing ACP in terms of the transtheoretical behavioral change model. Results only generalizable to outpatients who were introduced to ACP thru Ads.
19) Seymour, J., Gott, M., Bellamy, G., Ahmedzai, S. H., Clark, D. (2003), UK.*	Explore older people's views about advance statements (AS) and EOL care decisions.	Qualitative Descriptive study and content analysis of focus groups.	Focus groups with 32 older people or their representatives.	Advance statements aid personal integrity & help families; advance care statements & euthanasia; future applicability of AS; difficulties with discussing death & dying; need trusting relationships with physicians.	Rather than emphasizing AS completion, ACP process of discussion is preferable than a solid decision.
20) Stewart, F., Goddard, C., Schiff, R., & Hall, S. (2011), UK.*	To explore views on ACP in care homes for older people.	Qualitative, individual semi-structured interviews.	Staff at 34 care homes for the elderly in two London boroughs (care managers n=33, nurses n=18, & care assistants n=29), community nurses n=10, and families n=15.	Benefits of ACP seen by staff and families: providing choice to pts and better planning. Barriers: perception of pts' reluctance or inability to engage in ACP, prevalence of dementia among pts, family involvement & unforeseen medical circumstances problematic for staff. Facilitators: early	Overall, staff & families support the idea of ACP for pts in their care homes. Identified barriers to ACP need to be dealt with to help embed ACP as a consistent part of end-of-life care in care homes for the elderly.

				initiation of ACP, family involvement to establish preferences, pts & staff being well-known to each other, & staff training in ACP.	
21) The SUPPORT Principal Investigators. (1995), USA.*	To improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying.	A 2-year prospective observational study (phase I), followed by a 2-year controlled clinical trial (phase II) in 5 teaching hospitals in the USA. Physicians in the intervention group received estimates of 6-month survival, outcomes of CPR, and functional disability at 2 months. A SUPPORT nurse clinician had multiple contacts with the pts, families, physicians, and hospital staff to elicit preferences, improve understanding of outcomes, encourage attention to pain control, and facilitate ACP and pt-physician communication.	Phase I = 4301 pts Phase II = 4804 pts and their physicians randomized by specialty group to the intervention group (n=2652) or control group (n=2152) A total of 9105 hospitalized adults with one or more of nine life-threatening diagnoses (an overall 6-month mortality rate of 47%).	Phase I: documented shortcomings in communication, frequency of aggressive treatment, and characteristics of hospital death. 47% of physicians knew their pts preferred to avoid CPR, 46% of DNR orders written within 2 days of death, families reported moderate to severe pain in 50% of pts who died in hospital. Phase II: no improvement in: pt-physician communication; incidence/timing of DNR orders; physician's knowledge of pt wishes re: CPR; # of days spent in ICU; mechanical ventilation, or comatose before death; level of reported pain; and reduction of use of hospital resources.	Substantial shortcomings in the care of seriously ill hospitalized adults. To improve the experience of seriously ill and dying pts, more individual and societal commitment and more proactive and forceful measures may be needed.
22) Teno, J. M., Licks, S., Lynn, J., Wenger, N.,	To evaluate whether the lack of effect of ADs	Quant & qual Content analysis of ADs/record reviews.	All ADs in hospital med records from time	Only 90 had a directive that gave a specific instruction (of these 36 to	Improvement needed incl use of effective and targeted ACP.

Connors Jr., A. F., Phillips, R. S., O'Connor, M., Murphy, D. P., Fulkerson, W. J., Desbiens, N., Knaus, W. A. (1997), USA.*	on decision-making in SUPPORT might arise, in part, from the content of the actual documents.		of study enrollment thru 6 months of follow-up or until death (569 pts).	life-sustaining care, and 22 to forgo life-sustaining care).	
23) Teno, J. M., Gozalo, P., Mitchell, S. L., Bynum, J. P. W., Dosa, D., Mor, V. (2011), USA.*	Examine the association between ACP (as measured by facility rate of DNR orders in US NHs) & changes in terminal hospital rates.	Quantitative Study. Retrospective cohort study of changing prevalence of DNR orders. Fixed effect multivariate model.	15,784 NHs were assessed for DNR rate and pt terminal hospitalization between 1997-2007.	For every 10% increase in the facility rate of DNR orders, there was a 0.56% decrease in the rate of terminal hospitalizations.	Limitation is that one cannot assume that prevalence of DNR orders means ACP was done.
24) van Soest-Poortvliet, M., van der Steen, J., Gutschow, G., Deliens, L., Onwuteaka-Philipsen, B., …Hertogh, C. (2015), The Netherlands.*	Descriptive process of ACP in NG residents with dementia as perceived by family, doctors, RNs.	Qualitative descriptive study, in-depth interviews.	65 interviews, 20 family caregivers, 21 physicians, 24 RNs.	Physicians generally initiate the ACP with dementia pts and families.	More about doctors' roles in ACP.
25) Yokoya, S., Kizawa, Y., Maeno, T. (2018), Japan.*	To clarify the practice and perceived importance of ACP and the difficulties in palliative care in GHSF in Japan.	Quantitative statistical analysis of results of a Nationwide cross-sectional survey (by mailing a Self-report questionnaire to 3437 GHSFs).	844 head nurses at GHSFs.	There are discrepancies between the actual practice of ACP and the recognition of its importance and LTC residents may receive inadequate EOL care.	Poor staff education hindered ACP. And participants were head nurses rather than front-line nurses in this study.

Note. 25 ACP research studies in total: 12 qualitative studies, 8 quantitative studies, and 5 mixed methods (qualitative-quantitative) studies. (8 Black stars = RNs/LPNs/Nurse Managers only, 11 Blue stars = RNs mixed with other healthcare team members, 6 Red stars = Doctors, Patients, or documents).

Table 4

Breakdown of the ACP Studies by Settings

ACP Study Settings	**Number of Studies**	**Participant Breakdown**
LTC/Nursing Homes (non-acute care settings)	14	**6, 7, 1**
Hospitals/Medical wards (acute care settings/tertiary hospital)	8	**1, 3, 4**
Acute and Non-acute patient care settings (not specified further)	2	**1, 1**
Community	1	**1**

Note. 25 ACP research studies in total. A colour-coded breakdown by participants: Black = RNs/LPNs/Nurse Managers only, Blue = RNs mixed with other healthcare team members, Red = Doctors, Patients, or documents.

Table 5

Breakdown of the ACP Studies by Participants

Registered Nurses and/or Licensed Practical Nurses (RNs/LPNs) only	Nurse Managers only	RNs & Doctors only	RNs & Social Workers only	“Staff” or Healthcare Teams (including RNs)	Doctors only	Patients only	Doctors & Patients only	Documents
5	3	2	3	6	1	2	1	2

Note. 25 ACP research studies in total: Black = RNs/LPNs/Nurse Managers only, Blue = RNs mixed with other healthcare team members, Red = Doctors, Patients, or documents.

Table 6

Breakdown of Participant Demographic Information: Years of Nursing

Years of Overall Nursing Experience*	**Years of LTC Nursing Experience****	**Years of Experience in Current Facility*****
3	3	1
8	7	8
11	11	11
12	12	12
13	7	1
15	15	24
16	5	16
16	10	3
27	20	21
28	7 months	7
34	34	34
36	34	34
41	8	4.5
42	42	5
43	15	7

Note. A total of 15 LTC nurse participants in this study.

*Average years of overall nursing experience = 23 years.

**Average years of LTC nursing experience = 14.9 years.

***Average years of experience in current facility = 12.6 years.

Table 7

Breakdown of Participant Demographic Information: LTC Site Characteristics

Type of Healthcare Facility Currently Working In*	Number of Beds on Unit(s)	Typical Daily Nurse to Patient Ratio	Healthcare Team on Unit**	Physician Access on Unit
LTC	20-bed unit	1:20	HCAs, nurses, manager, OT, recreation worker, physicians	-physicians rarely physically present -see patients for special cases -available on-call 24/7
LTC	30-bed unit	1:6	Nurses, HCAs, physicians, SW, PT, OT, rehab assistant, RT, manager	-physicians available on-site & on-call 24/7 -physicians in-person & by phone
LTC	35-bed unit	1:20	HCAs, physician, manager, OT, PT, RD, nurse, SW, cook, dietary aide, housekeeper, maintenance	-in-person 1/wk. for rounds -available on-call 24/7
LTC/hybrid facility	30-bed unit	1:6	HCAs, nurses, manager, RT, PT, OT, SW, physicians	-physicians available on-site & on-call 24/7 -physicians available on-call 24/7
LTC/hybrid facility	42-bed unit	1:21	Nurses, HCAs, SW, OT, PT, RD, SLP, physician, HCAs, nurse manager	-in-person 1/wk. for rounds -available on-call 24/7

LTC/PCH	88 total beds in facility	1:24	Nurses, HCAs, SW, director of care, recreation workers, rehab assistant, PT, OT, physicians	-in-person 1/wk. -available on-call 24/7
LTC/PCH	116 total beds in facility	1:14	RNs, LPNs, HCAs, RD, OT, physicians, housekeeping, diet aides, director of care, recreation workers, managers	-in-person 1/wk. for rounds -available on-call 24/7
PCH	78 total beds in facility	1:27	Nurses, HCAs, rehab assistant, OT, PT, RD, SLP, director of care, housekeeping, dietary, physicians	-weekly visits -available on-call 24/7
PCH	136 total beds in facility	1:29	Housekeeper, dietary aides, HCAs, RN or LPN, maintenance, spiritual care, SW, cooks, nurse manager, superintendent, laundry, OT, PT, SLP, pharmacy, RD, physicians	-in-person 1/wk. for rounds -available on-call 24/7
PCH	80 total beds in facility	1:20	RNs, LPNs, HCAs, SW, RD, spiritual care, housekeeper, dietary aides, recreation worker, physician	-in-person 1/wk. for rounds -available on-call 24/7
Other	24-bed unit	1:8	Nurses, PTs, OTs, recreation worker, HCA, clerk, physician	-doctor 2 half days/wk. -doctor available on-call for emergencies -physicians available on-site & on-call 24/7
Other	30-bed unit	1:9	Manager, nurses, HCAs, SW, OT, PT, RT, spiritual care, RD, physician	-in-person 2x/wk.

				-available on-call 24/7
Other	30-bed unit	1:6	Nurses, HCAs, SW, rehab assistant, OT, PT, RT, SLP, manager, physician	-physicians in-person 3x/wk. -call or page doctors 24/7
Other/hybrid facility	420 total beds in facility	1:20	Nurses, OT, PT, spiritual health, RD, SW, nurse manager, physician	-in-person 2x/wk. for rounds -available on-call 24/7
Other/hybrid facility	24-bed unit	1:6	Nurses, HCAs, recreation worker, SW, OT, PT, rehab assistants, manager, spiritual care, clerks, RT, physicians	-physicians available on-site & on-call 24/7 -physicians not always in-person -all doctors available on-call 24/7

Note. A total of 15 LTC nurse participants in this study. A few units/facilities also had some access to Clinical Resource Nurses (CRNs), geriatric mental health professionals, and/or Nurse Practitioners (NPs).

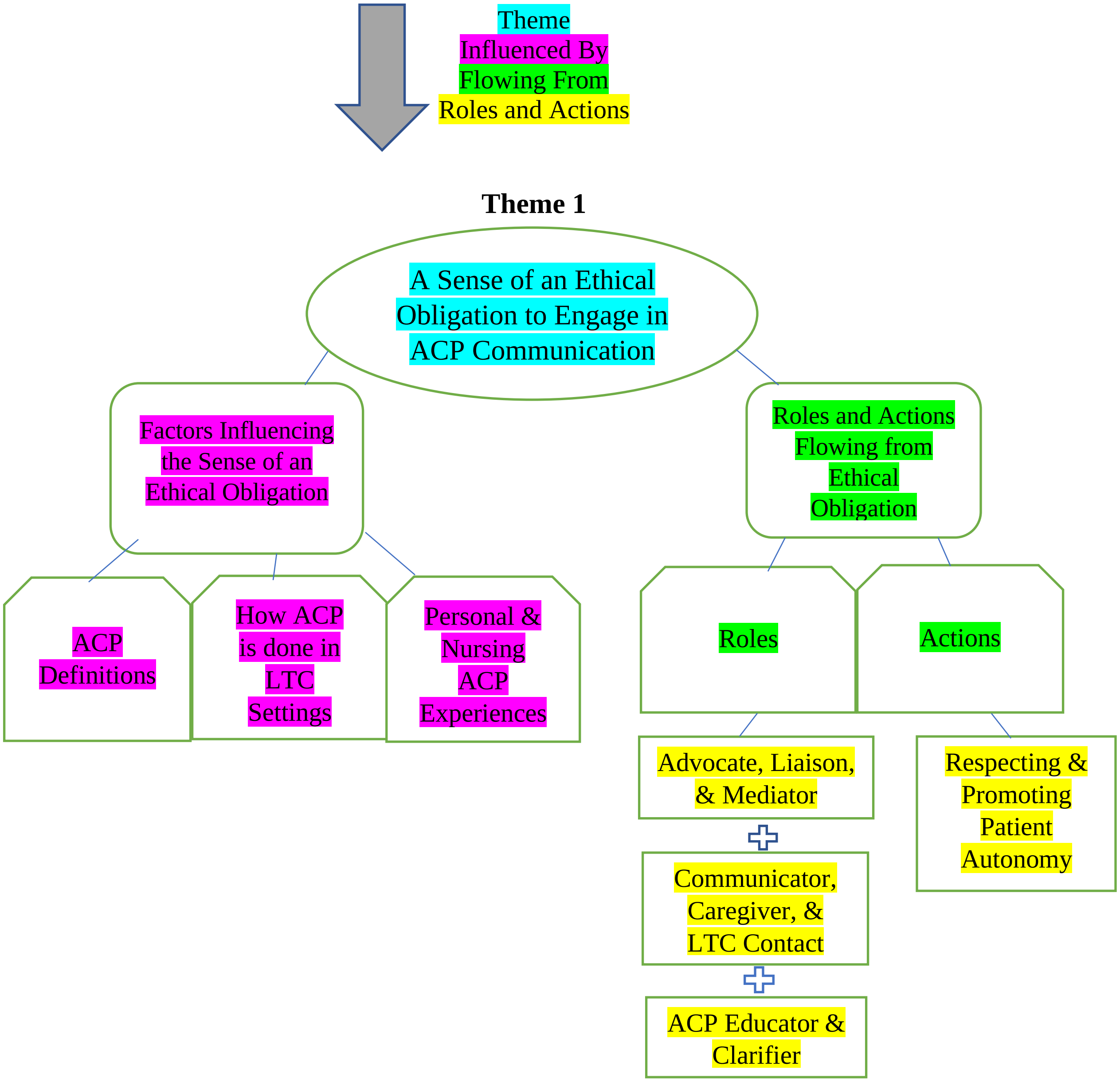
*LTC = Long-term Care, and PCH = Personal Care Home.

**HCA = Healthcare Aide, OT = Occupational Therapist, PT = Physiotherapist, RD = Registered Dietitian, RT = Respiratory Therapist, SLP = Speech Language Pathologist, and SW = Social Worker.

Figures

Figure 1

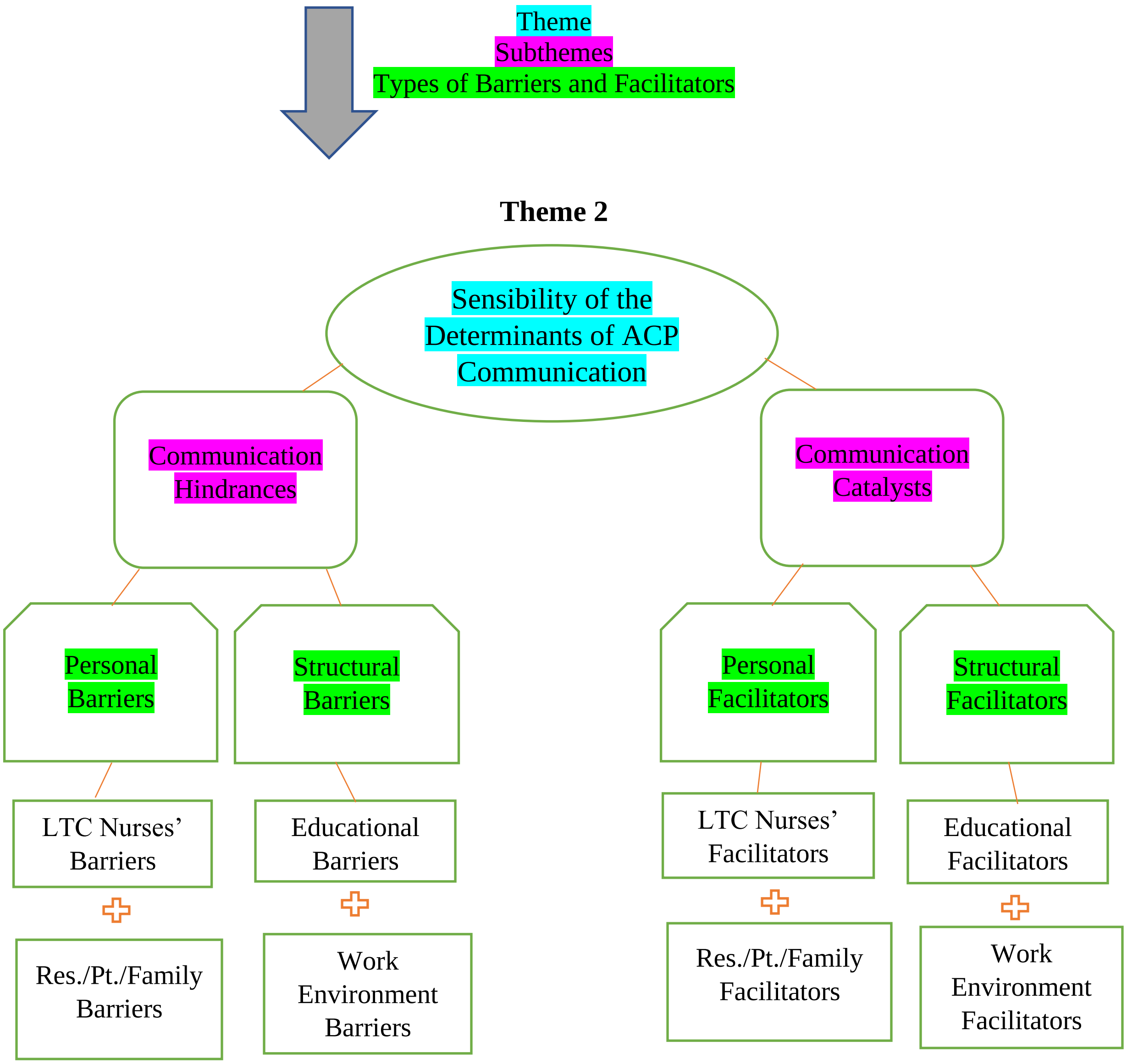
Diagram of the Relationships Within Theme 1



Note. A visual representation/diagram of the connections and relationships between the first main theme and factors that influence the theme and roles and actions that flow from the theme.

Figure 2

Diagram of the Relationships Within Theme 2



Note. A visual representation/diagram of the connections and relationships between the second main theme and subthemes.