Nurse Practitioner Role Enactment in Community Palliative Care

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Abstract

Background:

Access to adequate palliative care has been identified as a challenge globally, in Canada, and in the province of Ontario. While pockets of excellence exist, there is a national call for allocation of resources and implementation of best practices to improve the care for individuals with life limiting illnesses. Furthermore, the location of care along with a desire for dying at home has shifted responsibility onto family members often without the equivalent shift in community resources to meet patient and family needs. To respond to issues of access and quality, nurse practitioners (NPs) have been increasingly added to diverse practice settings across the globe and research showing how they are contributing to diverse care settings. As a strategy to improve community palliative care locally, NPs have been added to community settings in Ontario. However, because NPs are new to palliative care settings little is known about how NPs enact their role within this unique context. NP role enactment is defined as the actual activities that NPs engage in that constitute their daily work.

Aim:

The purpose of this study is to better understand how NPs enact their role as consultants in a specific community palliative care setting in Ontario.

Methodology and Methods:

A focused ethnography was conducted in one specific geographic health administration region of Ontario between July of 2018 and October of 2020. A convenience sample was used recruiting NPs from one community palliative care consultation team. Data collection methods included observation (487.5 hrs over 89 discrete observation sessions, distributed across 7 study participants), fieldnotes and semi-structured interviews with participants (n = 7 NPs).

Results:

The NPs enacted their role with patients by formulating relationships, that for them, facilitated a deeper understanding of the patient and family situation, strengths, challenges and desires. Using conversations and conversational skills to have difficult and important conversations, NPs facilitated future planning for patients. Conversations also included addressing questions about MAiD, which were nuanced and often about more than MAiD, also addressing fears of suffering and uncertainty. The NPs used advanced clinical judgment and skill to diagnose and treat complex and difficult to manage symptoms and supported families to understand complicated medication regimes. Valuing their role as educators, the NPs supported their peers by offering teaching and providing clinical support in complex care scenarios. Pull together disparate and loosely connected care providers, NPs created a shared understanding of patient needs. Deficiencies in community care resourcing and organization made it difficult at times for NPs to facilitate continuity in care or to build capacity. The NPs often navigated an environment where nursing staffing was transient, inconsistent and overextended and where physicians were inconsistently available to support rapidly evolving situations.

Conclusion:

Findings suggest that NPs have an important role to play in supporting patients and families as well as supporting their nursing and physician colleagues. Furthermore, the broader system would benefit from embedding palliative care NPs more systematically. However, broader structural enhancements like shared communication and documentation mechanisms and adequate staffing across care settings need to be addressed to maximize the potential contributions NPs are able to offer.

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Chapter 1: Introduction

Interest and Motivation for the Study

My interest in the NP role is highly personal in that I am myself an NP and have always been curious about the innovative ways that NPs can improve the current health care landscape. The NP role in primary care has always made sense to me, perhaps because of my exposure to community nurses. Growing up in a rural setting, I saw how these nurses played a central role in meeting the health care needs of patients. I encountered community nurses through school immunization programs and through aging family members and friends who relied on community nurses for health information. As part of their community-based role, nurses enabled seniors to remain in their homes and supported young families by offering screening, education, and immunization clinics. These nurses inspired me and influenced me to pursue nursing as a career.

As a new nurse, I spent my first few years working in remote communities where nurses were, and still are, the backbone of the health care system. As a nurse working in rural and smaller communities with limited staff, I was often the only primary care provider (PCP)[1]. Without formal preparation in transitioning to the broad range of my clinical and administrative responsibilities, I had to learn "on the job." I spent evenings and weekends reading and learning how to better respond to the health questions and needs of the people seeking help for their health concerns. I learned from my peers and relied on employer-provided practice guidelines; however, I still felt underprepared to address the complexity of the patient health needs

[1] Primary care providers (PCPs) are generally those health care providers who have the professional responsibility of meeting the primary care needs of patients in community settings. Physicians have traditionally been the main providers of primary care. In rural and remote settings, nurses often are the only PCPs. More recent changes to how primary care is organized and delivered has resulted in the integration of NPs as PCPs. In this study, I use PCP to refer to both physicians and NPs, however physicians were the most commonly encountered PCP.

encountered in my day-to-day work. My desire to feel better prepared to help patients with their health concerns led me to pursue a Master's degree with an NP focus that would strengthen my nursing capacity. A lack of established NP programs in Canada led me to study in the United States, where NP education was already well-established. During my graduate studies at the University of North Dakota, I experienced first-hand how NPs in rural North Dakota worked to support the health care needs of their communities. Through my studies and clinical experience as part of the NP program, I came to appreciate the potential for the NP role in Canada.

Following my NP certification, I re-entered the Canadian workforce as an NP in 2004 when stakeholders in primary health care in Ontario were trying to understand how and where this new type of nurse fits as a broader primary health care strategy with family health teams (Rosser et al., 2011). While these stakeholders recognized the potential for the NP role, the challenge they faced was how to weave NPs into an existing primary care landscape. Physicians, most commonly working in independent practices, served as the dominant model of how health care was (and to a great extent, continues to be) delivered. Newly funded pilot project positions in family health teams identified NPs (along with others, for example, primary care nurses, pharmacists, social workers and dieticians) as part of a broader primary health care team. In these early days of adding NPs to primary care settings, team members often struggled to understand what NPs *could* and *should* do and how they fit within the broader primary care picture. When hired into my current practice setting, I initially encountered patients and colleagues who struggled to understand my role as an NP. In conversations with NP colleagues, I learned about their similar experiences. Some NPs described challenging yet positive experiences of growth and adaptation by all involved in the setting. Other NPs described more significant challenges in integrating into established clinical practices. These challenges

represented local difficulty with understanding the operational role of NPs and their logistical integration. In many instances, limited resources and infrastructure contributed to the under-utilization of NPs. This finding was disappointing given my experience and insight as a nurse and NP. I witnessed how NPs in primary care settings contributed to timely care and optimized resources. With its broad legislative scope of practice, I could see how the NP role could improve the quality of available health care and access to these services. More patients could have their health needs addressed earlier and appropriately.

Reflecting on my own experience in my clinical practice, I would say that NPs are now well integrated and part of the broader team. I am privileged to work in what I would describe as an exceptional clinical setting with a complement of nurses, physicians, pharmacists, social workers and counsellors, physician assistants, and enthusiastic administrative staff. As an NP in this setting, I function independently and interdependently within this broader team. As a team, our shared role is to meet patients' needs and help each other address the needs of patients in our unique and overlapping capacities.

A few years after the introduction of the new primary care teams in Ontario, NPs were systematically added to specific long-term care (LTC) settings to improve the quality of care and reduce avoidable transfers to hospitals. In 2000, a pilot program added 20 NPs to specific LTC settings (Aestima Research, 2002). The NPs in LTC program was further expanded in 2017 by the creation of 75 positions (MoHLTC, 2017). In my conversations with these NPs, I heard about their work with patients, families and staff. In some settings, there was initial resistance to the new NP role. Nurses, managers, support workers, and physicians required time to understand and accept this new role. However, with time and exposure, patients and staff became accustomed to and reliant on NPs. Subsequent research shows that adding NPs to LTC settings improves the

skill and confidence of LTC staff and care for residents with complex needs (Sangster-Gormley et al., 2013).

After another few years passed, I learned about a new provincial initiative to add NPs to community palliative care. In 2011, the Ontario government announced that each of the 14 health regions would be funded to add 5 NPs to the local palliative home care programs (MoHLTC, 2011). I learned that each region structured the NP role a bit differently. In some regions, physicians transferred patients approaching their last months of life to NPs who assumed the responsibility for all the patient's primary care and palliative care needs until death. In other regions, NPs were added to palliative care consultation teams. As part of these teams, NPs are available as consultants to provide expert assessment and advice when nurses and physicians have difficulty managing patient symptoms. In this region, the NPs were added as consultants to an existing pain and symptom management team who offer expert assessment and management when patients were experiencing difficulty with symptoms. I became curious about how this role would work. I had no frame of reference for NPs to work this way. As a clinician, I didn't have any experience with palliative care in my clinical work. I doubt I even saw a patient who was "palliative" in my primary care practice. I didn't have any palliative care education. I was curious about how this role was structured and how NPs negotiated patient needs and professional responsibilities, given the uniqueness of the position. Reflecting on my own experience in primary care, I remembered how I needed to engage in ongoing conversations with physicians and nurses to work out my role in our clinic. I wondered what the experience was for NPs in this setting, where they were constantly involved with different nurses and physicians day-to-day. With my knowledge of NP work in other clinical sites, I anticipated that NPs could contribute, but given the consultation role, I had no preconception of what this might look like

and how it would work. My assumptions are that NPs can contribute positively to every type of care setting; however, every work environment has unique characteristics that inherently shape how NPs navigate their work. My curiosity about this new NP role in this novel setting led me to undertake this study.

I believe NPs can contribute to any health care setting; however, it is essential to consider how NPs carry out their work within their particular employment environment to understand it best. Only through situating NP work contextually can we best understand what NPs see as their role and how they strive to enact that role. Understanding what NPs do needs to account for a range of local influences, including their knowledge, skill, experience, interactions with patients and families, other health care providers, and the broader system organization and policies. This account of contextual influences will contribute to a more fulsome understanding of the NP role. A robust and contextualized understanding of NP work will inform how NPs can best contribute to the health care experiences of patients, families and other health care providers.

Statement of the Problem and Study Purpose

Access to adequate palliative care is a challenge globally, in Canada, and across Ontario (Canadian Cancer Society, 2016). While there may be pockets of excellence for palliative care in some areas, there continues to be a lack of timely and equitable palliative services to meet the needs of individuals (Office of the Auditor General of Ontario, 2014). As a result, there is a national call for allocation of resources and best practice implementation to improve the care for individuals with life-limiting illnesses (Health Canada, 2019; Murray et al., 2009).

Health care organizations across the globe continue to add NPs to clinical settings to address the changing health care requirements of populations (ICN, 2020). Studies indicate that NPs contribute in positive ways to diverse practice settings, including in older adult care (Kane,

Flood et al., 2002: Kane, Kechafer et al., 2002; Morilla-Herrera et al., 2016; Schultz et al. 1997), in the emergency department (Carthon et al., 2017; Fowler et al., 2019; Jennings et al. 2015; Woo et al. 2017; Villasenor & Krouse, 2016), and in primary care (Buerhaus et al., 2018; Swan et al., 2015). Research also shows that NPs garner high patient satisfaction, reduce wait times and provide safe and high-quality care in emergency settings (Fowler et al., 2019). NPs in primary care spend more time with patients in consultation and have equal or better outcomes than physicians in relation to cost, patient satisfaction, and physiologic measures (Swan et al., 2015).

As a provincial response to concerns about palliative care in community settings, Ontario has systematically added NPs to each regional health network as a strategy to increase access to quality palliative care. NP work in the clinical domain of community palliative care is relatively new. While the literature about NP work in palliative care is growing, it is still limited. Existing research shows that NPs have the potential to enhance palliative care to patients through a holistic approach to care, managing patient symptoms and supporting patients and team members (Deitrick et al., 2011; Kaasalainen et al., 2013). The NP role is new to community palliative care, and our knowledge about NPs in this context is limited. An in-depth exploration of how NPs enact their role in community-based palliative care is required.

The purpose of this study is to better understand how NPs enact their role as consultants in a specific community palliative care setting in Ontario. The research question guiding this study is:

How do nurse practitioners enact their role as consultants in a specific community palliative care setting in Ontario?

Objective 1: To understand how NPs engage with patients and families to provide palliative care.

Objective 2: To identify how NPs engage with physicians and nurses in their role enactment in community palliative care.

Objective 3: To identify the broader systemic influences that NPs see as problematic in their work in community palliative care.

An in-depth exploration of how NPs enact their role as consultants in community-based palliative care is required. Achieving a deeper understanding of NP role enactment will help inform us of what NPs do in the context of community palliative care and help develop an understanding of the influences that shape what NPs do, and further inform us about the full potential of the role in this setting. Most studies about NP work have used only survey or individual and focus group interview methods (Carryer et al., 2007; Haron et al., 2019; Martin-Misener, 2015). NP role enactment is best understood when examined and interpreted within the broader policy, health care organization, interprofessional and intrapersonal influences. Without considering the spectrum of influences in the NP environment, our understanding of the NP role will be superficial and limited.

I propose that a focused ethnography (FE) is best suited to achieve a broader and deeper understanding of what NPs do in their day-to-day work in community palliative care. A FE design can illuminate the local phenomenon of NP role enactment and the influences that occur due to being embedded in a social setting and interacting with various local actors (Schensul et al., 2013).

The following chapters present my research about how NPs enact their role in community palliative care. In the following chapter, Chapter 2, I offer a review of the relevant literature related to the current context of palliative care and the challenges that inhibit optimal palliative care in the community setting and the addition of NPs to community palliative care. In Chapter

3, I provide the theoretical and methodological considerations for this research. In Chapter 3, I also put forward an argument for FE as the best approach to answer my research question and provide an overview of my methods. I present my study findings in chapters 4-7. In chapter 8, I conclude with the discussion of my research, where I provide a synthesis of my findings and implications for research, clinical practice, and policy.

Chapter 2: Literature Review

This chapter will provide an overview of the literature related to NP role enactment in community palliative care. I first define palliative care and clarify related terminology. I then discuss the literature relevant to the context-specific challenges inherent in delivering and receiving this kind of care in the home setting. Home is often identified as the preferred place of care through to the end-of-life (EOL) and death. However, the reliance on the work and the capacity of family caregivers (FCGs)[2] in their caregiving responsibilities and the poor resourcing and organization of home care supports can result in tenuous care situations. I further outline the range of responsibilities that FCGs often assume in supporting their loved ones at home to identify potential areas for added support. I also highlight the literature that links how seeking care from hospitals by patients and families is seen as necessary and unavoidable when home supports are inadequate.

Following the literature overview related to the contextual challenges of care and dying at home, I introduce the NP and how NPs have been added to outdated systems of health care that are not keeping pace with population needs. Because definitions of NPs vary globally, I define the role and provide a brief history of the development of this role in Canada, including competencies, the scope of practice and local influences on role enactment. I summarize the literature related to NP contributions to patient and system health both internationally and locally in Canada. I conclude this literature review with a discussion of the research about NPs providing palliative care and their contributions. I also explore how studies have sought to understand how the role is enacted in different settings. I then introduce and define MAiD in the

[2] Within the context of this study, family caregivers (FCGs) are often relatives (most frequently spouses or children). However, FCGs may also be other relatives or friends who have a significant relationship with and assists an individual who has a life-limiting illness.

Canadian context, particularly related to the NP role. I conclude with an overview of the small but growing body of literature regarding MAiD related to NPs.

Defining Palliative Care

Because the terms palliative care and end-of-life (EOL) care are frequently used in this thesis, it is necessary to identify their meanings within the context of this thesis. In the literature, palliative care and EOL care are sometimes used interchangeably; however, they have different meanings. EOL care is a descriptive term that generally refers to any care provided during the last days, weeks or months of life. It includes the care aimed at assisting patients and families to prepare for death. Palliative care, is a more conceptual term used to refer to a particular style of care characterized by specific values, principles, and approaches.

Palliative care reflects a philosophy and an approach to care intended to best address the needs of individuals with life-limiting illnesses. A holistic approach to the care of the patient and family underpins the philosophy of palliative care (Janssens, 1999; Willard, 1999). The goals of palliative care include ameliorating suffering and maximizing quality of life (Pastrana et al., 2008). Suffering and quality of life are inherently subjective and best defined by the individual (Jocham et al., 2006; Neimeyer et al., 2011; Pastrana et al., 2008). Individual experiences at the EOL will vary from person to person, family member to family member and will likely change over time. It is incumbent on care providers to be sensitive to assess and provide support to individuals congruent with what their needs are at that time and to anticipate changes in their needs (Heyland et al., 2006).

Modern-day understandings of palliative care are rooted in the work of Dame Cicely Saunders. Informed by her extensive personal and professional experience in caring for the dying, Saunders was one of the first to articulate how care providers could better support

individuals in their experience of dying. Saunders advocated that health care providers focus on the individual (including their family) and their experience of the illness. Saunders' approach to care has played a significant role in shaping modern palliative care (Clark, 2007). Saunders encouraged attention to the individual's body and the physiologic effects of the illness (she was a strong advocate for good pain management) and the emotional, spiritual, and social domains (Seymour, 2012). Saunders also first articulated the potential contribution of the multidisciplinary team in supporting the care needs of individuals at the EOL, recognizing the benefit to the patient from the contributions of various health care perspectives (Clark, 2007). Many palliative care organizations advocate for collaboration as the ideal approach to care. Collaboration is promoted globally and locally (Champlain Hospice Palliative Care Program, 2017; Health Quality Ontario, 2016a; WHO, 2020). Most recently, the Canadian public has called for collaboration in a consensus statement on the delivery of palliative care (Covenant Health, 2016).

The definition of palliative care used in this thesis draws on the definition put forward by the World Health Organization (WHO, 2020). Palliative care is promoted as an approach is to care for all individuals experiencing the difficulties associated with life-threatening illness. The goal of palliative care where possible, is to prevent suffering or to relieve it through early identification through assessment and treatment of psychosocial, physical and spiritual concerns (WHO, 2020). The WHO further characterizes palliative care as person-centred, drawing on a team approach and focusing on the preferences and needs of individuals and their families, from practical to bereavement. Palliative care strives to help patients live as actively as possible until death. A broad range of care providers can engage in palliative care, including those who are regulated (e.g., nurses, physicians, social workers, physical therapists, dieticians, psychologists,

paramedics) and unregulated (e.g., personal support workers (PSWs), volunteers, spiritual care practitioners). Ideally, these care providers work in an integrated manner to best support patients and family members (Champlain Hospice Palliative Care Program, 2017; WHO, 2020).

In some instances, palliative care is delivered only by a narrow range of providers and possibly only by a primary care practitioner and home care nurses. In contrast, specialists or palliative care teams support situations where symptoms are more challenging to manage. Furthermore, palliative care is offered in various settings, including institutions (hospitals, hospices) and patients' homes (private, LTC, retirement residence, homeless shelters, prisons) through home care. Offering palliative care as early as the time of diagnosis of a life-limiting illness provides patients and families opportunities to learn to manage their condition and discuss their needs and wishes (Stajduhar, 2011; World Health Assembly, 2014).

Palliative care is often associated with specialized care services (Quill & Abernethy, 2013) delivered by specially trained health care providers. This association is natural given specialized palliative care has historically focused on the care of individuals dying from cancer and with relatively predictable disease trajectories (Reimer-Kirkham et al., 2016). Specialist palliative care, however, generally refers to the care that augments basic palliative care (a palliative approach) to assist with refractory symptoms or more difficult psychosocial or ethical concerns (CNA, 2015; Quill & Abernethy, 2013) especially toward the EOL. There is growing recognition of the relevance and value of extending the principles embedded in palliative care earlier in life-limiting disease trajectories, which is characterized as a palliative approach (Bacon, 2013; Rocker et al., 2016; Sawatzky et al., 2017).

A palliative approach requires an upstream reorientation and integration of palliative care principles to enable earlier conversations and planning with individuals with life-limiting chronic

illnesses across health care contexts (Sawatzky et al., 2016). A palliative approach necessitates that all health care providers should have at least a basic palliative care skill and capacity (Quill & Abernethy, 2013). Conceptualized broadly, a palliative approach involves the adaptation and integration of key palliative care principles (such as patient/family-centered care while attending to quality of life) early and throughout the disease trajectory with continuity as patients transition across health settings (Sawatzky et al., 2016; Stajduhar, 2011). Sawatzky et al. (2016) conducted a knowledge synthesis to identify the essential characteristics of a palliative approach. The three key characteristics identified include: 1) the early integration of palliative care principles to meet the needs of individuals with life-limiting illnesses; 2) the adaptation of palliative care knowledge to shape the care of patients with chronic conditions; and 3) the integration of palliative care principles into the broader health care system (Sawatzky et al., 2016). With this reorientation, palliative care extends far beyond the domain of specialty care and requires integration into mainstream care using a generalist or primary palliative care model. In order to achieve a palliative approach, a full spectrum of health care providers across a range of settings where patients seek and receive care (offices, home and LTC) need to possess the skills to have basic discussions and manage basic palliative care needs (Reimer-Kirkham et al., 2016). Furthermore, when patient needs exceed the care provider's capacity, the care provider needs to have both the knowledge and the skill to recognize when this occurs but also be supported by an infrastructure to seek additional clinical and professional help when needed.

Community Palliative Care Needs and Challenges

Translating the philosophy of palliative care into a system of care has proven to be a challenging undertaking. Ensuring that individuals have access to care that is adequate and appropriate requires attention at the individual health care provider, societal, and the health

systems levels. As presented above, palliative care represents a philosophy of how individuals should be treated at the EOL but is also promoted as an approach to care offered to all individuals with advancing life-limiting illnesses. Examples of life-limiting illnesses include cancer and advancing chronic diseases such as heart failure, chronic obstructive pulmonary disease, diabetes, renal failure and severe dementia. Challenges continue to exist in identifying those who might benefit from a palliative approach. For example, a recent Canadian report highlighted that patients dying with cancer, a disease trajectory that is often better understood, were three times more likely to receive palliative care than those with non-cancer diagnoses (CIHI, 2018). While this data is limited because it refers to palliative care in terms of palliative home care as a service in general, it still speaks to the challenge of identifying patients with palliative needs and connecting them to helpful services.

Challenges as a result of health care service funding and organization: The Canada Health Act and Insured Services

From a systems perspective, challenges to receiving palliative care have resulted from the variability in resourcing, organization and coordination of services (Sussman et al., 2012). The lack of a shared definition of palliative care in Canada and the standards for delivering it in practice pose a challenge to identifying what that kind of care means, the services that should be included and how best to measure these elements (CIHI, 2018). The *Canada Health Act* (1984) specifies how the planning, financing and delivery of health care services falls under provincial responsibility with funding support from the federal government (Marchildon, 2006). The *Canada Health Act* mandates coverage of medically necessary care; however, this care is limited to that received in hospital settings or provided in primary care settings by physicians. All remaining service coverage and organization are left to the discretion of the province (i.e.

community-based services by health care providers other than physicians, home care and LTC). This provincial administration of health care has resulted in a great degree of variability in the types and organization of services. This variability holds, especially in the domain of palliative care services (Williams et al., 2010). In Ontario, the Ministry of Health and Long-Term Care (MoHLTC) maintains the overall responsibility for health care services, including palliative care. The MoHLTC distributes funding to 14 geographically defined health administration regions that in-turn plan, co-ordinate and fund and monitor palliative-care services locally including hospitals, hospices and care in people's homes.

Regionalized Health Care

There has been a trend toward regionalizing health care within provinces, which intended to support the development of programs that are more responsive to local needs. Regionalization and the associated local capacity to make decisions resulted in the evolution of palliative care services that differ widely across regions. The lack of shared understanding of what palliative care should entail results in vast differences in what services are prioritized and allocated and service delivery structures across regions (Williams et al., 2010). Williams et al. identify contrasting examples of palliative care in one region conceptualized as one dedicated room in a local hospital and developing a coordinated palliative care program in another region. Rural communities can suffer from a lack of available funding as a result of regionalization. For example, one or two designated palliative care beds in acute medical units or residential care in rural communities. However, these beds may often not be available for palliative care as they are also used for other patients who require private rooms (Pesut et al., 2014).

The Canadian Institute for Health Information (2018) suggests that the lack of clear national standards and accountabilities also contributes to the jurisdictional variability in policy,

programs, and guidelines resulting in inconsistency or inadequacy of access across Canada. Despite the variability of allocation of funds for health care services that are not considered medically necessary, many provinces have worked on local strategies for palliative care. For example, British Columbia offers micro-grants for hospice societies (Government of Canada, 2017). Meanwhile, Nova Scotia and Prince Edward Island employ paramedics to support individuals with palliative goals of care to remain at home (Government of Canada, 2017).

There is a growing understanding that while many individuals with their families prefer to remain at home, at the same time, existing community-based care is are fragmented and inadequate (Morrison, 2017; Williams et al., 2016). In response to this growing understanding of deficiencies and as a result of public activism, the Government of Canada passed legislation in 2017 to develop a national framework on access to palliative care. As part of this framework, provincial and territorial governments expressed support for improving home and community care (including palliative home care and residential hospices) (Government of Canada, 2017). The organization of community care directly shapes how such services are delivered and, as a result, are experienced by patients and families. While some changes are underway, challenges continue.

Home Care Challenges

Publicly administered home care programs are responsible for supporting patients and their families with palliative nursing care and support services in the community. Patients and their families are reliant on these services to safely be able to remain in their homes throughout the dying trajectory. Because of funding allocation and constraints, service levels differ across health networks resulting in a patchwork and inequitable system of services (CIHI, 2018; Home Care Ontario, 2018). The Ontario Ministry of Health and Long-Term Care (MoHLTC) allocates

home care resources to 14 local health networks. Within Ontario, home and nursing care services are coordinated and administered by regional health networks that act as single points of access. These network hubs accept referrals for services, assess patient needs and coordinate home care services, placement in residential LTC and more recently, hospice (Randal & Williams, 2006). In Ontario, publicly funded home care services support individuals who require help to care for themselves in their homes. Services can include personal and nursing support, physiotherapy, occupational therapy, social work nutritional counselling, speech-language therapy, and medical supplies (Health Quality Ontario, 2016b). Ensuring that individuals receive the care and services they need throughout the trajectory of their life-limiting illness can be challenging, mainly because each individual will experience variable symptoms that evolve constantly and sometimes rapidly (Gomes et al., 2013).

The combination of diverse professional groups and organizations that make up the community-based palliative care health services can contribute to increased fragmentation of care (Bainbridge et al., 2010). A recent provincial report on home care organization and delivery (Donner et al., 2015) revealed concerns about poor communication across organizations. This provincial report highlighted sub-optimal communication between PCPs, tertiary care, care coordinators, and the multiple services offered by several different agencies. This sub-optimal communication and the associated lack of continuity in home care staffing negatively impacts the care experience of patients and families (Donner et al., 2015). In their provincial action plan, the Ontario MoHLTC (2015) acknowledges that the siloed and disjointed organization of health care (primary care, home and community care and public health) makes it difficult for patients and families to find and access the services they require.

Home Care Ontario (2018) reports that because of inadequate funding, the local health networks often engage in rationing of services by reducing the allocated time for a service, for example, reducing 30-minute visits down to 15-minute visits. Such a short visit barely enables focused tasks to be completed. These time restrictions disincentivize and obstruct broader discussions by nurses about overall health that might help the early detection of palliative symptoms or concerns (Home Care Ontario, 2018). There is also a lack of integration of health care providers across systems regarding patient health records. Privacy laws restrict home care nurses from accessing, sharing, and communicating critical patient health information (Home Care Ontario, 2018). This legal hurdle prevents nurses from editing and updating patient records that would contribute to more coordinated and seamless care.

Long-Term Care Home Challenges

LTC homes are a common place of residence for many individuals as they age when they require more personal care and support. As a result, many individuals in LTC settings, if not all, will also require some level of palliative care. Research about care at EOL in LTC settings has found under-resourcing and sub-optimal access to palliative care. For example, research has shown that pain and other symptoms are often poorly managed (Teno et al., 2004). For example, in a study by Tangh et al. (2020) that examined terminal care of pain or dyspnea, researchers found that opioids were underused in the last days of life to address uncontrolled symptoms. The findings in this study by Tangh et al. suggest either a lack of knowledge or comfort with using opioids to address shortness of breath experienced in severe end stage lung disease. Other research has shown that advance care planning and goals of care discussions are under-addressed (Ampe et al., 2017; Castle, 1997; Jeong et al., 2011) contributing to hospital transfers at EOL (Broad et al., 2012; Menec et al., 2009; Miller et al., 2001). Furthermore, the vast majority of

LTC staff are unregulated care workers with limited training in relation to palliative care (Kaasalainen et al., 2017).

Recent reviews of the LTC sector highlight a precarious employment and care environment that may jeopardize the ability for residents to be adequately supported in a palliative approach to their care. Policy adjustments related to LTC funding encouraged the encroachment of for-profit organizations into the LTC bed business, which is potentially problematic because of commitment to profit as the bottom line. The costliest element in LTC is staffing. A recent staffing report from the Ministry of Long-Term Care (MoLTC, 2020)[3] reported on the work climate. The report highlighted how employees often had to work multiple jobs to earn a living wage and how staff shortages resulted in missed care and care rationing in relation to bathing, personal care and toileting (MoLTC, 2020). Policy adjustments have also removed required minimum staffing standards (hours of care, staff mix) (Armstrong & Armstrong, 2018). Changes to staffing standards in 2008-09 allowed minimum staffing of one RN on every shift and funding to support 3.5 hours of care per resident per day (increasing to 4 hours by 2012) (Munro, 2011). There currently is no requirement to provide the 4-hour allocation. This staffing report (MoLTC, 2020) echoes previous calls for increases to minimum hours of care per resident. The staffing report by the Ministry of Long-Term Care (2020) further reveals a work environment with increasing levels of resident health acuity without access to corresponding levels of training and education and a lack of full-time positions (MoLTC, 2020). These deficiencies result in employees that are under-skilled and underpaid, creating an unstable workforce, reduced continuity of care and an environment where skill-building is difficult.

[3] In June 2019, the Ontario Ministry of Health and Long-Term Care was split into the Ministry of Health and the Ministry of Long-Term Care.

For individuals who require more support in their last year of life and who would like to transfer to a setting that can offer more support, access to a bed in a LTC setting is a challenge. Examination of current wait times in this region reveals wait times for placement in a home ranging from 138 days to 1836 days (with the average wait time of 500 days) for a basic room (shared) (Champlain LHIN, 2020). In some areas, LTC beds are allocated for crisis situations and for respite to relieve family caregivers (FCGs).

Home Care as the Context for Work

Nursing work in home environments, while often reported by nurses as rewarding and stimulating (Penz & Duggleby, 2012; Rose & Glass, 2006) also poses unique challenges to nurses as compared to institutional settings. Institutions provide controlled environments that are generally safe and predictable, with relatively easy access to equipment, medication as well as practical, emotional and professional support. In home care, patients, families and environments are unique and less predictable (Samia et al., 2012). Research exploring nurses' work in home care offers insight into the experiences of nurses working in home settings (Alvariza et al., 2020; Kaasalainen et al., 2011; Kaasalainen et al., 2012; Kaasalainen et al., 2014; Markkanen et al., 2007; Rabbetts et al., 2020; Penz & Duggleby, 2012; Samia et al., 2012). In studies about nursing in home care, nurses noted challenges with physical space that can have implications for physical safety including lighting and ergonomics, possible issues with family pets, limited space, variable levels of cleanliness, and aggressive patients and family members (Alvariza et al., 2020; Lang et al., 2009; Markkanen, et al., 2007). Nurses working in home care frequently identified difficulty in securing services, equipment and medications in a timely manner (Kaasalainen et al., 2011; Kaasalainen, et al., 2012; Kaasalainen et al., 2014; Penz & Duggleby, 2012).

Nurses working in home care also highlighted difficulty with access to patient information because of a lack of shared patient record across organizations (tertiary care, primary care, home care)(Arnaert et al., 2009; Penz & Duggleby, 2012) and a lack of systematic communication mechanisms (Kaasalainen, 2012). Working in homes also requires nurses to navigate treacherous road and weather conditions as well as traffic and parking (Alvariza et al., 2020; Kaasalainen, 2014). Nurses providing palliative care in community settings also report fragmentation and lack of continuity due to scheduling practices of supervisors who indiscriminately schedule nurses without consideration for continuity (Samia et al., 2012). Similarly, in a study by (Kaasalainen et al., 2012) continuity was impacted with staffing instability caused by poor working conditions. Continuity is valued by both patients and nurses but highlighted by nurses as critical in being able to better manage patients (Kaasalainen, et al. 2012).

Many studies report how nurses commonly had feelings of personal and professional isolation because of lone independent nature of practice, time spent mostly in transit and patient homes and limited opportunities to interact with others to debrief, collaborate or commiserate (Arnaert et al., 2009; Kaasalainen et al., 2011; Kaasalainen, 2012; Penz & Duggleby, 2012). When working in community settings, nurses at times rely on physicians for advice or support through prescribing medication that would help patients with problematic symptoms. There are assumptions that patients in the community are adequately linked to a PCP. Research shows that nurses have had difficulty obtaining the clinical support required because the patient does not have a primary care physician or a lack of familiarity with the patient resulted in physician reluctance to assist with medication adjustment or prescribing (Kaasalainen et al., 2012; Karlsson, et al., 2013). Arnaert and Wainwright (2009) investigated palliative nurse specialist

experiences in home care. Arnaert and Wainwright identified the importance of support from other nurses or physicians regarding decisions about patient care. In addition to the lack of professional support found by others, Carlson et al. (2014) found that home care nurses experienced feelings of isolation and loneliness.

Inadequate Palliative Care Knowledge and Practice

Addressing the palliative care needs of patients and families requires knowledge and skill based in the domains of communication, pain and symptom management and psychosocial assessment and support (Morrison, 2017). Furthermore, the level of knowledge and skill required can range from basic to advanced where issues are less straight forward, for example, refractory symptoms or conflict resolution within families (Quill, 2013). Individuals with life-limiting conditions can experience health effects unique to the stage and nature of their illness. Recognizing that these experiences will vary from person to person, particular aspects of symptom management are central to improving the quality of care. While there is variability in the extent of care that dying individuals require or desire (Franks et al., 2000; Gomes et al., 2013), common requests for support include those related to symptom management. A range of clinical knowledge is key to providing adequate palliative care symptom management, including psychological as well as physical symptoms like pain, breathlessness, fatigue, anorexia, nausea/vomiting, constipation, anxiety/nervousness, depression, dry mouth, and sleep disturbance (Kelley & Morrison, 2015). Individuals with life-limiting illnesses also place high importance on discussing issues related to their spirituality (El Nawawi et al., 2012). A study by Winkelman et al. (2011) showed that individuals who had their spiritual needs met were more likely to have a better psychological quality of life than those that did not. Communication skills are critical clinical skills required to support sharing difficult news, establishing care goals, and

navigating treatment options with patients (Back et al., 2009). Research shows that patients who had goals of care discussions with their care providers were less likely to receive undesired treatments like ventilation, resuscitation or die in a critical care setting (Wright et al., 2008). Identifying individuals who would benefit from palliative care can also pose challenges for clinicians. As a result, referral to hospice or palliative care has been demonstrated to be sub-optimal, with referrals provided late in the illness experience and often not at all (Barbera et al., 2006; Office of the Auditor General of Ontario, 2014). The low rate of referral to palliative care services may reflect the challenge in assessment and prognostication of individuals who may have less time to live.

Health care providers in community settings have identified that developing and maintaining adequate knowledge and skill to appropriately address palliative care needs as a challenge. For many physicians, palliative care is a small part of their workload making it difficult to maintain knowledge and skills (Barnabe & Kirk, 2002; Clark et al., 2004; Mitchell & Price, 2001; Mitchell et al., 2004; Pereira, 2005). The same has been reported by nurses providing palliative care in rural areas (Rosenberg & Canning 2004). The organization of care may restrict health care provider ability to develop skills to meet patient needs. For example, some physicians have identified a limited availability for telephone consultation or home visits (Office of the Auditor General of Ontario, 2014), with some physicians expressing the preference to transfer patient care to palliative care specialists as care needs escalate (DeMiglio & Williams, 2012).

At the health care provider level, health care professionals have expressed difficulty providing palliative care. While some physicians identify that providing palliative care is integral to their practice (Billings, 2002; Brazil et al., 2007) others have identified feeling unable to meet

the demands of such care. For example, some physicians have voiced a lack of comfort and knowledge in providing palliative care (Oneschuck & Bruera 1998; Wakefield et al., 1993). An international study reported that only 41% of physicians reported feeling well prepared to address the palliative needs of their patients (The Commonwealth Fund, 2015).

Previous research has identified that palliative care education for physicians and nurses has been inadequate (Bugge & Higginson, 2006; MacDonald et al., 1997; Oneschuck & Bruera, 1998) and although a variety of initiatives have focused on increasing palliative care education for health professions, ongoing improvements are needed. Physicians report that they have had little or no content on palliative or EOL care in their basic education (Block, 2002; Bugge & Higginson, 2006). More recent research in Canada reports that both medical students and practicing physicians require more education about palliative-care approaches and how to initiate discussions about advance planning (CHPCA, 2014b; Office of the Auditor General of Ontario, 2014).

Barnabe and Kirk (2002) found that physicians identified knowledge gaps in relation to bereavement, psychosocial elements of dying, professional issues such as resources for the bereaved, legal concerns, confidentiality and interdisciplinary communication. Recent evidence reveals that physicians and nurses still feel underprepared to address specific areas of palliative care. A recent survey of Canadian physicians and nurses' attitudes toward palliative and EOL care (CHPCA, 2014a) revealed that between 48% and 55% of physicians and nurses are only "somewhat comfortable" with providing palliative care, with pain control, managing depression, and patient's emotional needs being the most challenging issues they face in caring for patients with chronic or life-threatening illnesses. In relation to advance care planning, 24% of physicians felt they were "experienced and comfortable" with the process and 52% indicated having "some

experience", but were "not very comfortable". Only a portion of physicians expressed confidence in providing aspects of palliative care (i.e. managing constipation (53%), reacting to reports of pain from the patient (48%), discussing patient wishes for after their death (39%), managing limited patient decision-making capacity (30%), and managing terminal delirium (23%)). The remainder of physicians' responses indicated they needed some level of support to be able to provide the required care. Nurses reported lower confidence in managing terminal delirium (17% felt "confident"), limited patient decision-making capacity (20% felt "confident") and managing terminal dyspnea (26% felt "confident"). In this study physicians and nurses both identified interest in receiving help from palliative care nurses. A variety of policy, funding, education and service initiatives have been undertaken and as a result, quality and access improvements have been made in relation to palliative care; however, ongoing improvements are required (Office of the Auditor General of Ontario, 2014).

Family Caregivers Assuming Responsibility

Policymakers and health services across the globe are increasingly interested in supporting patients who desire to remain home at EOL to do so. Many Western countries have shifted from an institutional care model to a home-based care model (Lesemann & Martin, 1993). However, the reassignment of care from hospital to home shifts responsibilities to families (primarily women and often without the required structural support) to provide caregiving services (Armstrong & Armstrong, 2018).

The prominent preference for care at home until death has implications for FCGs because of reliance on FCG time and effort. Williams, Lum, and Morton-Chang (2016) estimate that unpaid family, friends and neighbors provide 70-90 percent of the routine care required by the elderly to stay at home. A growing body of research identifies family caregivers as integral to

supporting patients at the EOL and achieving a home death when desired (Costa, 2014; Gomes & Higginson, 2006; Jack & O'Brien, 2010). Several studies found a risk for FCGs to idealize home death while not fully appreciating the associated commitment and work (Gomes et al., 2013; Topf et al., 2013). For example, Topf et al. (2013) found that FCGs felt poorly prepared and informed about what to expect about the amount of work and perceived an insufficient level of help from services. Other researchers (Lang et al., 2014) identify the home as an unpredictable site of care because formal home care providers are generally limited to short durations in the home, leaving the bulk of personal and medical management to patients and their families. Patients and families are increasingly expected to effectively self-manage their declining health conditions to cope at home (Sun et al., 2017).

Family Caregiving Responsibilities: A Balance of Benefits and Burdens

Research shows that FCGs can experience caring for a loved one at home as both meaningful and a significant responsibility (de Korte-Verhoef et al., 2014; Morasso et al., 2008; Stajduhaur, 2005). For example, Morasso et al. (2008) investigated FCGs' experiences of EOL care. Morasso et al. found that FCGs experienced both positive and negative aspects associated with caregiving. Family caregivers reported a valuable experience, being grateful to spend the last days with their loved one, a sense of personal enrichment and strengthened family bonds (Morasso et al.). Other studies reported similar positive findings of FCG preferences for place of care (Woodman et al., 2016). Family caregivers also identified negative aspects of caregiving, including a lack of psychological and emotional support from public services when they needed help, feeling powerless to help patients with symptoms and decline, and fear associated with feeling unprepared for future changes (Morasso et al.). Findings from other studies reported similar impacts on FCGs, including feeling ignored, trapped and alone and feeling morally

obligated and expected to take on caregiving by family members and health professionals (Woodman et al., 2016). Morasso et al. found that FCGs experienced increased perceived burden (emotional, physical and psychological) in the last 3 months of life, with most perceived in the final weeks. Some research shows that FCGs who perceive and experience a lower level of burden are better able to undertake caregiving in the home until death (Jack & O'Brien, 2010; Visser et al., 2004). The findings from Morasso et al.'s study suggest that assessing the caregiver perception of burden and how they are managing is necessary to achieve a broader understanding of their situation. Other studies (Proot et al., 2003) highlight that when burdens outweigh individual capacity, there is a risk that FCGs can encounter burnout; however, additional support may be able to mitigate burnout. Research shows that FCGs experience physical and mental exhaustion from the 24-hour nature of care, the constant vigilance causing lack of sleep, and juggling home and work responsibilities (McSkimming et al., 1999; Waldrop et al., 2005). Caregivers also report stress from decision-making related to household management and final arrangements (Waldrop et al., 2005).

In addition to domestic, personal care and administrative responsibilities (Topf et al., 2013; Visser et al., 2004), FCGs also assume health care activities like coordinating and navigating complex health care environments and carrying out medical and nursing care in the home (NASEM, 2016). For example, Hoare, Kelly, and Barclay (2019) investigated FCG experiences of providing care at EOL. Spouses and adult children (who were FCGs) reported the added stressors of assuming medical and nursing responsibilities over and above usual care were time-consuming and draining. Medical and nursing responsibilities can include administering routine medications, recognizing and managing troublesome symptoms, and what to do in an emergency (Sun et al., 2017).

FCGs also manage complex and overwhelming medication regimes (Lau, Berman et al., 2010; Wilson et al., 2018). Wilson et al. (2018) conducted a critical interpretive synthesis of family caregiver experiences managing medications for their family member dying at home. Family caregivers reported difficulty recognizing generic and trade names, understanding onset and peak effect, and the difference between long-acting, short-acting and sustained-release medications (Wilson et al., 2018). FCGs voiced fears about overmedicating, under medicating and coordinating timings and volumes of medications (Wilson et al., 2018). Wilson et al. also found that the relationship with the health care provider was integral to FCG education and empowerment. Prepared syringes, 24-hour call support and written information were central to FCG success (Wilson et al., 2018). Lau, Berman et al. (2010) investigated factors that influence how informal caregivers manage medications. Lau Berman et al. found that medication management required organization, critical thinking, symptom assessment and is ultimately overwhelming for caregivers who are grieving, fatigued and ultimately overburdened (Lau Berman et al., 2010). Funk et al., (2015) found similar findings that administering medications caused great anxiety for FCGs. In addition, Funk et al. found that families also had to learn how to monitor and respond to symptoms, feeding and hygiene, and getting help.

In addition to the medical management, witnessing distress is difficult for FCGs. Research shows that FCGs describe that seeing their loved one in distress from uncontrolled symptoms (for example, pain, dyspnea, constipation) was stressful (Tilden et al., 2004; Funk et al., 2015). Family caregivers report that witnessing loved ones in distress as the breaking point for leaving home to seek care elsewhere (Topf et al., 2013).

The range of education support needs for FCGs has been investigated and reveals that family members have a broad range of informational needs that reach beyond symptom

management. Funk et al. (2015) found that important information for FCGs included approaches to feeding, hydration, personal care and hygiene, and getting help. Similar findings were found in other studies and highlighted information about resources (domestic and financial) and disease processes and progress (Rees & Bath, 2000; Thieleman, 2000). Beyond informational needs, caregivers also require attention for their personal needs and support through respite (Woodman et al., 2016).

Family Care Giver Experience and Needs

Family members who take on the care responsibilities simultaneously are impacted by their experience of having a loved one who is dying. These FCGs require support in caring for their loved ones and grief and loss experienced as a family member. There is ample literature that highlights the unmet personal needs of FCGs. For example, Funk et al. (2010) conducted a systematic review of the FCG experiences of caregiving at EOL and found that FCGs experienced a range of emotions. Funk et al. identified that FCGs experienced helplessness, hopelessness, anxiety, fear and dread, anger and disillusionment, as well as guilt and regret. These findings highlight how FCGs also have psychological needs related to but also separate from those of their loved ones. However, the contributions, efforts, and experiences of FCGs tend to be taken for granted by health care providers, resulting in a phenomenon that some authors have referred to as “hidden patients” (Kristjanson & Aoun, 2004, p. 359). A palliative approach to care necessitates that FCGs are also recipients of care (WHO, 2020).

In addition to their caregiving responsibilities, FCGs have reported enduring the emotional burden of knowing their loved one was going to die, anticipating the loss and witnessing their suffering and decline (de Korte-Verhoef et al., 2014; Funk et al., 2010; Proot et al., 2003; Waldrop, 2007). Other FCGs described grieving the loss of the person they knew

(Stajduhar et al. 2010) or the loss of a spousal relationship subsequently replaced by a parent or caretaker relationship (Ray & Street, 2007). Caregivers also reported fatigue from physical demands, especially when loved ones required more help with ambulating, toileting, and hygiene (De Korte-Verhoef et al., 2014; Oyebode et al., 2013; Proot et al., 2003).

FCGs have identified challenges with feeling homebound or trapped because of their fear of leaving their loved one alone or because of their loved one's fears of being left alone (Proot et al., 2003; Rollison & Carlsson, 2002). In a related theme, FCGs report experiences of isolation and loneliness (Mason & Hodgkin, 2019; Milberg & Strang, 2007; Proot et al., 2003; Rollison & Carlsson, 2002), which may be related to their physical sequestration or because of limited social supports or limited opportunity for social interactions.

Psychological impacts felt by FCGs also include tensions between work and caregiving responsibilities and associated financial strains. Caregivers reported stress associated with the need to juggle work and caregiving responsibilities or requiring leave from work with resultant financial implications (Broback & Bertero, 2003; Ray & Street, 2009). Concerning efforts around their caregiving activities, FCGs have also reported feeling that their contributions were taken for granted and unacknowledged by formal caregivers or patients (Hunstad et al., 2011; Milberg & Strang, 2007; Proot et al., 2003). Furthermore, FCGs have reported that health care providers ignored their needs as individuals (Broback & Bertero, 2003). While FCGs may be viewed as an important support for patients, it is critical that health care providers be cognizant of the separate and distinct needs of FGCs as both caregivers and as family members who are themselves experiencing grief, loss and burden.

Inadequate Home Care Resourcing: Hospital as the (In)appropriate Place for Care and Dying?

Hospital use by patients requiring palliative care has received significant attention over the past several years. Two discourses are evident in the literature, one of impact on quality of EOL experience and the other as inappropriate and costly place of care. Some research identifies that hospital use at EOL is often linked to aggressive, unnecessary or undesired interventions administered to patients in hospital where recovery, improvement or survival is unlikely (Cardona-Morell et al., 2016). Such interventions may include administering resuscitation to patients with established wishes for no resuscitation (Cardona-Morell et al., 2016) or admitting patients to intensive care (Hart et al., 2015) when outcomes are anticipated to be poor (van Gijn et al., 2014). The alternate discourse which is more common and situated in the domain of policy and resources relates to concerns about the social economic impact of hospitalization at EOL. Dying and EOL care in hospital settings is argued to cost more than care and dying at home; however, recent research suggests that this may be overestimated and instead of being less expensive, only shifts costs from institutions to FCGs (Yu et al., 2015). Gardiner et al. (2014) argues that often proponents of home-based palliative care make assumptions that alternate community-based solutions and supports are available to patients and families (Gardiner et al., 2014).

While a significant amount of research has focused on how hospital visits, admissions and dying in hospital is considered inappropriate or avoidable, more recent research has provided some insight that in certain instances, hospitals might be the more appropriate place of care (Gott, 2013; Green et al., 2016; Reyniers et al., 2014; Robinson et al., 2015). For example, Robinson et al. investigated the benefits of hospital admission from patients with palliative care

needs. These researchers used a qualitative study design and interviewed 14 patients to elicit the views of patients admitted to the hospital. Participants were often admitted to the hospital for symptom management, management of treatment side effects, investigating new problematic symptoms, and managing exacerbations of non-malignant symptoms. Participants described feeling safe and cared for (Robinson et al., 2015). Feeling safer in the hospital was reported by others (Reyniers et al., 2014). Robinson also found that hospitalization was a mechanism to secure additional supports to return home, as a respite for the family who was overwhelmed by care and decision responsibilities, and to achieve some level of rehabilitation and feeling better due to interventions.

Other research suggests that hospital visits are an outcome of insufficient resources in the home (Gott, 2013; Green et al., 2016; Hoare et al., 2019; Reyniers et al., 2014). Reyniers et al. (2014) explored the perspectives of health care providers about hospital admissions at the EOL. Reyniers et al. conducted focus groups with physicians and nurses from nursing homes, home care and hospitals. Similar to Robinson et al. (2015), Reyniers et al. found that these nurses and physicians considered the hospital the right place for the patient if the resources at home were inadequate (either because of a lack of family or professional caregivers). Palliative care units were preferred, but participants acknowledged beds were often unavailable on short notice (Reyniers et al., 2014). Gott (2013) reported similar results when palliative care consultants assessed that patient admission to the hospital was appropriate given the understood lack of available community services.

More recent research has focused on identifying the underlying reasons why patients and families seek help from a hospital setting. Hoare et al. (2019) took a more inclusive approach to investigate hospital seeking at EOL. Hoare et al. interviewed the decedent's next of kin,

physicians, community nurse, hospital staff and ambulance attendants to understand the challenges leading to a hospital admission at EOL. Interviews with both family members and staff contributed to a multifaceted understanding of factors leading to hospital admission. While dying at home was identified as desired by patients, often health care staff assessed that the home environment was unsuitable for EOL care due to a lack of professional or family resources. Nurses advised fearful family members to seek help at the hospital when nursing resources were inadequate. Nurses were often not available on short notice to assess rapidly evolving and unanticipated EOL symptoms. Also, the limited availability of hospice beds necessitated patients to use hospitals (Hoare et al., 2014).

In a Canadian study by Topf et al. (2013), FCGs described limited discussions with health care professionals about the work of caregiving. Unexpected events like breathlessness, increased pain, seizures, confusion and agitation resulted in calls to emergency services or community/palliative nurses who advised transfer to hospital or hospice. Addressing the concern at home was not an option because nursing was unavailable (Topf et al.). Health care professionals often regarded uncontrolled escalating symptoms as appropriate reasons for seeking attention in a hospital setting (Danielsen et al., 2018; Reyniers et al., 2014; Webber et al., 2020).

Webber et al. (2020) sought to understand reasons for seeking hospitalization by patients discharged home from a palliative care in-patient unit. Patients visited the emergency department for pain, respiratory distress, falls, delirium, bleeding, decreased level of consciousness and were admitted with delirium, respiratory distress, opioid toxicity, sepsis, hypoxia, fracture, atrial fibrillation, vaginal bleeding (Webber et al., 2020). These authors suggest that many emergency concerns could have easily been managed in the home. In ideally resourced situations, these

authors may be correct. However, these visit reasons that appear to be emergency scenarios to any average person or home visit nurse require immediate and astute assessment, family discussion and intervention requiring advanced nursing monitoring and management. While it was beyond the study's aim, it would have been interesting to know to what extent these services and supports were available. In the event of limited family and home nursing resources and a change in patient desire, the hospital may be the best location to seek support. Danielsen et al. (2018) interviewed home care nurses and general practitioners to identify the conditions that facilitate or hamper more time at home and home deaths for patients with a terminal disease. Danielsen et al. found that nurses reported that the rapid escalation of symptoms could make the situation at home unbearable for patients and their families, necessitating hospital support. Furthermore, if nurses could not secure emergency medications in advance from physicians to alleviate symptoms, hospitalization was inevitable (Danielsen et al., 2018).

Limited availability of home nursing and personal support for help on weekends and after-hours pose challenges to maintaining patients at home (Seow et al., 2014). Shortage of regulated health care providers often can result in individuals having to move to in-patient settings where their needs often increase. A study of access to home support showed that early access to home care services and access to personal support/homemaking and nursing services showed reductions in hospitalization rates (Seow et al., 2010). Finally, most family physicians do not make home visits which can become important for individuals experiencing a decline in health and unable to travel to have an advanced assessment (Marshal et al., 2008). A recent provincial report about palliative care service use identified that in the two provinces where statistics were reported, only 15% of decedents in 2016-2017 received publicly funded palliative home care services (CIHI, 2018). This same report further identifies that those who received

these kinds of services were 2.5 times more likely to die at home (CIHI, 2018). While the information from this report is limited in that it broadly refers to home support as palliative care, little is known about what that all entails in relation to home support and home nursing. What is noteworthy is that the impact of such support in enabling patients and families to be supported at home. Further inquiry is needed regarding patient and family experiences.

While establishing patients' and families' wishes about EOL and place of care is important, it is also important to understand that situations change, and because of particular circumstances, plans for a place of care may change. Jack and O'Brien (2010) conducted two focus groups with community specialist palliative care nurses and district nurses to explore their perceptions on why patients who had preferred to die at home sought help from hospital settings in the last days and hours of life. Participants reported that unrealistic expectations and understanding of what is available from home care, a prolonged time commitment for caring, caregivers who cannot provide the required care and the patient's perception of burden influence changes in preferences (Jack & O'Brien). Other research highlights similar findings that increasing demands on informal care providers, deterioration in the patient's condition, family members and resources in the home affect preference for place of death, and changes can occur at any time (Win et al., 2019). These findings suggest that while spending EOL at home is often preferred, the dynamic home environment and evolving care situations can prompt a change in capacities and preferences.

Advance Care Planning, and Goals of Care Planning

Advance care planning, which includes discussions about goals of care and preferences for EOL care and the preferred place of death, increases the probability that their preferences are achieved (Detering et al., 2010). Advance care planning helps patients and families plan for the

future, while goals of care put previous discussions about wishes into a current context (Dunlay & Strand, 2016). Goals of care include discussions that help patients to understand their prognosis and implications of treatments, therapies and care decisions (Kaldjaian, 2020) while at the same time help health care providers develop a shared understanding about patients' and family's values goals and priorities (Stanek, 2017). Goals of care help patients and families make informed decisions that best correspond to what is most important to them, and these goals can be better understood by the health care providers supporting them. Benefits of goals of care discussions include better progress, a better quality of life, more support, comfort and hope (Stanek, 2017). As one example, Ali et al. (2019) investigated the preferred and actual place of death for patients known to a specialist community palliative care service. Seventy-three percent of patients whose preference was about their preferred place on death achieved this preference. The thirty percent of patients who either did not establish a preference or refused to discuss preferences were more likely to be admitted to the hospital (Ali et al., 2019).

Advance care planning discussions are fundamental to establishing preferences, plans and ensuring that the right supports are in place; however, research has shown that plans and preferences may be subject to change in certain situations (Gomes et al. 2013; Jack & O'Brien, 2010). Continued communication is required to facilitate patient wishes (Stanek, 2016). Several authors suggest that ongoing EOL conversations are required to clarify goals for patients, families and team members to reassess preferences (Wahid et al., 2018; Win et al., 2019). Furthermore, because of their proximity and frequency of contact with patients in the home, nurses are important in facilitating ongoing discussions, and decision-making about the place of care and enabled respite care to support a longer duration at home (Woodman et al. 2016).

The Introduction of Nurse Practitioners to Clinical Settings

In general, population needs are outgrowing how health care has traditionally been structured in many countries (Maier et al., 2017). As a result, NPs are increasingly being integrated into practice settings across the globe to meet the changing health care requirements of populations (ICN, 2020). Over the past several years, there has been growing interest in advanced practice nursing (APN) roles. The promise of APN roles lies in their potential to transform current health care models to be more effective and sustainable (Bryant-Lukosius, & Martin-Misener, 2015) while offering a holistic, integrated and patient-centred approach (CNA, 2019).

Several countries have established some form of advanced nursing role; however, there is variability in what is understood to be part of that role, how it is defined, the minimum amount of education, titling and credentialing (Maier, 2017). In Canada, the Canadian Nurses Association (CNA) recognizes two APN roles, the clinical nurse specialist (CNS) and the NP (CNA, 2019). The International Council of Nurses (ICN, 2008) defines the APN as a nurse who

> has acquired, through additional education, the expert knowledge base, complex decision-making skills and clinical competencies for expanded nursing practice, the characteristics of which are shaped by the context in which they are credentialed to practice.

The ICN has undertaken considerable efforts to develop a shared international understanding and standardized conceptualization of APN practice and, within that, the NP role. As a product of a robust global consultation process, the ICN explicates the NP role and defines NPs as:

> Generalist nurses who, after additional education (minimum Master's degree for entry-level), are autonomous clinicians. They are educated to diagnose and treat conditions

> based on evidence-informed guidelines that include nursing principles that focus on treating the whole person rather than only the condition or disease. The degree of practice autonomy and accountability is determined by, and sensitive to, the context of the country or setting and the regulatory policies in which the NP practices. (2020, p. 18)

At a national level in Canada, the Canadian Nurses Association (CNA)[4] has played a significant role in Canada regarding the promotion and evolution of the NP role. Working with expert NPs, provincial regulators and stakeholders, the CNA has facilitated the development of a shared national understanding of APN and NP practice. The CNA provides the following profile of the NP and the NP role, which builds on the ICN definition:

> As autonomous health professionals with advanced education, nurse practitioners provide essential health services grounded in professional, ethical, and legal standards. Nurse practitioners integrate their in-depth knowledge of advanced nursing practice and theory, health management, health promotion, disease/injury prevention and other relevant biomedical and psychosocial theories to provide comprehensive health services. Nurse practitioners collaborate with their clients and other health care providers in the provision of high-quality patient-centred care. They work with diverse client populations in various contexts and practice settings (2019, p. 5).

Based on this profile, the NP role is characterized broadly and seems well positioned to navigate a range of patient and system concerns.

[4] The Canadian Nurses Association (CNA) is a national nursing association in Canada that aims to provide a unified voice for all nurses in Canada and to represent Canadian nursing globally. This organization is active in nursing advocacy, policy and in nursing practice support.

Expanded Nursing Roles in Canada and the Evolution of the NP Role

Nurses' contributions from within and beyond traditional nursing roles in Canada can be traced back to 1893 when the first nurses came to Canada through the Grenfell Mission (Graydon & Hendry, 1977). Nurses came from England to Labrador and northern Newfoundland to address the health care needs of the local rural and remote residents (Graydon & Hendry). In the 1970s, the introduction of universal publicly funded medical insurance, the perceived shortage of family physicians and endorsement by the Boudreau Report (1972) contributed to the initial momentum of the NP movement (Kaasalainen, 2010). This momentum waned in the 1980s due to a lack of standardized titling, education, and registration, as well as the absence of established regulation, legislation and remuneration (CIHI, 2006; CNA, 2019). Concerns about integration, access to primary health care and interest in health care reform in the 1990s rekindled interest in NPs. Formal legislation and regulation supporting NP practice were initiated in 1998, and now all provinces have established legislation and regulation for NPs (CNA, 2019).

Nurse Practitioner Knowledge and Scope of Practice

NP practice is rooted in nursing with additional education to support the advancement of nursing expertise across a range of professional domains. In 2010, the CNA, working with expert nurse practitioners and provincial /territorial nursing regulators, collaborated to develop an update of the Canadian Nurse Practitioner Core Competency Framework (CNA, 2010). This framework provides an outline of the expected knowledge, skills, judgment and attributes that are expected to guide NP education and practice in Canada. Assumptions identified within this document include that NP practice is grounded in the values, knowledge and theories of professional nursing practice. Graduate-level education is the mechanism through which NPs build on their existing registered nursing competencies with a significant focus on clinical

learning. Furthermore, NP practice includes health promotion, illness and injury prevention, rehabilitative, curative, supportive and palliative/EOL care. Expected competencies include the broad categories of professional responsibilities (clinical practice, collaboration, consultation/referral and, research) and clinical responsibilities, including health assessment and diagnosis, therapeutic management and, health promotion and prevention of illness and injury (CNA, 2010).

Competencies help establish the expected knowledge and skill held by NPs. Scope of practice outlines what NPs are legally authorized to do and is regulated provincially. These laws identify which providers are authorized to deliver particular aspects of care as part of their lawful range of activities (Safriet, 2002). In this thesis, the scope of practice refers to "The activities that nurses are educated and authorized to perform, as established through legislated definitions of nursing practice, complemented by standards, guidelines and policy positions issued by professional nursing bodies" (CNA, 2010, p. 18). More specifically, the scope of practice refers to the activities that an NP is legally permitted to perform (procedures, actions, processes), what population the NP can assess and manage and the particular circumstances for involvement. The scope of practice is generally associated with a particular designated title and level of education (ANA, 2015). The NP scope of practice differs from that of a generalist nurse in regard to the responsibility and accountability required to practice. The scope of practice is also an important mechanism to inform the broader public (individuals, administrators and other professionals) about the role and adequate preparation to undertake the associated nursing activities (ICN, 2020).

Historically, legal scope of practice has not always aligned with NP knowledge, skill and capability. During the evolution of the NP role, legislative and regulatory modifications often

lagged behind NP education, knowledge and skill development and as a result limited NP practice and restricted the NP role. A significant amount of progress has been made over the past ten years to expand and standardize the NP scope of practice across Canadian jurisdictions so that NPs are legally authorized to perform the activities for which they have the requisite knowledge and skill. In the 1990s, the renewed interest in primary health care reform spurred nursing (regulators and advocacy bodies) to address the earlier legislative limitations that hindered the progress of the NP role. Because nursing is primarily regulated provincially, I provide the Ontario experience as an example of regulatory expansion. The re-establishment of Ontario NP education programs in 1995 occurred as a result of close work with government and stakeholders as part of a movement toward PHC reform (Staples et al., 2016). Soon after the establishment of the educational programs, the passage of the *Expanded Nursing Services for Clients Act* (1997) amended the *Nursing Act, 1991* and four additional related acts (Government of Ontario). This statute shaped NP scope of practice and included the additional controlled acts of communicating a diagnosis, prescribing medications (based on a specified list) and ordering certain diagnostic tests, including laboratory work (e.g., complete blood counts, cholesterol, sodium, potassium, creatinine), x-rays (excluding skull, spine, hip and shoulder), and ultrasound (abdomen, pelvis and soft tissue) (Bill 127, 1997). Controlled acts are activities that, when undertaken by an individual who has not had the necessary education or training to implement them, have the potential to have harmful outcomes for the recipient of such acts (CNO, 2014). The Ontario government has been instrumental in facilitating legislative changes in Ontario by requesting a review of NP scope and barriers by the Health Professions Regulatory Advisory Council (HPRAC, 2008). As a result, Bill 179, the Regulated Health Professions Statute Law Amendment Act, 2009, amends 26 health-related statutes, including the *Regulated Health*

Professions Act and the *Nursing Act*, 1991 (CNO, 2017). The amendments resulted in changes to the NP legal scope of practice. Examples of changes include admitting patients to hospitals, providing patient care orders to RNs and RPNs, and broad prescriptive and diagnostic authority (as compared to limitation by a list; CNO, 2017). This alignment of legislation and regulation with NP knowledge and skill is key to maximizing the potential of NP contributions to patient and system well-being.

Much work has been done internationally (ICN, 2020; Maier et al., 2017) and in Canada (CNA, 2019) to standardize requirements for NP education, legislative support and regulated scope of practice. As a result of such efforts, in all Canadian jurisdictions, NP registration requires current RN status, graduation from an approved post-baccalaureate NP program (preferably at the graduate level) and successful completion of a specified entry-to-practice exam (Spence et al., 2015). NPs in all jurisdictions can perform health assessments, make and communicate a medical diagnosis ("diagnostic impression" in Quebec), order lab and imaging tests (some limitations to CT and MRI, changes are pending). NPs can also prescribe uncontrolled and controlled drugs and substances, independently refer to a specialist, prescribe massage/physio/acupuncture (except Quebec), prescribe orthotics, mobility aids, order home oxygen, insulin syringes and blood glucose monitors (except Quebec), order ostomy supplies (CNA, 2019).

While advances toward NP scope harmonization across Canada have been made by way of legislative amendment, differences remain. Some provinces now authorize NPs to admit, treat and discharge hospital patients, and some provinces still require NPs to establish a collaborative agreement with a physician to practice (Spence et al., 2015). Provinces also differ regarding what provincial medical forms NPs are authorized to sign (e.g., driver medicals; Spence et al., 2015).

In an examination of the provincial variation in authority and restrictions, it is difficult to see the logic behind these differences. The differences are a result of independent provincial efforts to integrate NPs into the health care system while working with existing legislation. This legacy originates in the original wording of provincial regulations, which at that time authorized only physicians to perform certain activities. Researchers and nursing organizations have made calls for legislation to undergo modernization to be able to draw on the advanced nursing knowledge and skill that NPs offer (CNA, 2019; Spence et al., 2015).

In 2020, there were 6,661 NPs licensed to practice in Canada (CIHI, 2021), with practice settings identified as different kinds of primary care clinics (community and primary care clinics and NP-led primary care clinics), LTC and hospitals (outpatient clinics, emergency rooms) (CNA, 2020). NP practice is often characterized by the patient population served, for example, family, pediatric, adult-gerontological or women's health and the location of practice may be primary care or acute care settings (CNA, 2018; ICN, 2020; Maier et al., 2017). Nurse practitioner roles are highly flexible, fluid and responsive to population health and practice settings. These characteristics make NPs highly effective for addressing local health care system needs; however, they can also be the source of role confusion (Bryant-Lukosius & Martin-Misener, 2015).

Nurse Practitioner Contributions to Patient and System Well-Being

There is growing global research that consistently shows that NPs provide care that is safe, evidence-based, patient-centred, and efficient. Research indicates that NPs have high patient satisfaction and fewer ER visits and avoidable hospitalizations and comparable to physician care across a range of practice settings, including care of older adults (Kane, Flood et al., 2002: Kane, Keckhafer et al., 2002; Morilla-Herrera et al., 2016; Schultz et al. 1997), in the

emergency department (Carthon et al., 2017; Fowler et al., 2019; Jennings et al. 2015; Woo et al. 2017; Villasenor & Krouse, 2016) and in primary care (Buerhaus et al., 2018; Swan et al., 2015).

For instance, Morilla-Herrera et al. (2016) conducted a systematic review of the impact of APNs who work with older adults. These researchers found that NPs in LTC assessed, diagnosed and treated patients with acute (episodic illness and injury) and chronic conditions while at the same time reduced avoidable emergency department transfers and improved family caregiver satisfaction. Studies examining NPs working in LTC settings have shown high satisfaction from family members (Kane, Flood et al., 2002; Kane, Keckhafer et al., 2002). A study by Schultz et al. showed that by adding an NP to a primary care team, nursing home residents were able to achieve more of their personal health care goals without affecting the cost of care (Schultz et al. 1997).

In studies examining NPs working in emergency settings, Fowler et al., 2019 found NPs in these settings garnered equivalent or higher patient satisfaction, reduced wait times and provided safe and efficient high-quality care. Jennings et al. found similar results with no differences found between physician and NP groups. A comprehensive systematic literature review from 2006 to 2016 in emergency and critical care settings findings demonstrated that nurses in advanced practice, including NPs, reduced length of stay, time to consultation and treatment, mortality, improved patient satisfaction and cost savings (Jennings et al. 2015; Woo et al. 2017). Studies examining NPs in urgent care and walk-in clinics found that NPs in these settings reduce costs related to health care, maintain continuity of care and optimized health outcomes (Carthon et al., 2017; Villasenor & Krouse, 2016).

Swan et al. (2015) conducted a systematic review of 10 randomized controlled trials investigating the safety and effectiveness of NPs in primary care for ongoing patient care or

consultation for acute concerns. This study showed that NPs spent more time with patients in consultation and demonstrated equal or better outcomes as compared to physicians related to cost, patient satisfaction and physiologic measures. A more recent study by Buerhaus et al. (2018), which examined NP contributions in primary care, showed NP care was associated with lower hospital admissions, readmissions and reduced inappropriate ED use and low-value imaging.

Studies to evaluate the quality of care provided by NPs have shown the same health care services to be comparable to that of physicians in terms of effectiveness and safety (Lentz et al., 2004; Mundinger et al., 2000; Swan et al., 2015). Htay and Whitehead (2021) conducted a systematic review to investigate the effectiveness of advanced nurse practitioners compared to physician/usual care. These researchers reviewed thirteen randomized controlled trials. Findings showed that a positive impact was seen on NP management and control on a broad range of symptoms and on patient physical function, wait times for care, and overall costs and patient satisfaction with care (Htay & Whitehead). Smigorowsky et al. (2020) conducted a systematic review of NP-led cardiovascular care as compared to physician or physician-assistant showed NPs achieved a 12% reduction in Framingham risk scores and no difference in health-related quality of life.

Nurse Practitioner Contributions in Canadian Settings

Research examining NP contributions in Canadian primary care settings is limited but growing. The studies tend to be small and center on the one NP in the setting. A few researchers have focused on patient satisfaction (Heale & Pilon, 2012; Reay, 2006; Roots & MacDonald, 2014). In their study of patient satisfaction in an NP-led model of care, Heale and Pilon (2012) investigated patient satisfaction, with most patients reporting being satisfied or very satisfied

with care from their NP. Satisfaction levels were associated with shorter wait times to schedule a routine appointment, the ability to obtain a same-day appointment and waiting less than 15 minutes. Patients who had achieved better control of a medical condition, along with those who received counselling about a lifestyle issue, were significantly more satisfied with NP services. Those who were very unsatisfied were younger adults and those aged over 70 (Heale & Pilon, 2012). It is not clear why this group of individuals reported lower satisfaction. Allowing individuals to provide comments on their surveys could have provided clarity of their rating. Reay et al. (2006), through interviews with physicians and the NP, revealed the perception that clients who consulted the NP were very pleased with the services received. The inclusion of patient perceptions through interviews or surveys would have provided an additional perspective of their satisfaction. Leipert et al. (2011) conducted interviews with nine women to explore rural women's experiences with care from NPs. These researchers found that patients expressed feeling they could approach the NPs with any concern; they trusted, felt respected and valued, and perceived the NPs to be non-judgemental. In this study by Leipert et al., patients also felt NPs offered a nurturing approach and used common language in explanations.

NP work was also reported to be associated with reductions in emergency room visits, hospitalizations and transfers. NPs in primary care reduced hospitalizations due to asthma as a result of an asthma education program (Reay et al., 2006), reduced emergency room visits in primary care patients (Roots & McDonald, 2014) and enabled on-site care of LTC residents in 43% (n=993) of cases that would otherwise have required a transfer to tertiary care (McAiney et al., 2008). In other research in LTC, findings suggest that NPs increase access to care directly and indirectly (Kaasalainen et al., 2010; Kilpatrick et al., 2020; McAiney et al., 2008; Sangster-Gormley et al., 2013; Stolee et al., 2006). NPs provide direct patient care, including assessment

and management of acute and chronic illness (McAiney et al., 2008). NPs also impacted patient care by supporting RNs, practical nurses and PSWs to be able to provide more advanced care through education and collaborative practice (Kaasalainen et al., 2010; McAiney et al., 2008; Sangster-Gormley et al., 2013).

Addition of Nurse Practitioners to Community Palliative Care

In Ontario, it has been recognized that there is a lack of timely and equitable palliative services to meet the needs of individuals (Office of the Auditor General of Ontario, 2014). As a result, there is a call for allocation of resources and application of best practices to guide the care for individuals with life-limiting illnesses and provide for services along the continuum of health and across care settings (Murray et al., 2009). NPs have been added to community care settings across Ontario as one response to try to address access to palliative care for individuals living in the community (MoHLTC, 2011). We have previously seen NPs implemented across a variety of settings, including, for example, primary care teams, LTC homes, and public health, with the addition to community palliative care being the most recent. Furthermore, each of the 14 health regions added the NPs to their existing infrastructure in different ways resulting in different models of care. Little is known exactly how the NPs in these different settings structure their day to day work. For example, in the region where this research takes place, NPs are added as part of a consultation team, while in other regions, the model implemented is that where NPs become the primary care provider through the patient's last months of life. While not the only influence, the model of care and the structure of work is anticipated to have a significant impact on how NPs enact their role.

Nurse Practitioners and Palliative Care

It is evident through a review of the literature that NPs, while relatively small numbers are increasingly involved in palliative care across a variety of settings and models of care. Studies from Canada, Australia, the US, and Israel have examined NPs work in palliative care. The studies available generally involve examining the addition of small numbers of NPs (often one or two) to a setting, with the exception being a study by Kaasalainen et al. (2013) which involved the practice of four NPs working in five LTC homes. In earlier publications examining NP work in relation to palliative care, NPs were reported as supporting hospice nurses through telephone support (Osborn & Townsend, 1997) and more recently supporting cancer patients and their families through internet discussion pages (Grant & Wiegand, 2013). In the studies of NP work in LTC settings, all NP participants report palliative care as an important part of their role within that setting (Cole, 2017; Kaasalainen et al., 2013; Liu et al., 2012). Researchers have also investigated the work of NPs who expanded their practices to meet the needs of different populations. For example, Picot et al. (2013) studied the work of an NP in providing palliative care as part of a community mental health service. Owens et al. (2012) investigated the work of a palliative care NP who expanded the role to be the PCP for their palliative care patients who did not have a PCP.

Most studies described the setting; however, some described the NP role in more detail than others. Three studies investigated the addition of an NP to an in-patient oncology service (Dusseldorp et al., 2019; Haron et al., 2019; Walling et al., 2017). Other studies described adding NPs as part of existing outpatient palliative care programs (Bhavsar et al., 2017; Hummel et al., 2017; Williams & Sidani, 2001) and as offering joint coverage of in-patients and community-residing patients (O'Connor et al., 2018). Nurse practitioners have also been reported working

within hospice settings (Haron et al., 2019) and providing community palliative care as part of hospital outreach programs (Edwards et al., 2019).

Studies also showed that NPs in primary care view palliative care as a natural part of NP work (Collins & Small, 2019; Quaglietti et al., 2004). However, there is surprisingly little literature examining the provision of palliative care as part of community primary care roles beyond those examining NP work in LTC settings. The research of Collins and Small (2019) was the only study found that investigated the NP role in providing palliative care in settings other than specialized palliative care. These researchers conducted semi-structured interviews with 19 NPs. Of the 19 NPs, 13 encountered palliative patients in their practice and six did not have contact with palliative patients. The NPs who reported providing palliative care worked in primary care clinics, in the emergency department or in LTC facilities. The NPs who did not see palliative patients worked in specialty clinics or hospital units without palliative patients. Study participants indicated feeling that the role was well-suited to the NP because of the NP's expanded scope, holistic approach, advanced communication and listening skills and their situatedness in primary care. These NPs perceived their ability to provide a nursing presence through "being there" by both being in attendance and being attentive (Collins & Small, 2019). In contrast to the limited research exploring NP palliative care as PCPs, four studies examine NP work in specialty palliative care consultation teams (Deitrick et al., 2011; Lukas et al., 2013; Mitchell et al., 2016; Parker et al., 2013).

Studies Describing NP Work Related to Palliative Care

Within the studies examined, a broad range of methods were used to try to elucidate the NP role in providing palliative care (Bhavsar et al. 2017; Deitrick et al., 2011; Haron et al., 2019; Kaasalainen et al., 2013; Osborn & Townsend, 1997; Williams & Sidani, 2001). For example,

Osborn and Townsend (1997) were the first noted to investigate the NP role in relation to palliative care. These researchers examined telephone communication between hospice nurses and NPs using a retrospective exploratory chart review. In this study, NPs were found to provide support and advice to hospice nurses about patient symptom management, provide clinical information and instructions, help with medication supply when nurses were unable to contact physicians, order equipment and supplies and assist with coordination of care. Williams and Sidani (2001) used a case study approach using interviews with one NP as well as chart reviews to identify the role of the NP in an oncology outpatient clinic where oncologists referred their patients to the NP. The NP role involved assessing patients through history and physical exams, reviewing diagnostic tests, consulting with other health care professionals about treatment plans and monitoring and educating the patient regarding treatment side effects. The NP addressed patient concerns, including pain, constipation, vomiting, fatigue, poor appetite, and difficulty sleeping. The NP also addressed psychosocial concerns like anxiety about medications, return to work and financial concerns. The NP in this study also coordinated appointments, home care services, connected patients to community resources and provided staff education.

Deitrick et al. (2011) investigated the role of three NPs in a specialty consultation team by interviewing the NPs and other program staff (i.e., physician, care coordinator, program director). Deitrick et al. describe the NP's role in providing palliative care in a broad sense and as developing an overall picture of the patient situation. The NPs were involved in the overall coordination of patient care and addressing the patients' needs in a holistic way. The NPs were also described as working as part of the team but also essential in bringing the team together to focus on issues important to the patient. In Deitrick et al.’s study, the NPs were noted to engage in all aspects of medical and psychosocial care of the patient. Teaching for patients and families

included the illness trajectory, self-management, helping them to determine priorities and determining their goals of care. Patients, families and staff were characterized by interviewees as appreciating the proximity and availability of NPs to be able to address concerns in a timely manner (Deitrick et al.).

Kaasalainen et al. (2013) conducted a case study of NP provision of palliative care in LTC. The study included data from 35 focus groups, 25 interviews with physicians, nurses, PSWs, managers, and allied health providers and family members about the role of NPs in providing palliative care in LTC homes. Families reported NPs as helping their family members with complex symptoms at EOL and valuing the NPs' presence, described as being physically there and available, listening, supporting, helping them through care decisions, and being accessible. In interviews, staff nurses identified that NPs worked with families and patients, conducted in-depth assessments to understand care needs and customize care, and worked with team members. Participants also identified that NPs functioned as a resource for staff, helped them develop their skills, and were influential in providing emotional support and building morale. Support staff described NPs as successful in addressing patient symptoms and that families and patients are happy with the NP involvement. Support staff also expressed that they perceived that outcomes would be worse if the NP were not involved (Kaasalainen et al., 2013).

Bhavsar et al. (2017) took a slightly different approach to try to understand NP work in palliative care. These researchers conducted a time and motion study of how health care providers spend their time in palliative care. Bhavsar et al. found that NPs spent 82% of their time doing clinical work, which was characterized as conducting general patient and family assessment, symptom assessment, and management. More recently, Haron et al. (2019) conducted a survey of palliative care NPs in Israel to identify their practice characteristics.

Thirty-nine of the possible 59 NPs returned the survey. The majority (72%) of respondents worked in hospital-based clinics and hospice units, with the remainder (28%) identifying working in home care or primary care clinics. NPs reported conducting physical assessments, pain assessments, detecting oncology emergencies (ascites, opioid overdoses, sepsis), establishing a patient plan of care, and collaborating with social workers. NPs reported symptom management as the central part of their role, along with determining a patient plan of care (Haron et al., 2019).

In some studies about NPs providing palliative care, benefits of NP involvement were reported as part of the findings. For example, NP work reduced emergency room use, reduced hospital admissions and enhanced symptom relief in patients (Murphy et al., 2013; Owens et al., 2012). NPs also facilitated patient enrollment to home hospice services earlier in their illness trajectory (Hummel et al., 2017) and improved advance care planning and hospice use (Hummel et al., 2017; Walling et al., 2017).

In their study of NP online support for cancer patients, Grant et al. found that patients and families expressed receiving helpful information from NPs about their cancer questions (Grant et al., 2015). Parker et al. (2013) found high rates of patient and family satisfaction with NP consultations and that they felt that NP intervention helped them achieve comfort while being treated with dignity and respect. Other reported benefits included improved communication and coordination of services for patients at home, prompt initiation of treatments, appropriate follow-up, and reduction of unnecessary hospital visits and readmissions post-discharge (Lukas et al., 2013; Mitchel et al., 2016). Patients and families also reported improved confidence to manage care at home (O'Connor et al., 2016).

The studies about NP work in palliative care provide some insight to the NP role. To some extent, these studies provide some description of the kinds of tasks that NPs assume. These studies, however, offer a limited understanding of the context for NP work, their responsibilities and how that context shapes their actions and experiences in relation to those responsibilities.

Medical Assistance in Dying and the NP Role

I conclude this chapter with an introduction to and discussion of Medical Assistance in Dying (MAiD) because of its ethical, legal and clinical relevance in the current Canadian context. The Criminal Code provisions of Bill C-14 became effective June 17, 2016, allowing eligible individuals to receive assistance in dying. Perhaps all nurses and physicians around the globe who work with the dying have encountered patients who wish to end their lives on their own terms; however, in Canada, MAiD now has specific implications for NPs. In Canada, MAiD now occupies a tangible position in the spectrum of EOL choices for a subset of persons (Canada, 2017).

MAiD is defined in the Criminal Code as prescribing for self-administration or the administration of a medication to cause death at the request of a patient (Bill C-14, 2016). The legislation enables practitioners (NPs and MDs) to administer or prescribe for self-administration, lethal medication. Patients requesting assisted dying need to be assessed by two separate and independent practitioners (NP or MD) to determine their eligibility. The legislation attempts to achieve a balance between ensuring fair access to medically assisted death for individuals and supporting the rights of providers who wish not to participate (Wasylenko, 2017). NPs who have moral, ethical or religious objections are not required to participate in MAiD; however, they are required to make a referral to another MAiD provider (CNO, 2021).

The federal legislation on MAiD, now part of the Criminal Code, protects health care providers from prosecution when providing or assisting in medically assisted dying, provided certain conditions are met (An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying (S.C. 2016, c.3). Established eligibility criteria provide safeguards to protect both the individuals desiring an assisted death and the professionals wishing to support them. Under Bill C-14 (2016) legislation, individuals qualify for a medically assisted death if they are 18 years of age, are eligible for health services within a province or territory, voluntarily submit a written request, give informed consent and have a grievous and irremediable medical condition. The requirement of grievous and irremediable medical condition requires that individuals meet three criteria: 1) have a serious disease or disability (excluding mental illness); 2) be in an advanced state of irreversible decline, and 3) experience unbearable physical or mental suffering from the illness that cannot be relieved (Bill C-7, 2021). Bill C-7 includes amendments made to the original legislation passed in 2016 to address concerns about limiting access to MAiD. Individuals requesting MAiD no longer need to engage in a 10-day period of reflection between approval for MAiD and having their procedure. The requirement for death to be determined as reasonably foreseeable, which was part of the original legislation, has also been removed. Individuals may also now provide advanced consent to MAiD, which protects their wishes in the event they lose their capacity to consent on the day of the procedure.

While Bill C-14 provides for some consistency regarding MAiD through a legal framework, individual provinces, territories, and organizations were required to develop their own local policies and protocols and organize human resources. For example, MAiD is facilitated through established teams in some provinces, while in others, individual practitioners are involved. This approach may support some level of flexibility to be locally responsive;

however, it also has resulted in local variability and ambiguity about processes (Pesut et al., 2019).

The legislated protection of patient rights to assisted dying has resulted in a paradigm shift in the legal, social and health care landscape that both patients and health care providers, including NPs, are learning to navigate. Brassfield and Buchbinder (2021) report that as of 2020, some type of assisted dying is available in six countries: Belgium, Luxembourg, the Netherlands, Canada, one state in Australia (Victoria) and ten jurisdictions in the United States. Canada is the first jurisdiction to authorize NPs to assess individuals for eligibility as well as to prescribe and administer lethal medications (Pesut et al., 2019). This historical change in legislation places NPs in a distinct position, extending their clinical and legal responsibilities as advanced practice nurses and situates them in a unique socio-historical, professional and moral context.

The federal legislation provides protections and safeguards for patients and practitioners engaging in MAiD; however, provincial regulatory bodies further detail expected professional conduct. Organizations are responsible for workplace policies and procedures to support practitioners (Pesut et al., 2019). In Ontario, nursing standards further guide practice expectations of nurses (NPs and RNs). For example, nurses must not be seen as encouraging or pressuring the patient to choose MAiD (CNO, 2021). While nurses are not compelled by law to participate, and the law upholds health care providers' rights to conscientiously object (Bill C-14, 2016), they must also not be seen to convey their objection or moral judgments about patients (CNO, 2021). In general, NPs may be involved in informing, educating patients and families, assessing eligibility and prescribing and administering medication to cause death. Nurse practitioners are expected to establish their ability to provide these services and make referrals to another NP or physician who can provide these services when required (CNO, 2021).

It is generally not well understood how NPs are currently involved in MAiD in Canada. While NPs are enabled by federal legislation to engage in MAiD, some provincial and territorial jurisdictions limit their participation. Furthermore, in provinces that do not limit NP involvement in MAiD, participation may be restricted or limited by employers. In some jurisdictions, NPs have been noted to provide MAID outside of their paid role and for free because of difficulty with reimbursement and compassion for patients (Crumley et al., 2021; Gemmill, 2018). Data are collected nationally around requests for and the provision of MAiD. In Canada (excluding Quebec, Northwest Territories, Yukon and Nunavut), since January 1, 2017, NPs provided MAiD for 286 persons (Government of Canada, 2019). In 2019, NPs provided MAiD in 7% of all cases and provided a second assessment in 7.1 % of all cases (Government of Canada, 2019). Little is known, however, about the discussions leading up to MAiD and NP involvement. Dierckx de Casterlé et al. (2010) found in their study of nursing care for patients requesting euthanasia that the care process for these patients was complex and dynamic as opposed to being based on one point in time or as simple as a choice. The determination of EOL care choices has been characterized by others as a process of discussion, allowing for reflection resulting in a process of co-construction between the patient and the individual (Munday et al., 2009).

In both the public and health care sectors, the issue of assisted dying has been seen as a divisive one, with proponents arguing for personal autonomy and choice and opponents often citing the sanctity of life and religious values (Wasylenko, 2017). In a 2015 poll about assisted dying, Canadians were asked their opinion about MAiD given that two conditions were met, one being an adult who consents about the termination of their life and the second being that they also had a grievous medical condition with intolerable suffering (Insight West, 2015). The public

responded with overwhelming support, with four in five Canadians (79%) responding as strongly or moderately supporting the notion (Insight West, 2015). In contrast, a 2014 survey of Canadian physicians showed that only 45% of those that responded supported MAiD (CMA, 2016). There has also been divergence among palliative care providers, with some adhering to the notion that palliative care is not reconcilable with assisted dying (Gerson et al., 2020). There is some suggestion that there may be some support for the coexistence of MAiD and palliative care (CHPCA, 2018) among palliative care providers in Canada. However, participants in the 2018 survey by CHPCA also had concerns about a lack of psychological and educational supports for health care providers and a lack of services in palliative care. Respondents felt that only with improvements to palliative care services could MAiD and palliative care coexist in a way that would improve the EOL care experience for all (CHPCA, 2018). The tension between resources directed to MAiD in light of perceived limited resources for palliative care was echoed in a study by Pesut, Thorne, and Greig (2020). Participants highlighted that while MAiD was introduced to address suffering for some, a lack of access to skilled palliative care in primary care and limited access to specialized palliative care potentially contributed to suffering (Pesut, Thorne, & Greig, 2020).

Nurses and physicians in other countries where some form of assistance in dying is legal have had to navigate patient requests; however, this is new to the Canadian context. Canada is the first country where NPs are formally integrated into the MAiD process through legislation. As a result, NPs occupy a unique position with respect to their responsibilities. With the recency of this change in legislation and NP practice, it is also thus understandable that there is limited research available about NP experiences with MAiD.

However, some early research provides partial insight into NPs experiences with MAiD (Beuthin et al., 2018; Bruce & Beuthin; 2020; Pesut, Thorne & Greig, 2020; Pesut, Thorne, Scheiller, Greig & Roussel, 2020). Beuthin, et al. (2018) explored Canadian nurse's experiences in providing care to patients choosing MAiD. Beuthin et al. used semi-structured interviews with 17 nurses (NPs, RNs and LPNs). This study found that most participants felt that their role in MAiD was part of offering holistic care, advocating patient choice and supporting a good death. This study, however, provides limited insight into the NP experience as only one NP participated. Pesut, Thorne, Schiller, Greig, and Roussel (2020) investigated how nurses construct good nursing practice in the context of MAiD. These researchers conducted a qualitative study using semi-structured interviews with 59 nurses, 13 of which were NPs. This study provided some insight into NP practice concerning MAiD. Findings showed some overlap in how NPs and RNs employed a unique nursing lens in regard to MAiD; however, their roles differed. NPs described having to rapidly establish rapport and intimacy while determining eligibility for MAiD enlisting a nursing approach in nurturing and caring to encourage people to tell their stories. The study by Pesut, Thorne, Schiller, Greig, and Roussel did not provide any insight concerning the context in which NPs worked or how their role was structured, and their broader role in relation to MAiD. More research is required to better understand how NPs engage in MAiD, under what circumstances and the associated tensions and achievements.

Chapter Summary

Improving the quality of palliative care has been identified globally and in Canada as a priority. Many individuals and families express a desired to be cared for at home for EOL. While care at home may not always be realistic, it is imperative that patients and families receive the support they require to be able to achieve this when possible and to support transitions to hospice

or hospital when they cannot be supported at home safely. A review of the current organization of community care services highlights possible challenges to palliative care in the community setting.

The literature highlights potential areas where patients and families need to be better supported. Advance care planning and ongoing goals of care discussions can help establish understandings, expectations, values and goals for the future that are mutually understood by the patient, family and care team. Improving understandings about what to expect and what supports are available can help patients and families. Furthermore, improvements can be offered by supporting patients with the practical and medical information as needed with links to home support resources.

NPs have been implemented across a range of primary care and outpatient settings and have been shown to contribute positively to patients and the broader health care system, including palliative care. There is potential for NPs to enact their broad range of nursing competencies to enhance the palliative care experience of patients. This research seeks to better understand how NPs enact their role in this setting of community palliative care. A better understanding of how they enact their role can identify the potential for NPs in this setting and other similar settings. This research addresses that gap and furthers our understanding of NP work beyond tasks to work that is carried out in a dynamic and challenging socio-political environment that is based in and reliant upon caring relationships (Benner, 1997). In the next chapter, Chapter 3, I present the theoretical and methodological considerations of my study.

Chapter 3: Theoretical and Methodological Considerations

In this chapter, I will present the theoretical and methodological considerations underpinning this study. I begin by situating this study within the constructivist/interpretive research paradigm and discussing my positionality. I will then advance my theoretical orientation to this study and introduce the lens of relational inquiry to provide a way to examine nursing work. Next, I will discuss my selected research method of FE. Given FE's grounding in classical ethnography, I will provide a brief overview the historical origins of this research genre before discussing nursing research that has used FE as an approach to inquiry about nurses' work. Last, I will present my study design, setting, recruitment, data collection, analysis, ethics, and strategies undertaken to ensure rigor.

Philosophical Assumptions/Worldview

According to Mertens (2014), a paradigm is a human construct concerning how one looks at the world and the particular philosophical assumptions that guide thinking and action; consequently, this directly affects every decision made in the research process. The researcher's philosophical worldview (or assumptions) will influence the entire research process, including the research questions, research design, and methods (Creswell, 2013). Mackenzie and Knipe (2006) have cautioned that, in the absence of a guiding paradigm during the initial steps of the research process, there is no basis upon which to build any subsequent research methodology. Kuhn (1970) described the paradigmatic view's influence on researchers in that "the proponents of competing paradigms practice their trades in different worlds…Practicing in different worlds, the two groups of scientists see different things when they look from the same point in the same direction" (Kuhn, 1970, p. 150). Ultimately, a researcher's paradigmatic positioning influences the study's objective and design and the type of knowledge produced from the research (Broom

& Willis, 2007). Denzin and Lincoln (2005) maintain that all research is interpretive. How the researchers see the world and their ideas about studying it guides their approach to interpretation. The interpretive framework (or paradigm) is a combination of a researcher's basic epistemological, ontological, and methodological premises (Denzin & Lincoln, 2005).

Interpretivist/Constructivist Paradigm

In examining the various paradigms and reflecting on my outlook and values, I have determined that my beliefs about the world and how it should be studied are best aligned with the constructivist paradigm. The constructivist paradigm maintains that the fundamental assumptions of knowledge are produced by those who are actively engaged in the research; that is to say, socially constructed (Schwandt, 2007). Schwandt (2007) further highlighted that researchers' goal is to strive to understand the lived experiences of others from their unique perspectives; however, the researcher and the research are inseparable and, as a result, to some extent, the researcher's values influence and shape the research.

Interpretivism views individuals as actors in the social world (O'Reilly, 2009). In an interpretivist approach, there is a need for the researcher to interpret what is observed by drawing on his or her cultural values. Interpretivism assumes both a relativist ontology and a transactional or subjectivist epistemology (Denzin & Lincoln, 2005). The constructivist paradigm (as part of the interpretivist paradigm) grew out of Husserl's philosophy of phenomenology and Dilthey's (among other German philosophers) hermeneutics (Mertens, 2014). The hermeneutical process refers to the interpretive understanding by which the researcher in the research process interprets written and verbal communication. It is a mechanism to achieve an understanding from the perspective of those under inquiry by entering into a conversation or dialogue (Schwandt, 2007).

Interpretivist/Constructivist Ontology

Guba and Lincoln (1994) identify constructivism as supported by relativist ontology. Relativistic ontology maintains as a central assumption that realities are apprehendable. Individuals have their own constructions of reality based on their experience with the world. These constructions can be altered by added experience and changing perspectives. While constructions are individual and local, Guba and Lincoln (1994) maintained that constructions can often be shared among individuals. The nature of construction is not about being more or less true but more or less informed or sophisticated (Guba & Lincoln, 1994), with the unfolding inquiry process contributing to more sophisticated understandings.

Because I am interested in how NPs engage in their day-to-day work, a relativist ontology is aligned with how I see the nature of reality. Relativism holds the assumption that multiple realities exist, and these realities are drawn from a variety of invisible mental and social constructions. Reality is regarded as subjective, multivariate, and influenced by diverse discourses, including social, experiential, and historical (Guba & Lincoln, 1994; Mertens, 2014). Individuals actively assemble their meanings of the world around them; hence, reality is constructed rather than existing objectively. The assumption is that there is no one static understanding of the world that all individuals hold and there are multiple and varied understandings among individuals. Reality is constructed by associating meaning with particular events, objects, things, or interactions (Bryman, 2004; Creswell, 2013). Creswell (2013) maintains that individuals seek meaning in the worlds in which they live and develop subjective meaning through social and historical influence. Because meanings vary and are multiple, the researcher's task is to examine the complexity of views rather than to distill and simplify views. The above description fits with my personal view. I view each participant both as a whole

individual who is also embedded in a community and influenced by contexts that are subject to change over time (Reed & Shearer, 2012).

Interpretivist/Constructivist Epistemology

Epistemology refers to "how we know what we know" (Crotty, 1998, p. 8) and the assumptions and beliefs about the relationship between the researcher and what can be known (Appleton & King, 1997). Constructivism assumes a subjectivist/transactional epistemology and maintains that realities are co-constructed through interactions between the researcher and the study participants (Denzin & Lincoln, 2000). The relativist ontology maintains that there is a reality, but access to this reality is through intersubjective construction within the context of social encounters and experiences (Guba & Lincoln, 2005).

This epistemology highlights the investigator's role in interacting with research participants to produce a local understanding. There is a necessary interconnection between the researcher and the researched in the production of research findings (Appleton & King, 1997). There is an assumption that it is impossible to separate ourselves from what we know in this epistemology. What we know influences how we understand others, the world, and ourselves. As a result, the researcher's values are inherent in all phases of the research process. Truth is negotiated through a dialogue between the researcher and the phenomenon of interest.

Ongoing dialogue between the researcher and the researched facilitates the creation of multifaceted understandings about the social world. This epistemology maintains that the knower and what is known cannot be separated, and that the researcher's experience and views play a significant role in data collection and analysis (Lincoln & Guba, 1985).

As a researcher locating my research within the interpretivist/constructivist paradigm, I maintain that knowledge is gained based on subjectivist/transactional assumptions. The

interpretivist/constructivist epistemology maintains that we cannot separate ourselves from what we know; it is this knowledge that shapes how we understand ourselves and the world. The researcher-guided dialogue facilitates the construction and co-construction of reality. In this process, conflicting interpretations are reconciled through discussion, and the participant and researcher collaboratively construct a meaningful reality (Lincoln & Guba, 1985). Subjectivist epistemology maintains that all findings are constructs that the participant determines, elucidated through the transaction rather than the objective, constant, and unchanging truths (Guba & Lincoln, 1994; Mertens, 2014). What is known cannot be separated from the knower (Lincoln & Guba, 1985). Constructivism maintains the necessity of ongoing interaction with the participants throughout the research process to identify multiple constructions (Appleton & King, 1997). Individuals who promote constructivism maintain that knowledge and truth are created and not discovered (Guba & Lincoln, 1994).

The focus of my inquiry is NPs' role enactment in the community palliative care context. In this study, I adopted a broad conceptualization of role enactment. Drawing on others who have examined nursing role enactment (Dery et al., 2022; Irvine et al., 1998), for this study, role enactment is defined as the actual activities that NPs engage in that constitute their daily work. These authors acknowledge that nursing is situated and nursing work is shaped by a range of influences. For example, Dery et al. (2022) identify how organizational characteristics and priorities shape nursing work. Ivine et al. (1998) take a broader view and identify that in addition to organizational characteristics (availability of human resources, organization of care, assignment of responsibilities), personal characteristics of the nurse (experience, knowledge, skill) as well as characteristics of the patient (age, gender, socioeconomic factors, illness severity, physical function) shape how nurses enact their role. These authors further characterize

that nurses are influenced by their professional colleagues in that their work may be independent, dependent or interdependent of these individuals depending on the structure of the setting. I anticipate that NPs face many similar influences on how they enact their role. The additional influence on NP role enactment as discussed earlier involves the legislated scope of practice. Legislated scope of practice outlines nursing activities that without the required knowledge and skill can be potentially harmful to the public. For example, in the province of Ontario, NPs are legally authorized to diagnose and treat patients. As outlined in chapter two, many legislative changes have occurred to enable NPs to undertake work that they are educated to do. However, if legislative regulations do not keep pace with educational and practice advancement, there is a risk that NP practice will be restricted. When legislation restricts practice, NPs are not able to contribute to their full potential, which poses barriers to delivery and receipt of timely and necessary health care. Many changes have occurred at the legislative and regulatory level in most Canadian provinces to support NP practice through a broad legislative scope. Any examination of the NP role needs to consider a broad range of influence at the micro, meso and macro levels to examine influences that shape the NP role.

I believe that the constructivist paradigm is well-suited to support the inquiry about how NPs enact their role. NPs conduct their work that is contextually situated and socially mediated through social and interpersonal processes and influenced by a broad range of interpersonal, social and structural influences. To best apprehend the phenomenon of NP role enactment, a subjectivist transactional epistemology can support an emic understanding. When situated within the constructivist paradigm, researchers study phenomena through people's perceived realities and social constructions while in their local environments (which are also embedded in larger social, cultural, and political contexts). Individuals and their contexts are considered inseparable

(Weaver & Olson, 2006). What this means is that individuals' interpretations, beliefs and values do not stand alone, but are shaped and influenced by their context and thus inherently embedded. To better understand their experience and to gain an emic perspective, research about NP work needs to incorporate a methodology that allows a better understanding of the influence of that environment. Reality is viewed as complex, multifactorial and context dependent (Monti & Tingen, 1999), necessitating a subjectivist transactional epistemology.

While the NP role is becoming more prevalent in palliative care, research and our knowledge about this role are limited. My goal will be to gain a broader understanding of how NPs enact their role in this context as members of a community palliative consultation team. Constructivism is well suited to address the aims of the study because knowledge access to this reality is achieved through intersubjective construction within the context of social encounters and experiences (Guba & Lincoln, 2005). I will explore how NPs engage in their role and their connection to specific events, activities, and assumptions; for example, the people with whom they work, for what purposes, and their interpretations of these experiences (Broom & Willis, 2007). In considering my research problem and question, my intention will be to identify patterns of meanings throughout the research process (Mackenzie & Knipe, 2006).

Positionality and Reflexivity

Positionality refers to an individuals' worldview and the position they assume when conducting research (Rowe, 2014). Positionality is influenced by who the researcher is and his or her experiences and beliefs. Influences shaping positionality can include gender, ethnicity, citizenship, skin color, life history, income, political views, and personal experiences (Chiseri-Strater, 1996). Positionality influences all aspects of research, including what the researcher is interested in, the research question, the analysis, and how the researcher presents the findings

(Rowe, 2014). Holmes (2020) identified that, to identify researcher positionality, researchers must situate themselves in regard to three areas, including "(1) the subject under investigation, (2) the research participants, and (3) the research context and processes" (p. 2). Reflexivity is the process through which researchers reflect on their positionality (Cheiseri-Strater, 1996). Cheiseri-Strater (1996) suggests that reflecting on positionality is an approach that can reveal what a researcher is positioned to see, know and to understand within the research project. Malterud (2001) recommended the following approach to reflexivity:

> Reflexivity starts by identifying preconceptions brought into the project by the researcher, representing previous personal and professional experiences, pre-study beliefs about how things are and what is to be investigated, motivation and qualifications for exploration of the field, and perspectives and theoretical foundations related to education and interests. (p. 484)

Reflexivity is a critical part of qualitative research. Holmes (2020) highlighted that self-reflection and a reflexive approach are essential before starting research and as part of an ongoing process to make transparent the effect of the researcher on the research process. Cohen et al. (2011) maintain that researchers should continually acknowledge and disclose their positions and scrutinize their involvement and impact on it at all stages. Atkinson (2015) highlighted the importance of acknowledging that social research has an interactive effect. Rather than trying to eliminate that effect, researchers must be conscious and self-aware of what they are doing. Atkinson highlighted the need to recognize that "the essential character of social research is a series of social, interpersonal events" (p. 27) and "fieldwork takes place in a mesh of social relations and in a web of interpretations" (p. 27) where both the researcher and participants engage in interpretations of social events and actions and the research process. The

goal is not to eliminate the researcher effect but to disclose and recognize the influence on the research process (Holmes, 2020). Throughout the research process, I tried to reflect on my positionality and its impact on how I approached the research at different stages. I have illustrated these reflections when presenting my methods.

Researcher Positionality and Reflexivity

In undertaking this research, I recognize that my life experience shapes my understandings, knowledge, beliefs and values. I situate myself in relation to this study as a white, middle-aged, middle-class female. I have always been interested in how health care is organized, delivered, and experienced. I have 8 years of experience as a nurse, 22 years as a primary health care NP, and 19 years as a primary health care NP educator. I started my health care career as a nurse in remote communities, where often the only health care providers were nurses. I soon realized that I required additional education to be better able to meet the primary care needs of the individuals seeking health care and undertook graduate studies with an NP specialty. My interest in this study relates to my own experiences of entering the health care world as primary health care NP.

I believe that NPs have much more to contribute to community care settings than is often acknowledged. My assumptions about the NP role include that a) NPs, when added to a clinical setting have the potential to improve the level of access and quality of health care experienced by patients in that setting; b) NPs, when added to a clinical setting can enhance the way that other health care providers experience their roles and responsibilities; c) Because of the flexibility and wide breadth of the NP role that extends beyond traditional nursing domains to incorporate elements of the biomedical domain, the role is often poorly understood by most other than those

who experience the NP as a care provider; and d) It is the flexibility and breadth of the NP role that add value in most clinical settings.

I acknowledge that my background as a nurse and experience as an NP have influenced my interest in this research, how I have undertaken this research, and my data interpretation (Foote & Bartell, 2011). In this study, I perceive my study participants as my peers, although I acknowledge they may not see me in quite the same way. I have deep admiration for what they do. One participant was a student of mine (albeit over 10 years ago) and two others know me as an instructor but were not my students. I had met another one of the study participants through professional meetings. I wondered if this familiarity would make it easier or more awkward for participants, if my background as an NP and program instructor would make participants feel their performance was being evaluated, or if they thought I should know more about palliative care. I was pleasantly surprised when, on my first day of participant observation (PO), one participant told me enthusiastically that the group was expecting me and wondering when I would start my research with them. This exchange provided me with some reassurance that my presence was not only anticipated but also welcomed.

Theoretical Orientation

To frame my inquiry, I draw on the conceptualization of nursing as a process, termed relational inquiry (RI), put forth by two Canadian nursing scholars, Doane and Varcoe (2021). Doane and Varcoe advance a relational understanding of the nursing practice that situates it as dynamic and embedded within multiple overlapping and, at times, conflicting contextual influences. This theoretical lens highlights the inherent interconnectedness between actors (nurse, patient and family, other health care providers), and the broader sociopolitical environment. This view emphasizes the interconnectivity of each actors' well-being, all reliant

on and affected by the other. Doane and Varcoe (2021) promote relational inquiry as a reflexive process. Nurses using RI engage in ongoing contemplation about how all actors in a scenario are interconnected and influence each other. While engaging in RI, nurses pay particular attention to how each may reciprocally shape the other (Doane & Varcoe, 2007). For example, in relation to my study, this would involve my paying attention to what NPs are doing in their encounters with patients and others and exploring with them their deliberations about what is shaping their approach and response. Observations and ongoing dialogue about NP considerations and decision will facilitate a better understanding about how NPs undertake their role with patients, family members and others who may be involved in any given patient situation.

Doane and Varcoe (2021) posit that nurses not only engage in a "relational orientation" (p. 28) but also in "inquiring action" (p. 32). This relational orientation highlights nurses' need to attend to the interplay of multiple relationships in any given situation. The relationships include those at an interpersonal level (what happens between and among individuals), intrapersonal level (within individuals), and contextual level (policies, resources, and competing demands) to best be able to respond to a given clinical situation. Doane and Varcoe (2021) describe inquiring action as a process in which nurses engage to determine good nursing action. This action requires that nurses continuously ask questions about themselves and others to determine what influences are at play in any situation and how these factors are integrally connected and may have influenced the situation. For example, a patient who is not taking their medication or is reluctant to take medication may be initially seen as "non-adherent." However, on deeper inquiry, the nurse may find that a number of factors may be influencing this behavior interpreted uncritically as "non-adherence." This requires nurses to examine their own assumptions and values related to adherence and what that means to her (unnecessarily uncontrolled symptoms) and judgements

about patient behaviors (possibly negligent self-care, irresponsible, lacking knowledge), and then consider the patient's perspective (possible fear of adverse effects, stigma of medication, lack of resources to pay for or secure medication) or contextual influences (lack of money to afford medication, difficulty to get to a pharmacy). Doane and Varcoe (2021) promote RI as an approach to nursing practice that aims to "enhance the capacity and power of people to live meaningful lives" (p. 58). Thus, effective nursing care relies on an awareness or at least an inquiry regarding of the relational complexities in any given practice situation (Doane & Varcoe, 2007).

In formulating their RI approach, Doane and Varcoe (2021) draw on the philosophies of hermeneutic phenomenology and critical theory. Doan and Varcoe clarify that while they draw on hermeneutic phenomenology, it is not in the sense of philosophy or methodology but as a perceptual tool to guide inquiry. The hermeneutic phenomenological lens aims to facilitate understanding of an individual as they are situated within meaningful relationships and contexts and acknowledges that the meanings of events, actions and situations are subject to change with time and experience (Doane & Varcoe, 2021).

The underlying assumptions of Doane and Varcoe's hermeneutic phenomenological inquiry lens include that people i) have experiences that are shaped by everything around them (for example, work, friends, family, culture to name a few); ii) will experience similar health situations differently; iii) have life experience that are both unique to them that at the same time share meanings with others; and, iv) are best understood when considered in relationship to their worlds because considering individual contexts makes what people value and find significant evident (Doane & Varcoe, 2021). These assumptions grounding the application of a hermeneutic phenomenological lens provide a comprehensive method for nurses to view nursing situations

and nursing practice from different vantage points. Using an HP lens helps nurses best apprehend all the influences of any situation and arrive at the best nursing action for the patient in that situation.

Doane and Varcoe (2021) further suggested that as part of RI that nurses employ a complementary critical lens to interrogate the influence of power at different levels. Power can be seen to exert influence at an individual (intrapersonal) level, between individuals (interpersonal), and within the broader sociopolitical context. Doane and Varcoe (2021) promote that examining situations for power dynamics enables nurses to be more aware of the source of power and how to respond in given situations. A critical lens invoking a relational view of power helps to make evident how societal structures (political economies, institutional policies, and government systems) shape people and interactions. Doane and Varcoe (2021) suggested that this critical lens also contemplates power from a feminist and gendered perspective to examine the potential influences of colonialism, a racialized system, and the role of language in shaping the experiences of patients, families, and health care providers. By interrogating situations through these lenses, taken-for-granted understandings can be questioned and challenged. For instance, consideration of the influence of poverty on health behavior helps to broaden knowledge about poor therapy adherence. The conceptualization of nursing as RI can provide a way to see nursing work as considering, accounting for, and interpreting each clinical situation as unique and in its full complexity to formulate a nursing action that is equally unique and responsive to that situation.

Using this lens from a research perspective can help make known the taken-for-granted aspects of NP work in a community palliative care setting. This same inquiry process can situate NPs with in the broader caregiving setting and situate patients and other health care providers, all

with their own individual perspectives and experiences, interacting to some extent with each situation being unique and requiring re-interpretation.

Methodology: Focused Ethnography

Situating myself in the constructivist/interpretivist paradigm and with the interest in learning about how NPs undertake their work, an ethnographic approach supports this inquiry. The FE approach provides a way to understand how NPs carry out their day-to-day work in community palliative care. As an approach to research, FE offers an effective way to describe and understand the experiences of individuals that are members of groups or sub-groups (Higginbottom, 2013).

Higginbottom (2013) promotes FE as having meaningful and useful application in research about health care practice. Higginbottom further situates FE within the broader genre of ethnography. Roper and Shapira (2000) proposed that, despite having a narrower scope than traditional ethnography, FEs still maintain the typical characteristics of traditional ethnography. Roper and Shapira (2000) argue that FEs can foster understanding of everyday situations and their inherent complexities. In my interest of how NPs enact their role in community palliative care, FE seems well suited to be able to allow me to understand the work of NPs as well situated within and in response to the contextual factors that influence how they engage in their work.

Before discussing FE in greater detail, I will provide a brief historical overview of the origins of the broader genre of ethnography from which FE is adapted. Ethnography, as a research approach, has its evolutionary roots in anthropology dating back to the late 19th century (Murchison, 2010). Early ethnographic work was concerned with learning about the histories, ways of living and experiences of living of people in settings that were outside of Europe (Schensul et al., 2013; Williamson, 2013). Ethnographers of this time wished to understand

participants' everyday environment and meanings associated with belonging to a group (Brewer, 2000). The undertaking of a study involved the anthropologist living in communities to study local ways of living and working along with community members to learn about their values and beliefs (Richards & Morse, 2013).

This approach, now referred to as classical or traditional ethnography, originated in Europe (primarily Britain) in anthropology (Macdonald, 2001). In the 1920s, Bronislaw Malinowski first articulated a distinct approach to social anthropology by using ethnography, PO, and fieldwork to study a specific group of people (Macdonald, 2001). This early version, or classical ethnography, involved researcher immersion in communities 24 hours per day, 7 days per week, during different seasons, and for extended periods, often for durations of over a year. This level of immersion and time is thought to allow the ethnographer to learn the local language, spatial dimensions of the research setting, dynamics of socio-cultural activity, and potential influences of the time of day, week, or season (Whitehead, 2005). The principal data collection methods that ethnographers used in their fieldwork included observation, interviews, and sometimes photography (Brewer, 2000). Early researchers undertook PO to learn about smaller groups of people with similarities (Tedlock, 2000).

Tedlock identified early ethnographers as scientists seeking to illuminate the truths behind human behavior. Researchers often regarded their backgrounds as separate from their analysis and findings and viewed their findings as true and representative of the reality held by those under study (Tedlock, 2000); in other words, they considered their findings objective truths (Williamson, 2013). Researchers focused on creating an archival portrait of the culture studied, accompanied by a belief that those studied could not be changed (Whitehead, 2005). Researchers portrayed themselves as observing cultures in a distant and detached manner, meaning that they

tried to separate themselves from the data collection and denied the influence of their beliefs and values (Murchison, 2010). The aim of such early ethnographic research was to produce an authoritative, objective account without consideration of multiple perspectives. This approach revealed a commitment to a positivist paradigm.

Murchison (2010) identified that these early studies presented their results as a distilled version of a culture's reality, presented as a homogenous entity. More recently, scholars have criticized these studies as providing only partial or inaccurate views of the cultural groups under study (Murchison, 2010). Ethnography has traditionally been descriptive, using PO to focus on the cultural context of behavior but, over time, has taken on other approaches, including interpretation and critical reflection (Richards & Morse, 2013).

In America, Robert Park and Ernest Burges established the Chicago School of Ethnography between 1917 and 1942 (Macdonald, 2001). These researchers advanced ethnographic approaches and have been likened to the classic early ethnographers in their interest in studying unknown cultures; however, in contrast, these cultures were most often distinct, locally situated, urban communities (Macdonald, 2001). Early in the Chicago School's work, populations of interest included sections of industrialized cities with marginalized urban groups, including the homeless, drug dealers, and immigrants (Brewer, 2000).

Deegan (2001) noted that, many of the scholars and students of the Chicago School were influenced by George Mead. Mead posited that community, self, and thought are products of human meaning and interaction and that people become human through interactions with others. Institutional patterns are learned within communities dependent on shared language and symbols. Reflective behavior depends on human intelligence (Deegan, 2001). Deegan identified that Herbert Blumer later termed this view as symbolic interactionism. Richards and Morse (2013)

highlighted that ethnographic research has, over time, embraced several styles with a range of philosophical underpinnings, with examples such as traditional, participatory action research; phenomenological research; auto-ethnography; critical ethnography; and visual and FE.

Despite these variations, ethnographic researchers have identified the core defining characteristics of any ethnography. These characteristics include: a) conducting research in the everyday context of the individuals studied; b) using a range of sources to gather data, with the main source as intimate face-to-face interactions with participants, focusing on a single setting or group and representing participant behaviors and perspective; c) data collection (inductive, interactive, and recursive) to build local cultural descriptions, explanations, and theories; d) situating human behavior in sociopolitical and historical contexts; and e) interpreting study results using the concept of culture (e.g., the meanings, functions, and consequences of individual actions and institutional practices (Hammersley & Atkinson, 2007; LeCompte & Schensul, 2010).

Culture and Ethnography

Culture is the main interest in ethnographic inquiry; however, culture as a concept is contested. Agar (2006) described how older conceptions viewed culture as a system of meaning and action that was closed, coherent, and enduring for the particular group studied. In the early days of ethnographic inquiry, culture was often presented as a reified "thing" and conceived as static and entrenched. Further elaborating on culture, Agar contended that modern conceptions of culture acknowledge its relational, dynamic, and often incomplete and pluralistic nature. Agar also promoted the notion that individuals are members of multiple groups and, as such, will be shaped by these overlapping influences and memberships. Wolcott (2008) described culture as an abstraction for studying human behavior. Culture is discerned through the interpretation of the

meaning of behaviour. Wolcott (2008) further proposed that culture does not exist in and of itself but "is revealed through discerning patterns of socially shared behaviour" (p. 71). Wolcott maintained that the overriding concern for all ethnographers is the "description of collective human behaviour and its analysis" (p. 37), elucidating social activity patterns.

Roper and Shapira (2000) support the notion that culture comprises a particular group's behaviour patterns and is evident within their customs, ideas, beliefs, and knowledge. By studying culture, ethnographers describe what people know, believe, and do; the meanings they ascribe to their doing in each situation; and how they relate to others (Goetz & LeCompte, 1984; Spradley, 1980). The purpose of ethnographic research is to describe what people occupying some particular place or status ordinarily do and the meanings they ascribe to the doing under ordinary or specific circumstances, presenting that description in a manner that draws attention to regularities that implicate cultural process (Wolcott, 2008). In my study, I focus on NP role enactment in the setting of community palliative care. My focus will be on what these NPs ordinarily do on a day-to-day basis and in exceptional circumstances to carry out their role. I will also focus on the meanings that they associate with their actions and interactions with others in the setting. For example, I will attend to how NPs respond to patient and FCG needs, how and who they communicate with, how they respond to their colleagues and the meanings they relate to these interactions. Culture as it relates to my inquiry about how NPs enact their role in community palliative care involves concern and interest about behaviour but also requires the interpretation of the meaning of that behaviour that are shared by the group. This means attention to certain behavioral practices undertaken by NPs in this setting as well as the meanings ascribed to those behaviors.

Chambers (2000) articulated the notion of culture as "understandings and ways of understanding" (p. 852) maintained by a distinct group. Groups share specific meanings that manifest as cultural understandings. Chambers suggested that researchers can gain cultural understanding by observing behaviour patterns, listening to group members' accounts of routine behaviour, learning about how a group interprets rules or patterns, or exploring the more hidden dimensions of cognitive processes like values, attitudes and judgements about experiences (Chambers, 2000). Processes of group interactions display elements of culture. Chambers noted that culture retains enough stability to be learned by new group members, but, rather than being static, it is changeable over time and influenced by context. Group members engage in an unstable and shifting process to derive meaning from evolving circumstances and relationships (Chambers, 2000). Given culture's elusive nature, Van Maanen (1988) highlighted the researcher's interpretive role:

> A culture is expressed (or constituted only by the actions and words of its members and must be interpreted by, not given to, a fieldworker. To portray culture requires the fieldworker to hear, to see, and, most important for our purposes, to write of what was presumably witnessed and understood during a stay in the field. Culture is not itself visible but is made visible only through its representation. (p. 3)

Holland (1993) identified nursing as a "subculture" (p. 93) of a larger social group, describing it as bounded and often having smaller sub-cultures. I would promote that NPs are a further nursing sub-culture. For example, as identified in Chapter 2, while having a disciplinary foundation in nursing, NPs also have additional scope of practice to include advanced assessment, diagnosis and treatment which fundamentally shifts their scope of responsibility. I will draw on an example from my primary care practice setting. One day as I was packing up to

leave for the day, one of the clinic nurses approaches me and asks me if I could do her a favor. She requests that I sign a prescription for a patient who needs a medication renewal as the patient's physician is not in and the patient is in significant distress. I can't help but feel compassion for the patient who is in distress and the nurse who has no other recourse. So, I look at the request, it is for a potent anti-inflammatory medication. I don't know the patient's history so I open the chart and review. Incidentally I see the patient has had a cardiac event and has hypertension, posing significant risks for taking an anti-inflammatory. There may not be a better option for the patient's immediate relief but I can't see any documentation that there has been a discussion around the risks that this medication poses. This is not a simple medication renewal. I will need to try to contact the patient to have a discussion, ensure that the diagnosis is correct and that the implications of using this medication now and into the future. While as nurses we share the same concerns and values about the patient's comfort, as an NP, my responsibilities are different and may influence my outlook, concerns and behaviour because of the influence of this sub-culture. The same can be said for NPs who work in community palliative care, who will be influenced by the philosophy of palliative care and share values, characteristics and responsibilities with other palliative care providers. In this study, the NPs that are part of the palliative consultation team represent a sub-culture within the broader sub-culture of NPs and nursing. NPs in this study also are situated within the overlapping sub-cultures of the palliative consultation team and home and community care teams. NPs also bring their cultural influences as members of other sub-cultures (for example, gender, religious affiliation, parents, caregivers).

Focused Ethnography

FE is selected as the research methodology suitable for investigating how NPs enact their role in community palliative care. As an adaptation of classical ethnography, FE retains several

of the core features of its parent genre with minor adaptations. Muecke (1994) identified distinguishing elements of FE. Cruz and Higgenbottom (2013) summarized these features as: a) problem-focused and context-specific, b) focusing on a discrete community/organization/social phenomenon, c) stemming from the conceptual orientation of a single researcher, d) involving a limited number of participants; e) using PO more episodically, f) acknowledging that participants have particular knowledge, and g) used in both academia and health care services. Elements of classical ethnography are adopted, adapted, and applied to enable research that is responsive to modern research environments, interests, and concerns. The approach of FE fits well with the theoretical perspective of RI in that RI recognizes that nurses are necessarily in relation with patients, other actors and the socio-political context in every clinical interaction. FE complements RI through promoting observation of NP work in natural circumstances and to explore deliberations as they relate directly to the real-life situations. FE can enable observation and exploration of the complex relational situations that NPs navigate.

Higginbottom et al. (2013) describe FE as primarily a qualitative research approach using an inductive paradigm with a goal of developing an in-depth understanding from a holistic perspective. Higgenbottom et al. maintained that FE is appealing to any discipline where the primary concern is exploring the cultural viewpoints of sub-groups of people within a specific context and about a particular problem. Over the past several years, FE has gained popularity as a research approach by nurse researchers and those interested in nursing phenomena. Roper and Shapira (2000) identified FE as helpful in nursing research where the focus is a particular concern situated within a distinct context among a smaller group of society. Roper and Shapira promoted that one of the primary purposes of FE in nursing research is the study of nursing practice as a cultural phenomenon. Mueke (1993) identified that FE is relevant to nursing where

the goal is to develop nursing knowledge and practice. Wall (2015) proposed that various aspects of culture, such as beliefs, values, knowledge and skill, power, and control, can be examined using FE, despite its differences from traditional ethnography.

FE generally assumes a narrower scope than traditional or classical ethnography but retains their central characteristics. Roper and Shapira (2000) maintain that these retained similarities make it helpful to improve our understanding of everyday events and situations in all their complexity. Because of the local, yet inclusive, focus of the research, researchers see FE as a valuable way to inform policy and practice (Boadu & Higgenbottom, 2015).

Ethnography has been identified as a beneficial approach for learning about what nurses do (Brink, 2013). Nursing work is often characterized as care and often contrasted with the work of medicine and its purported focus of cure. Brink reflected on nursing's claim of care over cure but also acknowledged that care is an elusive concept. She further proposed that if care is what nurses do, understanding what care is can be determined only by observing nurses' behaviour in different situations, groups, and settings. Brink advocated that ethnography remains the best way to discover the dimensions of nursing care wherever nurses practice.

Nursing and Focused Ethnography

FE has become increasingly popular as a research approach in numerous disciplines, including nursing. Several nurse-researchers have adopted FE in their research to better understand nursing work across a variety of health care settings, with a focus on either nurses, teams, or patients (Bull & FitzGerald, 2006; Elliott et al., 2018; Field, 1983; Griffiths, 2011; Jangland et al., 2018; Kennedy, 2002; Reblora et al., 2021; Scott & Pollock, 2008; Strandas et al., 2019; Williamson et al., 2012).

A few studies have focused on the nursing role. For example, Kennedy (2002) used FE to explore the nature of district nurses' required knowledge in community care settings to carry out first assessment visits. The researcher shadowed 11 district nurses during their first assessment with a patient and conducted semi-structured interviews at two intervals. This study showed that district nurses worked to build a bigger picture of the patient to provide a more holistic and individualized approach. Nurses identified building a relationship with patients as meaningful to them. Furthermore, nurses saw their role in the identification of patients' current and anticipated future needs. Nurses also reported working within system constraints and being conscious of available resources to provide what patients needed. Kennedy (2002) claims that observation contributed to understanding the role and impact of context on activities and generated questions that could be further explored through interviews to provide a deeper understanding of judgements and values.

Williamson et al. (2012) used FE to investigate the role of the advanced nurse practitioner in an acute care medical ward. These researchers used PO and interviews in their inquiry. This study identified the advanced NP's position as critical in translating medical information to nurses and NPs' stabilizing influence in communicating across shifts and disciplines. Furthermore, ward nurses saw these nurses as more approachable than physicians when care issues had to be resolved. The advanced NPs also prevented and detected early patient deterioration and acted as role models to junior nurses and physicians. Advanced networking skills facilitated their role, and easy access to nurses enabled patient care. Williamson et al. (2012) identified that observation in addition to interviews supported a contextual understanding generated questions and informed subsequent observations and interviews in data collection.

Williamson et al. argued that observation was essential to develop a full understanding of how the advanced practice nurses in their study communicate in the clinical reality.

FE has been used in nursing to better understand the role of nurses as situated in their day-to-day contexts to develop a deeper understanding of the role. The use of observations in addition to interviews supported the research by allowing researchers to collect naturally occurring data and events often taken for granted and to make contextual associations and interpretations about the phenomenon studied. Given the research reviewed here, FE is a promising approach to answer the research question of this study: How do nurse practitioners enact their role as consultants in a specific community palliative care setting in Ontario?

Methods

Setting

This study was conducted in one of 14 health networks in the Canadian province of Ontario. In Ontario, the administration of health care programs and services is a regional responsibility. Each health network oversees the organization and administration of all health services for the region; for example, those services offered through hospitals or as part of home care. The NPs in this study are employed by home and community care; however, through a negotiated partnership, they work closely and seamlessly with a hospital-based palliative consultation unit as part of a team of pain and symptom management consultants for adult patients receiving care in the community (see Appendix I).

The consultation unit, along with the five NPs, is comprised of four specialist palliative care nurses and a team palliative care physician. Historically, this service grew from one advanced practice nurse providing phone support to physicians and nurses in the community to address the complex care needs of patients nearing the end of their life; the service then later

integrated additional nurses. A 2013 provincial funding initiative supported the addition of NPs to home and community care to support palliative care services in each of the 14 health networks. As identified earlier in this thesis, each health network could decide on how to integrate the new NPs into the current organization of services and how their skills would be used. Little detail is known beyond the fact that NPs are added organizationally to the regional health home care program. In some regions, NPs became the primary care providers for patients when their physicians transferred the responsibility for all care to the NPs. Other regions have adopted more of a shared-care model; however, this is not well defined in public documents. In this study, NPs, while added to the community care setting operationally, were also integrated functionally across organizational boundaries to work as members of the existing palliative care consultation team coordinated through a local hospital.

All members of this palliative consultation team, including the NPs, are regarded as consultants who provide support in the form of advanced assessment and clinical advice to community PCPs, community nurses (CNs)[5], rural hospitals without palliative consultation specialists, and hospices. The NPs, as part of the team offer consultation about palliative pain and symptom management and complex EOL decisions. The consultation team members provide assessment of complex symptoms, provide management recommendations and offer coaching/mentoring and advanced palliative care education to nurses and physicians who are the primary contacts and health care providers for patients. When NPs are consulted for assistance, their role is complementary to the PCPs and CNs who are involved with patients in an ongoing manner. The NPs and other consultants schedule intermittent follow up with patients based on

[5] In this study, I use the term community nurse (CN) as an inclusive term to refer generally to the nurses that NPs frequently interact with in the community. Community nurses include nurses in LTC homes, retirement homes, as well as the VNs who provide nursing services to patients in these settings and private homes. VNs are employed by agencies who are awarded contracts by the regional health administration to provide home nursing services.

assessed needs. By nature of their role, they are more removed from patients, with assumptions that PCPs and CNs are the immediate and more regular contact for ongoing and regular support.

The work context for NPs in this study differs from those of health care providers who work in one specific geographic location (clinics, hospitals, and community offices). I refer the reader to Chapter 2 where I present an overview of the unique caregiving landscape of community based palliative care. While there is often a weekly group meeting where all team members meet in person, NPs typically perform their administrative work from offices in their homes. For their clinical work, NPs travel to assess individuals in their homes located across geographically diverse settings described as urban, rural, inner-city, and suburban. Patient homes can be private residences or supported living settings, like retirement homes or LTC homes. The patients that NPs are asked to assess are often, but not always, already enrolled in the local home care system. Enrollment in the home care system facilitates nursing and other home support services. These patients are also often linked to a PCP (physician or NP) who is expected to attend to their primary care needs. While patients may be attached to a PCP, these PCPs may or may not have substantive knowledge of the patient's situation.

For patients to receive an assessment from the NP, the requester submits a consultation request to the consultation team; any health care provider can request a consultation. To be eligible for an evaluation, a patient must have a PCP who agrees to the assessment and be actively involved in patient care. This notion of active involvement highlights the team's purpose as consultants who provide intermittent assessment and support through advice and guidance, as opposed to assuming the full range of the patient's ongoing health care needs.

The palliative team triage nurse assesses consultation requests and schedules an appointment for the patient with an NP, most often based on their geographic location. The

specialty consultation service aims to refer patients for an assessment within 10 business days. While the consultation team is not intended to function as an emergency intervention service, they make efforts to prioritize patients with urgent issues. Any health care provider can request a consultation, but most requests originate from care coordinators who are notified by agency nurses about patients who are experiencing a decline in their condition or having poorly controlled symptoms. NPs provide consultation to a wide range of patients in the last year, months, weeks, or days of their lives.

Over the past several years, the service has refined (and continues to refine) the geographic coverage distribution. The NPs responsible for seeing patients in the urban core typically have a smaller geographic catchment area but an increased population density and a greater number of retirement homes and LTC homes. Other NPs who cover more suburban and rural geographies tend to have fewer retirement and LTC homes in their area and have greater distances to travel between patients.

NPs navigate multiple structures and actors that influence CPC. Regional care coordinators (also known as case managers) employed by the regional home and community care organizations manage care coordination. When patients require services beyond what can be supported at home, care coordinators facilitate a bed in a more supportive environment, for example, in a LTC home or hospice. When an application for LTC is created, the case managers assess patients based on the priority of need. While there are differences in wait times depending on the LTC home's location or whether a basic, semi-private, or private bed is requested, average wait times range anywhere from 2 months to well over a year (Champlain LHIN, 2021).

Depending on the patient and the LTC home, patients either retain their PCP for medical needs or transfer their care to the "house" physician. If patients retain their primary care

physician, they are required to physically visit their physician's office, which is a challenge for patients with restricted mobility. When patients accept the care of the "house" physician, the physician is available for consultation during specified hours, once every 1 to 2 weeks, depending on the residence. In either case, consultation availability and support for retirement or nursing home nurses during and outside regular office hours are limited.

The regional Home and Community Care Support Services employ care coordinators who develop, monitor, and modify service plans for patients enrolled in the home care program and authorize services (nursing and home support) from agencies. Currently, the region has contracts with five different agencies that provide visit nursing and personal support. Three of the five agencies are mandated to have nurses with some palliative care education to win contracts to supply services. There is a mix of private and public service providers for LTC homes and agencies that provide visit nursing and home support. Challenges with staffing also characterize this environment, often resulting in high rates of nurses and support workers entering and leaving these employment settings. I refer the reader to Chapter 2 where I present the challenges of the community palliative care landscape. Where hospice care is desired, care coordinators facilitate hospice applications through a central intake; however, wait times can vary from a few days to a few weeks.

Entry to the Setting

To gain entry to the research setting and before applying for ethical review, I met with the two program managers involved in the collaborative team. These program managers were directly involved in supervising the consultation service and considered "gatekeepers" (DeWalt & DeWalt, 2011, p. 45; Hammersly & Atkinson, 2019). Consulting with these local leaders was a critical step in determining feasibility and gaining initial approval for the research and access to

the setting. I met with the home care program manager, who provides oversight of the NPs in this specialist consultation role. I also met with the manager of the original palliative care consultation team. While NPs are supervised by the home care program manager, the manager of the palliative care consultation team, with whom the NPs work, has operational oversight over how the team functions and integrates.

I explored the feasibility of and openness to the idea of research about NPs, and both managers were supportive of my study. Because the NPs are employees of the regional home care program, a letter of support was sought from and provided by the home care program manager and submitted with the application for ethics approval (see Appendix II). I also arranged a phone conversation with one NP on the consultation team to explore the group's potential openness to the study and explore its feasibility and logistics. She shared information about the NPs' role and expressed her support for the study from her perspective.

Recruitment

After research approval from the University of Ottawa's Research Ethics Review Board (see Appendix III), I met with the NP team and their manager to introduce myself and present my proposed research. In this meeting, I explained the purpose of my research and what participation would involve (observations and informal and formal interviews). The manager of the NP group agreed to circulate an email emphasizing that participation was voluntary (see Appendix IV). The email included a short description of my study and requested that NPs interested in participating contact me (see Appendix V). Upon contacting me, I provided each NP with a copy of the consent form that detailed their involvement, what to expect, and their right to withdraw from the study (see Appendix VI). The NP informed consent form outlined the purpose of the study; its risks, benefits, and costs; limits to privacy and assurances of

confidentiality, and anonymity; and freedom to withdraw from the study at any time. The consent form also outlined the study purpose and methods (PO and interviews), that their participation was voluntary, and that they could refuse to answer questions and withdraw from the study at any time.

In the informed consent form, I advised participants that there were no direct benefits to agreeing to participate outside of contributing to a body of knowledge and having their voices heard. I also advised participants that an indirect benefit may include the development of a deeper understanding of the NP's role within community palliative care settings that could facilitate measures to locally support the NP role, potentially inform practices in other settings, and possibly enhance professional satisfaction with the role and employment. I also informed participants about the minimal risk of harm, as in comparable observation studies; however, there could have been instances where topics of discussion or recollection of stressful events may trigger NPs to experience strong emotions. If these instances occurred and participants required support, I advised them that a referral to their employee assistance resource or a private counselor was available. Participants were advised that interviews would occur at least once with possible additional interviews as required; however, they were free to decline further interviews without penalty or harm by prejudice. I sought ongoing consent in my field observations and

Over the course of my research, there were some staffing changes. When I met new NPs, I introduced myself and provided them with information about my study and my contact information to enroll in the study. I recruited NPs based on convenience. All were members of one specialty palliative care consultation team. All NPs employed in this specialty palliative care consultant role were eligible to participate in this study with no exclusion criteria for participation. Seven NPs participated in the study.

Participant Demographic Profiles

I asked all participants to complete a demographic questionnaire (see Appendix VII). Questions focused on previous education and work experience to build a deeper understanding of participants as NPs. All NP participants had obtained their NP education through graduate-level education or post-graduate certification programs. All but two NPs were certified in the primary health care NP specialty, with two NPs having their graduate education focus on adult care. The NPs' experience ranged from three years to 19 years. All the NPs had several years of experience as an RN before their NP education and career, ranging from eight to 24 years. Most of the seven study participants had been in their current position with the consultation team between four and seven years. Three NPs were newly hired and on the team for less than six months.

There was a consensus that graduate NP education did not address issues specific to palliative care. However, many of the NPs commented that their education provided a solid foundation in primary care and leadership that facilitated their transition to being palliative care specialists. All the NPs reported seeking additional learning to support specialty knowledge development in palliative care. Each NP in this study had completed the Learning Essential Approaches to Palliative Care (LEAP)[6] course. Four of the seven NPs were also LEAP instructors educating other care providers in the community. Participants identified a range of other courses they had taken to support their palliative care learning, such as, for example, courses offered through Victoria Hospice or Hospice Palliative Care, regular conference attendance, and self-directed learning. Four participants were certified through the Canadian Nurses Association certification in Hospice Palliative Care. Four participants identified having

[6] The Learning Essential Approaches to Palliative Care, commonly called LEAP, is a well-known curriculum that supports knowledge development in the domain of palliative care. LEAP is offered by Pallium Canada, which is a national non-profit organization with a focus on improving the quality and accessibility of palliative care by supporting knowledge development related to quality palliative care.

palliative care experience in either community or tertiary care settings as RNs, while others had experience in intensive care, advanced chronic illness care, and LTC.

Data Collection

Data collection included over 500 hours of fieldwork, which included participant-observation of NPs in their work as well as initial exploratory interviews with non-participants (i.e., two NPs in other regions), community palliative care program managers and informal and formal interviews with NP study participants. I began my fieldwork by having preliminary meetings with managers and one team NP to explore whether my research was feasible and welcome. I also had phone conversations with two NPs in other parts of the province working in a different model of community palliative care to obtain their insight into NPs' experiences in different care models and to inform my observations and analysis. I conducted data collection between July, 2018 and October of 2020. Observations began on July 17, 2018, shortly after ethics approval and stopped in October, 2020. Initial interviews with the NPs were conducted for most participants approximately half way through the study and for some NPs nearer to the end of the study. Interviews were conducted in private locations based on each participant's preference and schedule. I conducted most initial semi-structured interviews in a private room at the regional home care organization's central office, with one interview conducted in the participant's home. Most follow-up interviews were conducted by phone as agreed upon by participants. A few additional observations were scheduled toward the end of the study, but the COVID-19 pandemic required a shift in health service delivery practices based on safety concerns for health services providers. I was unable to undertake the remaining days of observation that I had planned with NPs. These last few days were targeted to address particular questions that arose during ongoing data analysis. I was able to address many of the questions in

subsequent phone interviews. The duration of research allowed adequate sampling of NP work across the spectrum of situations that may not have been feasible over a shorter duration of time (O'Reilley, 2009). The duration of time in the field was intended to offer an interpretation of the NP role and an understanding of the setting complexities (Murphy et al., 2014).

Participant Observation

Depending on the goals of the study, researchers can undertake different levels of social involvement with their researched group. Gold (1958) characterized participation levels that researchers might assume in their studies: complete participant, participant as an observer, observer as a participant, and complete observer. In this study, I adopted an observer as participant role (Gold, 1958). The observer as participant classification highlights that the researcher is not naturally a part of the research setting and has minimal involvement in that social setting. Knoblauch (2005) noted that in FE observational research, it is common for researchers to adopt observation as more of an observer than participant. Pope (2005) highlighted that it may be challenging to take on a participant role when studying specialized workers. Walshe et al. (2011) discussed that it may be less critical to be a member of the specialized group than to become trusted and accepted.

While registered as an NP, I am not a part of the consultation group and thus not part of the natural setting. The work of palliative care NPs demands a specific knowledge set related to addressing the needs of palliative patients, which I did not have. The goal of ethnographic research is to develop an emic, or insider, perspective to uncover tacit understandings of research participants (Atkinson, 2015). However, some scholars have suggested that the insider/outsider dichotomy may be artificial, with the position that the researcher assumes being on a continuum (Mercer, 2007) and dependent on the time, location, participant, and topic.

My “participation” in this study did not involve being able to “adopt a way of life” (Atkinson, 2015, p. 35) but rather assuming an active role in inquiry and engagement in what was happening. My participation involved my consciousness and perceptions of making sense of what was going on by observing, trying to see from the participants’ perspective when interpreting their world (Atkinson, 2015). I assumed an observer role, much like that of a student learning from a preceptor in a clinical rotation. Occasionally, I would help with minor tasks, like patient positioning and helping the NP to carry items. The NPs infrequently sought my advice, as they had excellent knowledge of palliative care issues, and I do not have expertise in this area. Occasionally, NPs would ask for my opinion regarding the management of primary care issues. When they asked, I had to consider how to respond and what that would mean to the situation. For example, during one visit, a patient described difficulty managing symptoms of acid reflux. The NP asked if I had any recommendations, and I shared some insights that I thought would be helpful. The NP and patient seemed to appreciate my contribution.

NPs are accustomed to having students and proved to be natural teachers. While with them, NPs would often narrate their reasoning, rationale, and deliberations out loud (when not with patients) so that I could understand their perspectives and thought processes. My participant activity as a researcher who is also an NP extended into discussions about clinical scenarios, such as what they were planning to do and how they were planning to move forward about the needs of the patient. My “insider” status as an NP allowed me to have conversations using the same “language”, mostly when I required clarification about specific terms and program elements.

PO is about more than looking at observable phenomena; it involves sensory attentiveness to a variety of actions along with actors, settings, attention to space and time,

conventions, and rules for action, with attentiveness to situational enablers and constraints (Atkinson, 2015). While I did not use a checklist or observation schedule to structure observations, I was influenced in part by Spradley's (1980) observation matrix to help to organize and orient my observations. Spradley recommends recording three major features of all social situations including actor, place and activities. Other key observational points advised by Spradley include the event, time, goal of the encounter, the act involved and the objects present (Spradley, 1980). More specifically, I recorded who requested the consultation, the purpose of the NP's involvement with the patient more broadly, the location with its physical characteristics, the nature of the visit with the patient and type of discussions, and the approach of the NPs in their interactions with patients, families, and other health care providers (nurses, physicians, care, coordinators, and specialists). I noted how and why the NPs interacted with others and the ease or difficulty of the interactions. I engaged my senses—vision, hearing, and smell—during my observations and monitored my emotional responses to situations. Observations and discussions of observations with NPs made it possible to link environmental and situational factors with what the NPs did, how they did it, and the meanings they attached to these events.

In addition to observation, I engaged in informal interviewing where I asked questions as part of informal conversations and interviews to gain a nuanced understanding of why the NPs did what they did as well as their thoughts and opinions. As suggested by Murchison (2010) in conversations, I encouraged participants to direct the conversations and to talk about topics of interest to them. This approach allowed participants to establish what was most interesting or important to them and what they thought I should know. I employed interviewing techniques recommended by DeWalt and DeWalt (2011) including requests to expand on experiences,

seeking clarification and asking naïve questions. I tried to balance allowing participants to lead with seeking opportunities to clarify understandings or explore topics more in-depth, at times making notes to revisit the issue with the participant or other participants during the following observation session. During these conversations, I encouraged participants to articulate their thoughts and clarify their motivations and meanings about situations and actions (their own and others). My observations, along with the conversations, helped me to construct a picture of NP practice and determine patterns that were emerging across the data.

The majority of my fieldwork involved PO. The following table (Table 1) details the distribution of hours and discrete observation periods with NPs.

Table 1

Distribution and Duration of Observation Periods

Summary of Observation Hours		
NP	Observation periods	Hours
Erica	9	62
Christine	18	90.5
Andrea	16	90.5
Grace	12	58.5
Nadine	11	69
Donna	7	31.5
Barbara	5	26.5
Group*	11	59
Total	89	487.5

Note. Group observations denotes primarily meetings where all NPs participated

I shadowed the NPs in their day-to-day work for 487.5 hours. My PO was conducted with each of the seven participants ranging from 90.5 hours (over 18 discrete observation periods) to 26.5 hours (over five discrete observation periods). Observation of activities and interactions within a setting provides access to events, behaviors, and contextual factors that are often taken for granted. This approach allows for linking context and activity (Ritchie & Lewis, 2003).

Observation with opportunity to discuss the situation was essential to support an in-depth understanding of NP activity in its broader context, particularly home and community care.

I shadowed the NPs in their daily routines during their regular office hours of 8:30 a.m. to 4:30 p.m. Each of the NPs took turns providing after-hours "on-call" phone consultation from 4:30 p.m. to 8:30 a.m. and on weekends, starting at 4:30 p.m. on Friday through to 8:30 a.m. on Monday. I did not shadow NP after-hours because this would have necessitated spending the night in their home; however, NPs would often offer a debrief of their on-call experience. My days often began together with the NPs in their homes, where they worked from their home offices. Our days together started with the NPs reviewing patient files; returning phone calls to nurses, physicians, specialists, and care coordinators; and completing dictations. While I occasionally met the NPs at patients' residences (private home, retirement residence, or LTC), we often drove together from the NPs' homes, which allowed us to discuss events of the previous days, review patients we had seen together, and discuss the patients we were about to see. As part of their work, NPs participated in meetings with others within and outside of their organization. Such meetings could include weekly team rounds, team administrative meetings, NP operational meetings, teaching sessions, inter-organizational presentations, and policy/procedure development meetings. When I learned about specific meetings, for example, meetings about MAiD reporting, or meetings with community stakeholders, I tried to arrange my participation.

Most of my scheduled observations were based on the NPs' availability. I often had to work around others who trained with the NPs, like medical residents, NP students, and newly hired team nurses and NPs. I tried to group observations with the same NP to help develop rapport and a sense of work style. When I initially started my observations, I learned that one NP

was leaving the team in a few weeks, so I quickly changed my schedule to shadow her as much as possible before her departure. Toward the end of my observations, I tried to work with the NPs to tailor observations to focus on specific situations, for example, when they knew they would engage in particular conversations such as MAiD.

Tacit understandings and insights from being a participant make PO a valuable method. Through informal interviewing and conversations, I built on my observations to gain a better understanding of the processes, meanings, attitudes, beliefs, and values that the NPs held. For example, when one of the NPs described that she did not know nurses in a particular geographic area, during my next observation I followed up with questions about how that influenced her work. Through this directed conversation, the NP clarified that the lack of familiarity with the nurses doing home visits would lead her to follow up on patients more closely. I was able to conclude that concerns about potential limitations in nursing knowledge and skill to detect subtle patient changes influenced NPs to schedule more frequent patient follow-up.

Field Notes

During my fieldwork, I recorded observations and interactions in a notebook that I carried with me. I assigned participants pseudonyms to ensure anonymity in my field notes. I took notes during meetings, patient visits, and one-on-one moments with the NPs without difficulty. The NPs and the NP manager knew that they could ask me to stop note-taking during specific discussions; when they did, I would promptly put down my pen and notebook for that part of the discussion. I was asked to not take notes only three times during my fieldwork. During observations, I tried to capture the sense of what was occurring by recording dialogue and conversations as close to verbatim as possible using the participant's language. My field notes described scenes, events, and associated context; meanings that participants attributed to

the event; and my understanding of the event. At the end of each day, I transcribed my field notes to include a fuller and more detailed account of what I had seen and heard. I transcribed most notes the same day, with the remainder completed the following day. As I transcribed my field notes, I tried to consider how my perspectives and attention to particular details impacted my interpretations of observations. I made memos—including insights, ideas, assumptions—to help guide future observations and interviews for further clarification or exploration.

While I tried to be as inclusive as possible in what I recorded in field notes (details regarding conversations and interactions), my values about what I felt was noteworthy ultimately influenced my role in data collection. It is also was limited to my attention span and note-taking skill. I acknowledge that as much as I tried to keep the research question in mind during my data collection and analysis, my ideas about what was noteworthy influenced what I recorded and at what level of detail. I also made methodological notes, often within field notes, that helped to orient my efforts in future observations.

Interviews

In addition to observations, informal conversations, and field notes, I conducted semi-structured interviews with each of the seven study participants. Broad topic categories, which I formulated based on analyzed observations to date, guided the interviews (see Appendix VII). I added and modified the questions based on the responses in previous informal and formal interviews. I formulated question probes to help participants to explore topics. To permit a deeper understanding, I also encouraged participants to explore topics they felt were important.

All interviews were audio-recorded. I started my initial interviews after 300 hours of observation. Initial interviews lasted between 50 minutes to 1 hour and 45 minutes. While my observations informed the interviews, the interviews then informed additional observations.

Where questions arose, I requested a second interview for further exploration. I requested second interviews from five of the seven study participants to address questions generated in other interviews and observations. Because the passage of time may have influenced participant responses, I noted when interviews and field notes were conducted and during analysis, I reflected on what had transpired since earlier conversations that may have contributed to differences in analysis.

Journal Notes

Throughout the research process, I made notes regarding my navigation of the research process. To remain aware of my feelings and ideas about the data and how these might influence my interpretation of the data, I reflected on and recorded my perceptions. For example, one interaction made me reflect on my effect on participants:

> After leaving a patient's home together with the NP driving, we were discussing some non-research-related topics. As always, my notebook was in hand with my pen at the ready for when our discussion might shift to a patient we had seen or going to see or an experience that the NP was reflecting on. Our conversations often shift spontaneously from research topics to everyday life conversations. While driving, the NP commented to me about having seen me in the past pick up my pen and start writing and how it made her feel both anxious and curious about what she said was so interesting. This comment made me reflect on how I must have an effect, even subconsciously, on my participants with their awareness that I am noting their actions and views. (Reflective Journal)

I made notes of my thoughts and feelings about what I was seeing and hearing during my data collection and to tried to become more aware of my impact on the research. Where possible, I tried to examine my own feelings and prejudices and how my personal characteristics might

influence my interpretations. I also noted my approach in the research. For example, when I started my data collection, I arranged my time with each NP so that I shadowed one NP at a time and then the next, which may have limited what I could observe. Closer to the end of the data collection process, I felt comfortable enough with each of the NPs that I could ask if there were visits in which they thought I might be interested or to ask them to identify days where they might address a particular concern for patients, such as, for example, inquiries about MAiD. I also used the journal entries to track my ideas about what I was seeing and what to further explore with participants.

Notes also helped me to reflect on situations where I felt uncomfortable, perhaps not in relation to the study participants (NPs), but regarding their patients and how I perceived the role of my presence on them. For example, in attending larger family meetings with multiple family members, the NP, often a nurse, sometimes a physician, as one of six other attendants sitting around the kitchen table, I felt I was invading something that seemed intimate, despite the family or patient welcoming me.

Rapport and Observer Effect

Rapport is identified as critical to ethnography and PO because it has implications for the researcher and participant interaction and subsequent data collection. DeWalt and DeWalt (2011) stated: “Rapport exists when both investigator and informants come to share common goals or move to develop joint goals for the research. The participants in the study must come to agree to help the investigator; however, they understand the project” (p. 53). DeWalt and DeWalt also highlighted that, depending on the topic of research, rapport facilitates discussions, for example, in instances where study topics are more sensitive and where activities might be perceived as criminal, shameful, or there is fear of exploitation. In my interactions with study participants, I

was clear about my goal to understand NPs' role enactment as palliative care consultants in this setting. This inquiry appeared to be embraced, and participants seemed to go out of their way to facilitate my participation in events that were meaningful to them. I do believe that being an NP facilitated this rapport and access, particularly by having similar educational backgrounds, despite my lack of palliative care experience. I had prior knowledge and interactions with a few participants, having met them previously at educational events and meetings.

Data Analysis/Analytic Process

It was my goal to understand how NPs engage in their work, what the regard as important and their experience in doing their work. Hammersley and Atkinson (2019) maintained that ideas help make sense of the data in the analysis, while data can also change our ideas about what we are seeing. My approach to analysis drew on recommendations for analysis in ethnographic research proposed by Murchison (2010) as well as recommendations put forward for FE (Roper & Shapira, 2000). I engaged in a process of reflecting on what I know and ideas that I have formed through my experience as an NP and in my scholarship in the analytic process. As part of this process, I alternated between immersing myself in the data by reading the data and taking breaks, allowing myself to reflect on the analysis experience to facilitate identifying and articulating patterns or themes. I engaged in writing analytic memos that contributed to shaping my understanding of the data and organizing themes. Engaging in analytic writing helped me to sort what I was seeing and determine its social importance (Geertz, 1973, p. 10).

The analytic process involved a continuous examination of the fieldnote and interview data and regular dialogue with my thesis advisors about patterns emerging in the data keeping in mind, the research question and objectives. I synthesized the interview and fieldnote data as throughout the data collection process and grouped NP activities into patterns around described

and enacted nursing values, relationships attitudes and perspectives as held by NPs about their role.

I focused on the ways NPs spoke about different elements of their role and how they experienced enacting their role and their interactions with patients, and other health care providers in the setting. I analyzed the extent to which participants' attitudes, values and behaviors seemed to be similar or different from each other and to try to account for the differences based on ongoing data collection and analysis.

Regular team meetings with my thesis advisors were integral to the analytic process and allowed us to discuss the theoretical ideas that were seen to be arising from the ongoing data analysis and synthesis and to challenge the conceptualization of those ideas in relation to how NPs enact their role in community palliative care. The writing and re-writing of the findings further assisted the analytic process helping to refine themes. The findings were organized as main themes with subthemes representing smaller related elements of broader themes.

Rigor

Ensuring rigor in research is essential as it is the mechanism through which the researcher persuades her readers that research findings are worthy of attention (Tracy, 2010). To provide some guidance on quality in qualitative research, Tracy (2010) developed criteria driven by the desire to establish an approach to evaluating the quality of qualitative research that would be applicable across paradigms. Tracy identified eight criteria that include "a) worthy topic, b) rich rigor, c) sincerity, d) credibility, e) resonance, f) significant contribution, g) ethics, and h) meaningful coherence" (p. 839).

The criterion of a worthy topic includes that the topic is "relevant, timely, significant and interesting" (Tracy, p. 840), as established in the literature review. Tracy stated that a worthy

topic of study can originate from timely societal events. In my Chapter 2, my literature review, I have established an understanding of the challenging landscape of community palliative care. Patient care is being shifted from institution to home settings and as identified in the literature review, FCGs often take on the responsibilities of caregiving and require support to navigate their caregiving role. Furthermore, the literature review has shown that the structures of community care and as a result community palliative care are often under-resourced with human resources and knowledge to address advanced symptoms. A better understanding of NPs' work experience in this setting can offer important insights about both the nature of NPs' knowledge and work and their potential to contribute to broader care systems.

In the criterion "rich rigour," Tracy (2010) highlights that an adequate time in the field and adequate data collection approach are required to support study rigour. The evaluation of time is more a question of did the amount of time allow for the gathering of enough data of interest that address the research question. My 487 hours in the field supported the development of rich descriptions in the findings. This time allowed me to foster relationships with NPs to allow more nuanced conversations to support understandings. This amount of time also allowed me to ensure that I was exposed to the broad range of situations and scenarios that NPs encounter in their day to day work, to see an average day and a non-average day and how NPs navigate their work, what they think about these situations and how they respond. Shorter times in the field characterize focused ethnographies (part-time immersion as opposed to residency for a year or more) (Knoblauch, 2005). Shorter exposure durations from those in classical ethnography can be considered because the nature of environments, geographies, and cultures is often partially known. Partial knowledge of the field can facilitate focusing (Knoblauch, 2005). Classical ethnography proponents have described the necessity for long periods in the field (often over a

year), while advocates of FE have highlighted its utility because it requires “less time”. Ultimately, the adequacy of time guided and judged by the sufficiency of the data to support a deep understanding of the phenomena under study (Murchison, 2010).

The criterion of sincerity refers to the notion that the research conducted is marked by honesty and transparency about researcher-based goals, biases and shortcomings and how these influenced the research (Tracy, 2010) I attended to Tracy’s criterion of sincerity through self-reflexivity and transparency. I aimed for sincerity through my self-reflexivity about my subjective values and biases. In Chapter 1, I introduced my background and how it has influenced my interest in this research and my point of view and in Chapter 3 I presented my assumptions about the research. For transparency, I sought to make clear the process undertaken for the research by a clear description in Chapter 3, the methods section (Tracy, 2010). Throughout the research process (conception, data collection, analysis, and writing), I tried to remain aware of my influence on participants, as well as what I was focusing on, how I was interpreting it, and what I was privileging in the data in order to remain transparent and aware of my impact on the research. I provide a detailed account related to the context, my level of participation in the study, interactions with participants, how and what I recorded in field notes, and opportunities and challenges when encountered.

Credibility refers to the “trustworthiness, verisimilitude and plausibility of the research findings” (Tracy, 2010, p. 842). I show credibility through offering a thick description in my research findings. Geertz (1973) qualified that, in the thin description, attention is given to what is being done, and thick description goes beyond thin description to further qualify what is being done regarding associated meanings. I have presented my findings such that I convey

participants' experiences of their day-to-day work, how these experiences are socially situated along with an interpretation of those experiences and their meaning to participants.

The approach of drawing on multiple data types (observation and informal and formal interviews), participation in a range of patient encounters, and examining data through multiple perspectives contributed to a particular understanding of the participants' social world. This approach aligns with Richardson's (2000) notion of crystallization. However, that understanding might differ depending on who is collecting the data and from what vantage point they are examining it. This process is likened with looking at a crystal, what is highlighted and seen can change depending on the design of qualitative research and its components, and understandings can grow, change, and alter. In the crystallization process, the author presents different points of view, resulting in "partial, situated, open-ended conclusions" (Denzin & Lincoln, 2011, p. 5). With this understanding, the goal remains not to arrive at a more valid single truth but to develop a more nuanced, albeit partial, understanding of what is occurring (Tracy, 2010). In my study, this notion of crystallization was supported by not only my own reflection and analysis, but also that of my two thesis advisors who contributed immensely by bringing their views, experiences and interpretations of the data in our regular meetings to discuss the data. Through this process, multiple angles and lenses contributed to the analysis and findings.

Tracy (2010) identified that transferability supports the criteria of resonance. Tracy defines resonance as the research's ability to meaningfully affect an audience. I sought to achieve this through constructing the composite "A Day in the Life" to convey what an actual day of NP work would entail and how the NPs navigate the responsibilities. Transferability (Tracy, 2010) refers to the notion that others who read research and its associated findings observe where they see overlap in their own situation and how it might be applicable and useful.

For example, while the context of NPs in community palliative care is specific, NPs in other specialties providing consultation may recognize the relevance of these findings to their situation. Furthermore, NPs working in different settings may also regard the findings as relevant to their work in relation to palliative care. Nurses who work in community palliative care may read the study design and identify that the research findings resonate with their experience in community palliative care.

The ethics criteria in Tracy's (2010) conceptualization of rigour include attending to both situational and procedural ethics. I will discuss procedural ethics separately in the ethical considerations section. Procedural ethics refer to the ethical standards dictated by institutional review boards. These include the elements of not doing harm, avoiding deception, negotiating informed consent and privacy and confidentiality. Situational ethics involve the particular reasoning for an action in a specific situation (Tracy, 2010). An example of situational ethics relates to the monopolization of NP time during my fieldwork. I tried to respect that the NPs had work that they needed to get done, to not take advantage of their goodwill, and let them know that they could ignore if they needed to focus on their work. I also needed to remind myself of this as it was easy to ask questions constantly. I did not want to become a burden. I also tried to balance social conversations against my research-oriented questions. Fortunately, the NPs expected and seemed to enjoy my questions, but, if we were driving and in traffic, I also tried to keep conversations light in focus to avoid posing a safety hazard.

Ethical Considerations

I refer the reader to the section on data collection which details the informed consent process. The concept of consent is related to participant's the right to privacy and involves the control over disclosure of personal information. However, in this study, privacy may not be able

to be maintained and the related principles of anonymity and confidentiality were employed. I assigned a pseudonym to each of the participants to provide anonymity of research participants. Confidentiality involves the ethical duty that is central to respecting the participants who participate in the research project. Confidentiality is sought through the safe storage of information. The list of participant names linked to pseudonyms and informed consent forms is locked away separately from the raw data, which is identifiable only by the assigned pseudonym. This list is locked in a filing cabinet in the thesis supervisor's office. The participant consent forms have been scanned and saved in an electronic password-protected file stored on a password-protected computer and the paper copies of the participants' consent forms have been destroyed by secure shredding. I saved a master list of participants and assigned pseudonyms as a password-protected file, which is stored on a password-protected computer.

I recorded the interviews on a password-protected recording device and transferred the recordings to a password-protected computer. I then transcribed the audio files using a secure transcription service. I saved the transcribed files as password-protected documents on a password-protected computer that is stored in a locked file cabinet in my home when not in use.

I will keep notebooks with my fieldnotes and transcribed notes stored in a locked file cabinet in my home. Raw data access is restricted to myself and my thesis supervisors, to ensure participant confidentiality and privacy. In future publications, I aim to protect the participants' anonymity through masking identifying characteristics and the research setting. However, because descriptions of events and quotations of participants are used, I warned participants that complete anonymity may not be possible because of the uniqueness and small scale of the setting and that recognition may occur.

I will conserve electronic and written data for a minimum of 5 years after completion of the doctoral thesis. I will store electronic data in password-protected files on a password-protected computer. I will store paper records in a locked file cabinet in the thesis advisor's office. Beyond the conservation period, I will dispose of paper data via shredding and erase electronic data permanently through secure deletion.

While NP work is the focus of this study, I also obtained verbal consent from the patients or their family to observe the NP in their homes. Before patient visits, the NPs asked patients and their families if they would agree to allow me to attend the visit with the NP. Upon entry to homes, I introduced myself as a graduate student researching NP work and confirmed that they agreed to have me attend the visit with the NP. I provided patients and families with a written study description (see Appendix X). When peripheral caregivers (family members, PSWs, or nurses) were present and closely involved with patients during the visit, I introduced myself as a student researcher with a research focus on NP work (see Appendix XI).

When I observed and listened to the NPs' telephone conversations with their NP peers and consultants, the NPs informed their colleagues regarding my presence and obtained verbal consent before continuing the conversations. When I attended NP meetings with care teams, management groups, and during education sessions, I introduced myself before the session, notifying the group of the purpose of my presence and that my focus was understanding the NP role. I informed all NP study participants of the measures I used to protect their privacy, confidentiality, and anonymity.

Chapter Summary

In this chapter, I presented my positionality and situated this qualitative research in the constructivist paradigm. I also presented the selected research methodology of FE and provided a

rationale for its suitability for research about nursing work. The use of FE offers a robust approach to investigate NP work as situated within a context I discussed the methods used in this study, including PO, formal and informal interviews, the approach to field notes, and journaling. I also presented the lens of RI as Doane and Varcoe (2021) describe it, which, while not dictating analysis, helped to support a broad view of nursing work. I then introduced the setting and discussed my approach to rigour. I concluded this section by reviewing the ethical considerations for this study. In the next four chapters (4-8), I will present my research findings. The next chapter, Chapter 4, is divided into two parts. The first part presents "A day in the Life" which characterizes typical day to day work and how NPs undertake this work. The remainder of that chapter and the chapters that follow present the findings of this study presented in four major themes.

Chapter 4: "A Day in the Life"

In the next four chapters, I present the findings of my research. In this chapter, I begin by providing a sample of how NPs experience a typical day in the section titled "a day in the life," to provide the reader with an impression of how a typical day for an NP might unfold, their characteristic approaches, and the challenges they encounter. I follow this illustration of a typical day for NPs with the four main themes of my findings: "relationships as foundational to NP work" (presented in the second part of this chapter), "having the conversation" (Chapter 5), "building capacity for palliative care" (Chapter 6), and "navigating an imperfect system and local challenges" (Chapter 7). These themes represent key NP activities and how NPs engage within this setting to enact their role. These themes can also be seen woven throughout the section on "a day in the life."

The first theme proposes that relationships are foundational to NP work, traces why they are foundational, and how NPs develop these relationships. In Chapter 5, I present the second theme, having the conversation, which represents a significant way in which NPs enact their role through conversations and, more specifically, how they approach conversations to meet the specific desires of patients with palliative care needs. Chapter 6 follows by presenting the theme of building capacity for palliative care. It focuses on how NPs see their role in building capacity and how they do this by engaging with both patients and FCGs, as well as their community colleagues, namely PCPs and CNs. In Chapter 7, my final findings chapter, I present the theme of navigating an imperfect system. This theme focuses on how NPs undertake their work while embedded in the broader social structure of health care, particularly community health care and how it is organized, resourced and administered. I highlight how the NPs drew my attention to

the problems that are associated with the realities of these structures, particularly the quality of care and how effectively they can support the quality of care.

The following discussion of "a day in the life" is a composite of my observations and interviews with NPs over 2.5 years of fieldwork. I have structured this narrative to portray a typical workday for NPs. I aim to provide a sense of the characteristic actions, patterns, and dynamics of how NPs approach the day-to-day care of patients. Through this in-depth description of an NP's typical day, I provide insights into the usual flow and commonplace patient encounters, relationships discussions, and challenges. I will highlight how each patient and encounter is inherently different from the next, requiring NPs to develop an in-depth knowledge of patients and their situations to ascertain their needs in that moment, to best care for them, and even to anticipate and prepare for future needs. I will also demonstrate how NP work is situated within a broader landscape of community care, where NPs are positioned between more constant yet possibly loosely connected care providers (i.e., physicians and nurses).

This "day in the life" begins in the morning at the NP's home office, a common starting point for my fieldwork. The NP, Margaret, does not represent any particular NP in my study but is a composite character. I introduce Margaret as she starts her day by completing the previous day's documentation. I show how Margaret then prepares for the new day by reviewing the patient information available to her. Next, I depict how Margaret approaches each of her three visits. One visit is with a new patient Margaret has never met, while the other two visits are with patients she knows. I draw attention to the notion that for NPs to provide care for their patients, they engage in an ongoing process of collecting and interpreting a broad range of information from and about patients and families to identify their needs and how they can best be addressed. I also highlight the unpredictable nature of patients' EOL trajectory and how NPs must quickly

pivot their focus to analyze and act promptly. I aim to show how NPs apply solid clinical and analytical skills, judgment, and decision-making. At the same time, I highlight how NPs engage in an approach to address the rapidly evolving needs of patients, families, and colleagues while interpreting the interplay of a range of professional, patient-related, and contextual factors. The NPs in this study recognize the interconnected nature of the lives of patients and families with their own actions and those of other care providers. Each influences the other in some way and is situated within a broader health care landscape, with strengths, limitations, and particularities that influence each of these lives.

A Day in the Life

The time is 8:30 a.m. Margaret has sent her kids off to school and her husband has left for work. It is time to begin her workday. She makes her way to her home office, sets down her coffee, and powers up her laptop. She notes she has an hour before she has to leave to see Joe, her first patient, which gives her just enough time to review his files. Joe is her only new assessment and is scheduled for 10 a.m. She also has two “follow-ups” scheduled for this afternoon. These visits are with patients she has been involved with over the past few weeks and has come to know well. She does not anticipate any difficulties as she has not heard anything from their physicians or visit nurses. She checks her email and text messages. She sees there is a request from a care coordinator to assess a patient who is having troubling symptoms. The visit nurse is worried the patient is not doing well. Margaret looks at her schedule and finds it already full for the week. She had originally set time aside tomorrow morning to catch up on her consultation notes and phone calls but proceeds to book him for tomorrow morning. Her notes will just have to wait. Thankfully, she has already met the patient and already knows a bit about

him. She had originally planned to discharge him from her roster because he appeared seemingly stable last month when she saw him.

She quickly reviews and approves yesterday's dictated notes so they can be sent to the physicians, care coordinators, and nurses. In the notes, Margaret has outlined her conversations with patients and families, including their challenges, concerns, and plans for the future. One patient is determined to stay home for their last days, but Margaret worries that this patient does not have adequate support services in their rural location. Margaret spent most of the visit with her second patient talking about his experience, recent diagnosis, and hopes for alternate therapies, as this was his current focus. Margaret plans to check in with him again in a few weeks to revisit some discussions and decisions about future planning that she has introduced for consideration. In her notes, Margaret has outlined how they are managing with all the changes, their supports, their symptoms. Margaret provides a detailed and updated list of the patient's current medications and dosages along with suggested medications and dosages for managing anticipated symptoms: nausea, pain, thrush, and constipation. In addition, Margaret also provides therapeutic options for if and when the patient becomes unable to take oral medication. She hopes this will help the patient's PCPs and nurses keep their patients moving forward comfortably.

For one patient, Margaret was able to coordinate a joint visit with the patient's physician, VN, and care coordinator. She feels confident that everyone working with this patient knows how to support them moving forward. The physician is new but has expressed interest in providing support, and Margaret knows the VN well and is confident that the VN will call if she has concerns. Margaret was not so lucky with the second patient's associated physician and VN. The physician was unable to attend a joint visit, and Margaret is still trying to connect by phone

to introduce herself. They have never worked together, and she is unsure of how this will go. The physician has indicated on the consultation that he is available for home visits and phone support, but Margaret is skeptical until she gets to know him and what that really means. Margaret had also booked her visit to coincide with that of the patient's VN, who Margaret understands visits regularly, but the VN canceled her visit. It would have been a good opportunity to meet her and get to know her. She will keep trying.

Margaret then turns to the task of preparing for today's visit. She looks at her watch. She has half an hour and decides she should be able to collect all the information she needs in that time. Her first visit is with Joe, who is 74 years old and lives in his own home with his wife. She reads that the care coordinator requested a visit from the team a few months ago. However, at that time, Joe's physician declined the need for a consultation because he planned to transfer Joe's care to the local physician palliative care group when he approached the end of his life. The VN made a second request earlier in the week when she noted Joe's condition seemed to be changing. Margaret flips through screens of information to gather details about his diagnosis, specialist visits, and his current nursing and home supports that will help her better understand his situation. She is grateful to find this information because it is often fairly limited. The information helps provide her with a basic understanding of what to expect. She searches for documentation about EOL discussions and decisions. It appears he does not want any more hospital visits. She reviews the medications he is taking, specialist discussions, and diagnostic test results to better understand what is happening. She learns Joe has advancing liver failure. Through the notes, Margaret learns that a VN sees him three times a week and drains the fluid from his abdominal drain and that Anne, Joe's daughter, has recently moved in to help. Margaret checks her watch, notes it is 10 a.m., and leaves to see her first patient, Joe.

Margaret parks in Joe's driveway and Mary, Joe's wife, greets her at the door, thanking her for coming. She escorts Margaret down the hall to Joe's room, where Anne is tidying up. Margaret finds Joe in bed and notes that he seems sleepy but responds when she introduces herself. Mary indicates over the past 2 days he has been different, sometimes sleepier and sometimes more awake and unsettled. She also reports that, at times, he claims to see things on the wall that she cannot see. Margaret becomes very focused; she knows she has to figure out what is causing Joe's apparent symptoms of delirium. She notes Joe is on a minimal dose of opioids for his abdominal pain, which Mary reports is well controlled. There has been no recent dose change. Margaret examines Joe. His abdomen feels firm and distended and she suspects, in addition to his advancing disease, his bowels may not be moving. When asked, Mary indicates that he has not had a bowel movement for 10 days. Margaret sighs. She thinks to herself, "this was so preventable." She further wonders why the VN did not notice this. She explains to Mary and Anne how a suppository might help Joe. They agree. With Anne's help, she administers a suppository. Based on her assessment, Margaret determines she needs to have a serious conversation with Anne and Mary about Joe's condition. Margaret joins Mary and Anne who are waiting at the kitchen table:

> Margaret: Mary, we can't be sure Joe's confusion will get better. There is a small chance it is from his constipation, but it is possible that this is part of his disease process and his condition may continue to decline. [Mary tears up]. Have you had discussions with Joe about how he would like to be treated? We can send him to the palliative care unit to see if his delirium will clear up, or we can adjust his medications here to see if that helps.
>
> Mary: We have talked and he doesn't want to go anywhere anymore.

Margaret [leaning in]: Mary, how you are managing with all of this. It is a lot and you look tired. I am worried it might be too much.

Mary: I knew this was coming, but it's still so hard. I don't know what I'd do if Anne wasn't here.

Margaret: I understand Anne is a great help, but sometimes it can be overwhelming. We can find a hospice bed for Joe if needed.

Mary [tearfully]: We've been married 46 years. He's my husband. I want him to be at home with me. Anne is a great help to me. [Margaret nods. Anne looks at her, teary-eyed, and smiles back. Margaret listens to Anne's descriptions of how Joe has been a loving partner and how they made it through many of life's adversities.]

Margaret: It sounds like you and Joe have been good partners for each other. Mary, I would like to arrange for a nurse to stay overnight for the next few nights to watch over Joe and give you a break. I would also like to order a hospital bed. It will be more comfortable for Joe and make taking care of him easier. Would that be ok?

Mary: Yes. Thank you.

Margaret: If your dad doesn't settle or is more uncomfortable before the night nurse gets here tonight, you can call the visit nurse who can come and assess him. Her number is right here at the front of his chart. Don't be afraid to call. If the nurse has questions, she knows I am a just phone call away. [Margaret looks at her watch. An hour has passed since giving the suppository. She goes to check on Joe, who is now sleeping. He has passed a moderate amount of stool.] Margaret: Joe, we are going to get you all cleaned up, okay? [He continues to sleep.]

Margaret helps Anne clean Joe up. She will ensure in her notes that the VN knows to reassess this during her daily visits and administer suppositories if needed.

Margaret makes a few calls and requests the bed and extra nursing help. She then calls Joe's primary care physician and updates him about Joe's condition; she further clarifies how it is too late now to refer him to the palliative physician group given there is a 2-week wait time to be seen. Margaret further clarifies that she does not think Joe has much time left to live and that she will arrange for extra nursing support. Margaret advises Joe's physician about the medications needed to keep Joe comfortable. Joe's physician agrees to order the oral medications but states that he is not comfortable with the other emergency medications since he is not familiar enough with them. Margaret has worked with him before; he often needs more support when it comes to injectable medications. She understands his hesitancy; he really does not prescribe these medications often enough to feel comfortable. While she does not mind prescribing the medication, it can be problematic as a consultant. Margaret agrees to order the SMK and writes the specific orders for medication administration for the nurses in the patient's chart. She has now spent 3.5 hours attending to Joe. This was not what she had anticipated today. She must leave because her next patient is waiting.

It is now 1:30 p.m. Margaret starts her car and checks her messages. She receives a text from a VN with a patient update and is reassured all is well for now. Margaret wishes she had this kind of relationship with all the VNs, as she appreciates the exchanging of updates. Margaret texts back, "Thanks for the update." Margaret then listens to a voice message from a physician who is returning her call from yesterday. She calls back and is sent to voicemail yet again: she leaves another message. A glance at her watch tells her she is late for her next visit. She juggles

driving and eating a granola bar. Margaret was hoping to stop somewhere for lunch, but the granola bar will have to suffice.

The next visit is a routine check-in. The patient is Sharon. She is 73, has pulmonary fibrosis, and is bed-bound. She is on oxygen and has been stable, although she has been requiring progressively higher amounts of oxygen to breathe. She has a daily visit nurse. Margaret has been alternating home visits with Sharon's physician, who visited Sharon earlier in the week and texted Margaret that everything was fine and that they were just waiting for a hospice bed. They often text each other updates. Margaret wonders if her visit is even needed today since Sharon's condition has been stable and since she is running behind. Before arriving, she calls to see if they actually need her. Sharon's husband, Ian, answers: "Oh, thank goodness you called. She is having so much trouble today." Margaret reassures him she is on her way.

When Margaret arrives, it is 2 p.m., and she finds Sharon in the hospital bed, restless, gulping for air, and grabbing at her sheets and oxygen tubing. Sharon's eyes are as large as saucers. Margaret gets to work quickly, listening to Sharon's lungs, taking her oxygen saturation, and checking the oxygen flow. Sharon is already using the highest possible flow rate. She takes Sharon's hand and says to her, "Sharon, hang in there. I will give you something to make you feel better." Margaret scans the room for the SMK and is relieved to find it; the kit has the supplies and medication she needs. Margaret applies a device that will allow administration of medication without a syringe and administers a trial dose of midazolam 0.5 mg subcutaneously. Over the course of a few minutes, Sharon settles and is no longer writhing and grabbing. She is sleepy but mumbles in response to verbal cues. Margaret calls the care coordinator to inquire whether a VN can come this evening and if a shift nurse can spend the night. They are still waiting for a bed in hospice.

The care coordinator arranges for a VN who will arrive at approximately 7 p.m., and the shift nurse will start at 11 p.m. until the next morning. Margaret checks the medication supply. There is not enough medication to make it through the night. She will order more and have it delivered this evening. Margaret then draws up enough syringes of medication to last until the visit nurse comes at 7 p.m.

Margaret: Ian, the medication in these syringes can help Sharon if she becomes uncomfortable again. The medication will make her sleepy but you will still be able to talk to her. Is that okay with you?

Ian: Yes, yes, if it will keep her comfortable.

Margaret: If she is restless again, do you think you could take this syringe and squirt it into this plastic port?

Ian: Yes, I think so. [Margaret notes that Ian sounds hesitant even though he agrees.]

She shows Ian how to administer the medication. He agrees to administer the medication but seems tired. Margaret must leave for her next visit. She documents her findings and medication orders in the in-home chart. She worries about how Ian will handle the next few hours. She leaves, reassuring Ian that the visit nurse will arrive in a few hours. It is now 3:30 p.m. and Margaret has one last visit. Margaret starts her car and drives to her next patient. Before leaving, Margaret texts her NP colleagues for help. She asks for someone to order more medication for her last patient as she does not think she will get home in time to submit the prescription online. She wants to make sure it will be delivered tonight. Her colleagues respond, and she is grateful for the help.

Margaret's last patient is Jennifer. She has known Jennifer for a long time, and Margaret feels connected to her. Margaret will often bring Jennifer a large coffee with two creams, though

today she regrets she is empty-handed. Jennifer is 42 and has ALS that is steadily progressing. Jennifer is now confined to her bed and has use of only one weak arm and hand, which she uses to text and make calls. Jennifer lives on the top floor of a three-story walk-up building. The hallways are dirty and malodorous. There is no buzzer system, but there is a key in a lock box that Margaret uses to gain access to the building. Jennifer lives alone with her cat, who is the love of her life. While Jennifer has a father and brother who live nearby, she cannot rely on them for any assistance. Jennifer enjoys watching TV programs, and her cat is her faithful companion. Jennifer naps often, as even the smallest position changes are exhausting for her.

Jennifer does not get out of bed anymore except on the rare occasion when her linens are changed. A machine helps Jennifer breathe and she has no control over her legs, making it difficult for her to leave her bed. Because she cannot assist at all in moving her from her bed to the chair, she considered requiring a "two-person transfer," but the agencies do not generally provide that level of service. Previously, Margaret and Jennifer had talked about the future. What if there came a time when Jennifer can no longer be safely supported at home? Jennifer had not been sure. Margaret knows Jennifer likes her own space and does not feel afraid to be alone. Margaret and Jennifer have had long discussions about her fears, what to expect as time passes, and what her options are.

Margaret knocks and enters and encounters a support worker in the kitchen tidying up. Margaret introduces herself: "Hi there, I'm Margaret. I'm here to see Jennifer." She takes off her shoes and walks in. It is a small apartment and there is a hospital bed in the living room. The air is thick with the smell of cat urine. There are empty boxes everywhere. Some boxes are for the cat to play in and some look as though they are waiting to be filled. The kitchen table and chairs are piled high with books and clothes waiting to be assigned to the boxes. Jennifer smiles widely

when she sees Margaret. Margaret finds her propped up in her hospital bed with all the necessities strategically in place on her tray table: phone, remote, tissues, water, and lip balm. They talk about her cat, what she is watching on TV, and how she is managing. Jennifer explains that her weakness is advancing and how her arms are now weaker, but her shoulders and neck are still strong.

Margaret brings up how she worries about Jennifer's safety and that they need to talk about plans for the future again. Jennifer agrees and adds that she is now considering a LTC home but is reluctant because she does not want to leave her cat. Margaret proposes a program that finds homes for animals in similar situations. Jennifer takes comfort in the idea that her cat would have a good home. Margaret asks, "I understand that you asked your doctor about assisted dying. Do you want to talk about what that means?" Jennifer agrees and explains how she is terrified of suffocating to death with her disease progression. Margaret nods in understanding.

Margaret wonders if she should have presented MAiD as an option for Jennifer earlier, since she has known Jennifer awhile. In her experience, Margret usually relies on cues of how patients are responding to her questions but struggles with not wanting patients to feel like she is promoting MAiD. Margaret reflects on her experience and knows suffocating is a common fear for patients as their symptoms of ALS progress. However, Margaret worries that asking about assisted dying can also trigger fears about suffering and the feeling of being a burden. She will explore this more. Margaret thinks about how to best reassure Jennifer that she can be supported and kept comfortable and that this is not the only choice, but it is still a choice. Margaret also knows it is the only acceptable choice for some people, and others find having this preplanned option offers reassurance.

Margaret further discusses and explores concerns about the future with Jennifer. Jennifer explains how she does not want to suffocate and is anxious about that. Margaret explains how MAiD would be coordinated and what it would look like. Margaret assures Jennifer she will bring the papers early next week to start the process and to explain the required signatures and witnesses. Their conversation seems to reassure Jennifer. Margaret knows that this is an ongoing conversation that will require further discussion next week. They say goodbye. Once in the car, she checks her voice messages. The care coordinator informs her that there is a hospice bed for Sharon and that she will be transferred in the morning. This is good news. The next call is from the physician she was trying to contact earlier; she will try to call back once she gets home.

It is 4:20 p.m., and Margaret walks through her front door. She starts her computer, types her notes, and texts updates to Sharon's and Jennifer's physicians. Margaret also tries to quickly review her urgent "fit in" for tomorrow. Margaret notes that she has seen him previously, a few weeks ago, and he was doing well at that time. It is now almost 5 p.m. Margaret shuts down her computer and starts to make dinner for her family. While making dinner, she finds herself preoccupied and worried about Ian and Sharron. She feels she needs to ease her mind. She is not on-call, but decides to call Ian to see how he is managing:

Ian: Oh, thank goodness you called! Sharon is really flailing around again. [Margaret pauses and motions to her husband to take over the dinner preparation.]

Margaret: Did you give her the medicine I laid out?

Ian: No, no, I completely forgot it was there. I don't know what to do.

Margaret: Do you remember how I showed you to give the medicine?

Ian: No, I don't, I am sorry. This is all too much. [Ian's voice is trembling, and he sounds panicked. Margaret's heart sinks. She reassures Ian and talks him through giving the pre-

drawn medicine using the special port. Margaret stays on the phone and reviews with Ian when she can have another dose. Sharron settles shortly after.]

Ian: Margaret, thank you so much for calling. I don't know what I would have done.

[Margaret tries to reassure Ian that the visit nurse should be there in the next hour or so. She hangs up. It has been a long day.]

A Day in the Life: What Is Really Going On

Developing an understanding of a patient's situation and circumstances is foundational to NP practice. As she begins her day, Margaret reviews her patients' charts to establish a foundational knowledge to build on. As portrayed in "a day in the life," gathering information about the patient is an important first step that involves reviewing the available information from the home-care database and multiple hospital system databases. The information reviewed includes diagnosis, prognosis, treatments, specialists, medications, diagnostic testing, and documentation from home care coordinators, where available. Additional information NPs gather includes family involvement, home care support in place, discussions to date about EOL planning, and if there are particular concerns others have highlighted that will need addressing during the visit. While helpful when documented, this information is not always available and is often limited. This information helps provide a starting point to understand the patient and family situation and to orient the NP to the nature of conversations that will be required. Reviewing the chart also reveals to NPs who has been involved with care, the caregiver's role, and which nursing and medical care resources are available to the patient and family.

In Margaret's first visit, we start to see how NPs apply their clinical and diagnostic reasoning once Margaret detects that Joe's condition is changing. She quickly sets out to collect the information required to try and determine whether an EOL delirium, exacerbated by

constipation, or his opioid medications are causing his symptoms. Noting Mary's fatigue, Margaret checks in with Mary and Anne to reassess how they want Joe to be treated (she confirms that they do not want a transfer to a hospital or active intervention beyond the suppository and agree to reducing the opioid dose). Margaret determines, despite her concerns about their fatigue, that they still feel they can support Joe at home. Margaret recognizes that Mary's obligation to Joe is shaping her decision to keep him at home. Anne's supportive relationship with Mary and Joe, along with her willingness to administer medications, is contributing to the feasibility of supporting Joe's preference to remain home. Additionally, there are apparent manifestations of some system-level cracks in how the VN did not monitor or attend to Joe's lack of bowel movements, possibly precipitating this delirium. While unclear, it is possible that Joe did not want to take anything for his constipation, that the VN did not recognize this as important, or that the VN did not perceive he or she had enough time to attend to this and other tasks. Furthermore, Joe's physician, while well-meaning in intending a transfer of Joe's care to a palliative care group, did not do so in time. This oversight also speaks to the nature of patients who require palliative care, many of whom are often seemingly stable until they are not and begin to rapidly decline. It is also evident the NP prescribes the injectable symptom management medications the physician is unfamiliar with to extend the physician's capacity to remain involved.

In Margaret's second visit, I illustrate how, despite fairly regular visits, situations can rapidly evolve and become stressful for families who witness the suffering of their loved ones. Again, we see Margaret employ strong clinical skills to ascertain Sharon's condition and treat her with medication that relieves her symptoms temporarily. Margaret also recognizes the system limitations, as Joan is still awaiting a hospice bed after a week. While families may desire a

hospice option, a hospice bed is not always available when patients are ready. With her knowledge of the system, Margaret is also able to mobilize additional support for Joan and Ian in the form of overnight nursing and an extra visit. Nevertheless, Sharon continued to struggle with dyspnea—a terrible experience for Ian to witness. Margaret also perceives a moral obligation to check on Ian despite not being on-call, disrupting her own family dinner.

During her last visit, I portrayed the special relationship Margaret had developed with her patient, Jennifer. During her time with Jennifer, the way the home care system is resourced and organized became apparent. Because of her loss of strength and bodily control, Jennifer is now required to have two people help transfer her, which is not a service the home care agency has funded or provided. This lack of resources prevents her from staying home for EOL. Margaret and Jennifer have had many conversations over the past few months about her plans as her symptoms progress, and she has considered moving to a LTC home. During her visit, Margaret identifies one concern holding Jennifer back—her worry about what will happen to her cat if she moves into LTC. Margaret offers to connect her with an adoption agency, which provides Jennifer with some reassurance and enables her to think more about the future. Margaret also addresses Jennifer's questions about assisted dying. At the same time, she wants to make sure Jennifer knows that her care providers can keep her comfortable at the end of her life despite her fears. While Margaret knows from experience that she can keep Jennifer comfortable, she also recognizes Jennifer is terrified of suffocating as her disease progresses, thus influencing her decision to consider assisted dying.

Through an established collegial relationship, this "day in the life" also demonstrates that quick, impromptu communications from a VN offers Margaret some peace of mind about a

patient she would otherwise have been worried about. Margaret's expressed appreciation and reciprocal communication fosters the ongoing relationship with the VN.

The "day-in-the-life" portrayal provides a broad overview of what a typical day may look like and gives some sense of the nature of NP work. I will now turn my attention to my specific findings regarding the NPs' approach to care. The remainder of my findings are organized according to the four main themes of how NPs engage in their nursing work: relationships as foundational for NP work, having the conversation, building capacity for caregiving, and navigating an imperfect system. Each of these main themes is further broken down into subthemes that provide further detail and insight about how NPs enact their role.

Relationships as Foundational for NP Work

The first theme I will discuss as part of my findings is that of the centrality of the patient relationship to NP work. In this study, the NPs considered the relationship with their patient as both a way of understanding their needs and as directing how they provided their care. This theme is further subdivided by the subtheme of building trust, as this was how NPs approached building relationships.

In their day-to-day work, I observed how NPs viewed the importance of developing a breadth and depth of understanding of their patients, and how this was fundamentally tied to engaging in and building relationships with them. Developing this understanding was considered essential in shaping how they responded to meet their patients' needs. To be able to do this, the first critical step for the NPs in this study was to learn as much as possible about patients and their situations even before meeting them, which required searching out, piecing together, and interpreting information from a broad range of sources. This work served to lay a foundational and preliminary understanding of the patient. I observed how NPs in this study considered the

perspectives and experiences of patients and families, as well as others involved in patient care. Furthermore, NPs regarded this undertaking as an ongoing process, subject to reinterpretation as new events or changes reshape previous understandings. As part of this broader process, a commonly valued starting point was the review of available, documented patient information. Even at this preliminary step, NPs in this study were seen to begin to form relationships with their patients through what had been recorded about them. This first step, while providing only a partial snapshot of the patient situation, was considered important in facilitating an introduction and sound foundation for the NP to understand the patient's situation moving forward. Furthermore, in many instances, the available information was limited or absent, restricting the NPs' access to knowledge about the patients before meeting them.

When available, NPs in this study were seen to draw on knowledge acquired from previous documentation to start conversations that facilitated the exploration of and comparison between perspectives of "what was going on." For example, NPs would start a conversation with "I see you had a visit with your respirologist. How did that go?" or, "the visit nurse mentioned you were talking about 'wanting the needle.' Can we talk about what this means for you?" The initial visit with the patient was where I observed NPs trying to make sense of all they had learned so far about the patient and to measure it against the patient's views and concerns. In her interview, Grace explained her view of the centrality of her relationships with patients to both understand them and as a meaningful way to work. Grace reported that, while developing a relationship begins with the first visit, subsequent visits contribute to a better understanding:

> I also think the first visit is so involved with so many questions that you don't really get a chance to develop a therapeutic relationship with the patient, and that's part of my goal, too, as a nurse practitioner. So, I really kind of understand (whether I agree or not, it has

> no consequences) what is important to them and their family. So, by going back and visiting, I get to learn that. It also gives me some personal satisfaction in that you develop a relationship with these families, and that you care for them, and that's part of the job satisfaction.

For NPs in this study, relationships were instrumental to understanding patients' perspectives and are more deeply developed over time and a source of work satisfaction. However, as illustrated in the "day in the life," on occasion a patient's condition may be rapidly changing, redirecting the pace and priorities of the visit.

Building Trust: "What Else Are You Worried About?"

For the NPs in this study, building trust with patients was integral to their relationships. One afternoon, while the NPs were waiting for a meeting to start, I explored how they were able to develop trusting relationships in the short amount of time they have with the patient. In response to this question, Grace answered, "Because we take our time. We talk about intimate topics. We answer their questions." Nadine added, "We talk about very intimate parts of their lives. We don't pass the buck." I saw these approaches enacted while shadowing the NPs in my fieldwork. I saw how patients who were worried and feeling like they were missing information or seeking clarity turned to NPs for answers and explanations. On occasions where the NPs did not have answers, they promised to return to patients with answers. I saw how the NPs also followed up with patients with the answers they promised. I saw the NPs jump into action right in front of patients, making calls to specialists and pharmacies to clarify patient questions about treatments and next steps. I listened as the NPs asked patients about a broad range of personal health and social questions. During an interview with Donna, I explored how she develops a

trusting relationship with her patients. Donna identified giving patients the time they need and responding to their inquiries honestly as a core part of her approach:

> Never rushed. If they have something to say, as long as it takes for them to communicate their message, or don't lie. If they want to talk about death, then I'll talk about it if they want to know what it is going to look like. As much as I can, I let them know. I put the patient first. (Interview)

In my fieldwork, I observed how NPs in this study engaged with patients and families, offered their seemingly undivided attention, listened attentively, and responded to and further explored their concerns. Visits with the NPs never felt rushed, and it was evident that the patients' and families' concerns were the focus of the visit. The NPs aimed to engender trust, facilitate a relationship with their patients, understand what the patients were thinking and feeling, and learn what they perceived as important. The NPs viewed these activities as central to providing good care. This process often took the appearance of informal conversations, highly directed by patient priorities and concerns. The NPs commonly started these conversations by encouraging the patients and families to share their health stories and personal experiences, in order to explore their perceptions.

Depending on the patients, the NPs would be more or less directive in how they learned about the patients' concerns. For example, during a visit to assess a patient who had recently been admitted to a nursing home, I watched how Erica conversed with the patient to explore their worries, hopes, and goals. Erica asked, "What else are you worried about?" The patient responded, "I want to keep my strength! My legs are getting weak." Erica then asked, "And how are you managing with that?" The patient answered, "I take 1 day at a time." Finally, Erica asked, "What do you hope for?" The patient responded, "Living long enough to see my

granddaughter get married and have my first great-grandchild." Through this exchange, the NP established a foundational understanding and set the stage for a broader conversation with the patient. Erica created a space for the patient to share what matters most to her. By the end of the 2-hour visit, Erica understood that, despite the patient's concerns about her physical weakness, she was most concerned about connecting with her sister about an important appointment. The patient had recently moved to the LTC home and did not have access to a phone. Erica assured her that she would call her sister for her and ask her to call the nursing desk and to speak with her. While directed questions were needed for less interactive patients, the NPs used a less structured approach for more social and verbal patients to make space for them to share and to allow them to focus on their specific concerns. For example, in response to my question about how she advanced conversations with patients, Grace shared, "I leave it as an open question. Do you have any questions about the future of your care?"

During follow-up visits where there were no apparent urgent concerns, I noticed how patients greeted the NPs warmly, as though their visit was highly anticipated and welcomed. Visits began with a convivial nature that shifted to discussions regarding personal and clinical concerns when the NPs encouraged them. When urgent concerns were present, the NPs, patients, and their families quickly and easily transitioned to discussing the concern at hand. In their visits with patients, I observed how the NPs in this study worked to reduce anxiety levels and put their patients at ease. The NPs used relaxed body language and an unhurried cadence in their conversations. They carried out their interviews with patients at kitchen tables, living rooms, and bedrooms. Unless there was concern about rapid decline or uncontrolled symptoms, discussions were casual yet directed. Their body language was relaxed, and physical assessments were unhurried. Their demeanor was calm, and the NPs appeared attentive to the patients' stories as

they listened to their life histories and journeys with their illness and treatments and were responsive to their specific concerns.

I often noted how patient and family anxiety levels and worry that seemed high at the beginning of visits decreased by the end of the visits. Formal exchanges of information at the beginning of visits often later evolved into informal, jovial conversations. Patients and families often thanked the NP and expressed their wish for the NP's continued involvement in their care to display their connection and trust. For example, during one home visit, I observed how Nadine engaged with a patient and the patient's daughter. The patient's daughter was upset because she felt that physicians were not answering her questions or addressing her mother's symptoms. During the home visit, Nadine explored the trajectory of the family's experience, discussed the specific concerns and symptoms, and offered to arrange for emergency medications, which seemed to reassure the family and reduce stress levels. Nadine stated, "Sometimes when we plan ahead, it helps people. At this point, I looked at the daughter. She appeared highly relieved. Her voice was less pressured and her posture relaxed. The NP's response seemed to ease her anxiety. The patient's daughter remarked in response, 'Excellent! I like that. I am a planner.' The patient responded, 'Thank you so much.' The daughter added, 'We are finally getting some answers. We have the right team now!'"

During their conversations with patients, the NPs tried to establish an understanding of what was most important to them. For example, Christine visited a patient whom she had come to know well over the previous months. The patient had a steadily growing neck tumor that was causing pain and limiting his ability to swallow. Christine learned that, while her patient relied on feeding through a stomach tube, he still found cooking for others pleasurable and an important part of his life. Having a good understanding of how his disease would likely progress,

the patient had requested to arrange for MAiD for when his situation became intolerable. Christine explored with the patient what he valued and what he considered unacceptable:

> The patient stated, “I don’t want to die in hospital or call 911 and be admitted and under their control and can’t get out or be a vegetable in bed for a year or in severe pain.” Christine then asked, “What if we reached a point where treatment meant that you would be constantly groggy?” The patient responded, “No, that would trigger my decision if I couldn’t be alert or do things for myself.” Christine further inquired, “How is your family doing with this?” The patient answered, “I told them this week. They were crying. They understand.” Christine then asked him, “Have you thought about what it would be like?” The patient answered, “Yes. In the bedroom, with the kids in the house, but not in the bedroom.”

It is through intimate conversations like this one that the NPs in this study aimed to build trust and in-turn develop a deeper understanding of what is important to patients, what they value, and how they see the end of their life supported. Understanding the patient’s perspective helps NPs more effectively support them.

In my fieldwork, I noted the importance the NPs ascribed to developing trusting relationships in their day-to-day work. These elements were evident in how they talked about and interacted with the patients. While the NPs in this study valued the individual relationships, they also viewed themselves and the patient as situated within a broader network of relationships, worked to foster patient trust with this broader network, and located their position in it depending on other established relationships. Grace described her perspective during an interview:

> I want them to feel that they have a team. And I always say that we are forming a team: the nurse, the care coordinator, your PCP, the occupational therapist, and your (medical) specialist. We're a team to support you and the community so that you are safe and you know that you're supported. And whether it's me or someone else that supports you—whatever, whoever has the best relationship—and that's what's important to me… I don't want to be everything for someone. That's too much responsibility. But I don't want to be so distant because I think that it's therapeutic relationships that bring benefits to the patients and their families. It also brings benefit and satisfaction to myself.

Grace's description is characteristic of how the NPs in this study viewed themselves as not only in relationship with the patient, but also with a broader team (e.g., nurses, physician, and family). For example, when the NPs in this study sensed that patients had a well-developed, intimate, and trusting relationship with their nurse or physician, they assumed more of a supporting role. Further, the NPs recognized these relationships as enacted in a broader health care context, with local strengths and limitations. The NPs in this study identified that they might be more or less involved with patients depending on what their needs were and who else was involved and the practice patterns of those involved. For example, the NPs in this study tended to be less involved when either physicians or VNs were meeting patient needs and more involved or vigilant if the NPs perceived unmet needs. In my fieldwork, I saw how the NPs situated themselves in relation to the broader team and modified their involvement based on the needs of the patient and who else was involved in the patient's care.

When describing the patients and families we would be seeing that day, the NPs in my study were able to paint a detailed picture of the patient, portraying them not just as someone with a specific diagnosis and uncontrolled symptoms but someone situated within a family and

with a history. Some participants also referred to patients with whom they had developed a relationship as someone they might consider a friend if they were not a patient. For example, Christine ended a visit with one patient. They said goodbye at the door. There was an ease and familiarity between them. When we got into Christine's car, she looked at me and said, "You know when you meet someone, and you think under other circumstances 'I could be friends with that person?' That's how I feel about this patient."

While feeling that having a connection was valued, this was not always positive but still important. At times, the NPs described working with patients with whom the relationship was a bit tenuous. While making a personal connection in these circumstances may have been more challenging, developing an understanding of patients and the way they responded was still as important. For example, Nadine explained how she was following up with a patient who was usually antagonistic toward her throughout her visits. During a team meeting, she described how his change of demeanor toward her caught her attention and suggested that there was a problem and that his condition was declining. Nadine stated, "When I went to see him, and he didn't tell me immediately to 'f… off', I knew something was wrong." While not all relationships are positive or generate feelings of closeness, the NPs still searched to understand the patient's perspectives and patterns. The NPs relied equally on altered patterns to offer cues that something might be wrong or require closer examination.

Chapter Summary

In this chapter, I introduced the reader to a typical "day in the life" of NP work to provide a sense of how their days are structured, the kinds of situations they help patients navigate, and the challenges they encounter. I also presented the first theme of my findings, relationships as

foundational to NP work. In Chapter 5, I present the second theme of my findings, having the conversation.

Chapter 5: Having the Conversation

As illustrated in "a day of the life," a significant part of the NPs' role in this study is enacted through conversation. Conversations were central to how the NPs in this study enacted their roles. The NPs in this study relied on conversations with and about patients to learn about patients and their concerns, challenges, and wishes. The NPs in this study used conversations as the primary way by which to provide support. In "a day in the life," Margaret engaged in conversations with patients and families across all three visits. In her first visit with Joe, Mary, and Anne, Margaret developed an understanding of Joe's condition and the family's ongoing desire to keep Joe at home through conversation. In her visit with Sharon, Margaret tried to understand Ian's comfort with Sharon's sedation and whether he felt he could take on the burden of the medication administration until the VN arrived. With Jennifer, the conversation picked up where it left off with planning for the future of care and discussing the desire for MAiD but also understanding how Jennifer's worry about her cat was central to her concerns.

The NPs in this study used conversations to establish values, wishes, and desires for EOL care, and while some patients found this comforting and reassuring, others found it anxiety-provoking. Here in Chapter 5, I present findings related to the theme of "having the conversation" and what that means to NPs and their work. This theme is further organized into five subthemes that each provide further nuance to how the NPs undertake this work. The subthemes include: navigating readiness for conversations, conversational skills as learned, initiating and building on previous conversations, clarifying resources and realities, and conversations about MAiD.

Navigating Readiness for Conversations: "Would You Like to Talk About the Future and What That Might Look Like?"

The NPs in this study regarded EOL planning discussions as one of the main ways they supported patients and their families. Through these conversations, the NPs helped patients and their families navigate the decisions required to support the difficult EOL transitions. This subtheme shows how the NPs recognized the importance of these conversations as part of their role expectations. However, the NPs also had to navigate considerations of patient readiness to engage in such conversations and balance this readiness against other situational considerations.

While the NPs in this study expressed that these discussions were one of the important ways they supported their patients, they also believed that patient readiness was an important consideration. The NPs also perceived pursuing discussions and decisions when patients were not ready or actively resisted to risk the loss of patient trust. However, the NPs also recognized the risks of not having these discussions. These included leaving patients and families without an established and agreed upon plan, resulting in undue stress from the unknown and unwelcomed approaches to care (e.g., transfer to hospitals or CPR). The NPs in this study described assessing patient readiness as a skill that they developed over time, and one that required attention to verbal and physical cues and responses. When the NPs perceived a lack of readiness, they outlined the important topics that needed to be discussed at the next visit to allow patients time to consider the questions and be more prepared for the upcoming discussion. At times, the NPs needed to implement particular techniques to assist the conversations. The NPs sought opportunities to initiate conversations through patients' cues and often rephrased conversations in less intimidating, more meaningful ways.

For example, during an initial consultation with a patient, I observed how Nadine engaged the patient in a discussion about EOL planning. During the visit, Nadine learned that the patient had, after several months of vague symptoms and endless tests, recently been diagnosed with an abdominal tumor that was inoperable. After learning about the patient's situation and assessing her physical and psychological needs, Nadine proceeded to explore the patient's readiness to talk about the future. Nadine said to the patient, "We've talked, and I've heard you say, 'In the future when I am unable to walk…' Would you like to talk about the future and what that might look like?" The patient responded, "I think the future may look better once I heal… I am not ready, but my daughter may want to talk. It's too new for me. Right now, my focus is on healing." Nadine replied, "And that's okay. We just want you to know we are here." Based on her patient's verbal cues, Nadine interpreted a lack of readiness to discuss EOL wishes. Nadine focused on building the patient's trust by responding to her questions and providing information about resources. In the meantime, Nadine created a space to return to this discussion and instead addressed the daughter's immediate need for information. Nadine judged that the patient's physical condition was stable enough to safely postpone the discussion for a few weeks.

On my next day of fieldwork with Nadine a few weeks later, she described her follow-up visit with this patient:

> I wasn't going to discuss DNR at this visit because, during the last visit, she was not wanting to discuss it. She did not want to know her prognosis. The patient shared that, when she saw the surgeon, he advised her to do her advanced care planning. During the visit, the patient said to me, "Advanced care planning, what is that?" This was the chance, so I jumped in, and we had the full conversation. (Fieldnote)

In this fieldnote excerpt, Nadine described how she used the patient's inquiry as an entry point to the broader discussion. Furthermore, this excerpt also illustrated how conversations are not one-time events. Conversely, conversations evolve over time and care providers benefit from building on previous discussions, regardless of how partial they are. Furthermore, contextually, Nadine was able to build on the specialist's brief but important reinforcement of the importance of future planning.

These previous discussions were important in facilitating patient readiness. In my discussions with the NPs, they often expressed the need to navigate patient readiness. Some patients engage in EOL discussions about future planning with ease, while others become upset and are reluctant to talk about anything related to the future and planning. The NPs in this study used strategies to navigate readiness, like looking for cues that opened the doors to conversations, as Nadine demonstrated in the example above. Other strategies used by the NPs included reframing discussions to be less intimidating and more meaningful for patients. For example, Grace described how one patient was initially distressed by the idea of talking about the future and how reframing the questions facilitated the discussion:

> She said, "I don't want to think about that." So instead, I just kind of eased into, "Well, you know, we're hoping that you will continue this way. But I worry that if something happens and things change more quickly than we expect, maybe we should have a conversation now as to what we should do instead of waiting until then when it's a crisis. Then everybody gets distressed," and she's like, "Oh." And then I just carry on: "And then so, if per chance, let's say you were here and you were too weak to get out of bed. What would be important to you?" And then we carried on. Now if she has a strong "No, I don't want to talk about this" response, then I've got a second "no" and then I stop. But

> she didn't. And then, usually, during these sometimes-difficult conversations, I see the body language, and if it is indicating that they're having increased stress and distress related to the conversation, then I will veer off the conversation and I'll talk about that beautiful picture of their daughter and that their dog is so cute. And that relaxes them. You see their shoulders drop; you see the change in their face and relax. And then I kind of slip in just a couple more little, tiny questions but not too much… so as to not overwhelm them, and then they are able to come back to it. (Fieldnote)

The NPs in this study highlighted how their approaches to conversations about EOL care were dependent on how patients responded to the discussion topics. The NPs then tailored their speech accordingly "so as to not overwhelm them." The NPs viewed translating important discussions into meaningful and easily manageable portions as an important skill. Often, the idea of the conversation was more overwhelming to patients than the smaller, individual pieces of the conversation. The NPs often tried to translate to the patients what would be at stake for their loved ones, such as the stress or strain on their loved ones or the last-minute panic, which contextualized the importance of those conversations and decisions.

Conversational Skills as Learned: "I Used to be Very Gung-Ho in the Beginning When I Started in this Role"

This subtheme revolves around the notion that conversations about EOL planning are more than the task of having the conversation, but also how NPs learn the importance and skill of timing. While expecting to address certain issues in their visits, I observed how the NPs discussed EOL wishes in a manner that appeared conversational, casual, and natural. However, the NPs also described their approach as a learned skill. Barbara, who had been on the team for only a few months, indicated how building rapport is essential but challenging: "It's not easy to

talk about goals of care when you first meet people. It's easier after a few weeks. I am still trying to sort it all out." Christine also identified the judgments and approach to these discussions as a skill learned with experience:

> I used to be very gung-ho in the beginning when I started in this role. And I used to feel I had to talk about CPR and code status at every face-to-face visit because I'm an expert, and that's my job. I used to always feel I had to do it. And then I got feedback from our 360-review process. And one piece of feedback that I got from a visiting nurse who I asked to be one of my 360 reviewers was that some of the patients felt that I had the conversation with them too soon. And so, after I had that feedback, I talked to Andrea [an NP], and I was saying, "You know, do you talk about it at your first assessment every time?" And she said, "Absolutely not. And for many patients, I don't talk about it. We need to build a relationship." (Interview)

Christine described reflecting on how she valued the opinion of a peer to help gain insight into how patients perceived her actions. She initially prioritized the expectations of her role because of her perceived obligations (i.e., having "the conversation" on the first visit at all costs). In reflecting on her action and the feedback from the VN and her peers, she modified her approach to consider patient readiness along with other patient factors. However, the NPs quickly engaged in these conversations when patient conditions were rapidly changing to mobilize the families paralyzed by grief and fear so that they and their loved ones could receive the appropriate care and support. The NPs in this study contended that rapport, relationship, and trust can, in many cases, be developed over the course of their initial 2-hour visit, but relationships still benefit from time and repeated encounters.

In my observations of the NPs' interactions with their patients, I noted they often used humor to develop a rapport with their patients and reduce tensions. Grace also mentioned humor as an important part of her approach to patients: "I like to lighten things up during a visit. Some people can't talk about that [EOL care]. If discussing a heavy situation, I will often joke, take a break, talk about something else, and come back. It's my technique."

Initiating and Building on Previous Conversations: "I Want to Make Sure We Have All Our Ducks in a Row"

Under this subtheme of initiating and building on conversations, I present the notion that the NPs in this study situated themselves and how they proceeded with patients in relation to conversations that needed to happen, had happened, or had possibly been avoided. In this study, I observed how the NPs initiated conversations where none had been started, built on previous conversations, and confirmed understandings about EOL wishes through conversation.

For example, during an interview, Christine outlined how she approached discussions about EOL issues. Christine's response represents how the NPs in this study generally approached EOL conversations with their patients:

> I mean, often we address code status… and then for sure preferred place of death. Initially, you try to get an understanding. First of all, you try to get an understanding of… do they understand that they are palliative is the first thing, you know. Do they seem to understand their disease is incurable? Do they understand, you know, that we're entering the end stages? Where do they think they're at in terms of their trajectory? And where do they think they're at, in terms of their prognosis? So, I start with that, try to get a feel of their understanding of their disease and where they're at in their illness trajectory. And then I just try to get an understanding of their code status, or if they've ever had

> discussions around their will, their power of attorney, or a DNR. And then if that conversation has gone well, then we often tackle the EOL planning. So, I often want to get a feel for, you know, if they reach a point where they need a significant amount of care, where do they want their care to be? And are they aware of their options, including hospice? The other thing I suppose I want to understand is, what are their goals as they move along? Like, is it important to them that they have no pain? Or is it important to them that they maintain their cognitive function right to the end? You know, kind of what's important to them as we move along. And then the other thing that sometimes I try to ascertain is, have they thought about MAiD? Are they putting up any feelers about MAiD? Are they aware it is an option for them? (Interview)

As Christine described in this excerpt, NPs generally have an overarching approach to important discussions with patients. However, in reality, other factors, like particular patient concerns, or urgent issues, like uncontrolled symptoms that prevent comfort, often shaped the timing, approach, and content of the discussions. The priorities shifted depending on the NP's interpretation of how the patient was responding and interacting. As evident in Christine's description, the conversation was influenced by both what the NP believed might be important to the patient and by the patient's response. For instance, fears or concerns patients identified generally took priority in the discussion. Approaches to discussions were highly dependent on the NP's perception of the patients' needs, the urgency of these needs, and the patient's perceptions. This excerpt also highlights how the NPs appreciate that the patients' situations and perceptions are not static but dynamic and subject to change, and thus engage in ongoing inquiry.

The NPs in this study tended to approach conversations as ongoing and within a potentially shifting landscape. The NPs tailored their conversations to the patient's situation

(e.g., their anticipated disease trajectory). Furthermore, where possible, the NPs situated these conversations as part of a broader team effort picking up where others (e.g., care coordinators, nurses, physicians, or specialists) had left off. Conversations were also adjusted in response to patient reactions in an effort to appreciate the patient's resources and develop a shared understanding of the advantages and limitations of decisions. Furthermore, Christine's example about asking patients about where they stood with MAiD demonstrates how the NPs perceive themselves as sensitized to verbal cues. Such cues are seen as important to open conversations not only about assisted dying but also fears and concerns that may contribute to patients who perceive assisted dying as the only logical option.

In this study, the NPs viewed the timing of referral as important in creating opportunity to build a relationship and trust to ease these discussions. For example, Donna explained how EOL planning is an important part of her discussions, even with patients who might be in the earlier stages of EOL care and do not require much active symptom management: "We can at least talk about wishes and the DNR or put the bug in their ear and have the discussion about where would you want to spend your last days." The NPs saw having conversations early as a way to allow the patients time for contemplation, often with an understanding that the conversation would be revisited when the NP returned. I saw how the NPs enlisted a range of approaches to explore what patients desired for their EOL care, such as asking if they had thought about the future, if they had made plans, or if they had questions about their future.

During an interview with a patient she just met, Nadine outlined questions for the patient to think about with a plan to revisit in future visits:

> Part of what would help us to understand if we know your wishes…What would you want us to do if your heart stops? Would it be okay for us to let you die naturally in your

> sleep? Where would you like to be, in a hospital or in your own bed…We can talk about this again and let this evolve. (Fieldnote)

Using her understanding of the patient's medical condition, Nadine judged there was time to revisit the discussion at a later date, but that it was also important to introduce it at this time to allow contemplation. Nadine introduced the decisions that would need to be made in the future and informed the patient that the conversation would continue. At this point, Nadine also recognized a decision might be premature and possibly unrealistic, given what she knew about the patient (i.e., the patient's knowledge, readiness, and disease process). Nadine also considered her knowledge of local resources to shape what was available for this patient. For example, in this situation, there was no local hospice in this particular rural area, but there was a hospital with palliative care beds, and this shaped how she presented options for care. Some patients had given a great deal of advanced thought to how they would manage their last days, where they wanted to be, and how they wanted to be supported. Other patients had given less thought to their EOL plans or avoided this altogether because of how painful contemplating EOL can be. It is possible these patients do not comprehend, or find it difficult to accept, the reality of their situation. In this study, the NPs viewed their discussions with patients as a process of initiating a dialogue that would require revisiting to develop ongoing understandings and plans for the future as time passed and conditions changed.

I observed how the NPs in this study not only structured the timing of the discussions but also specific language. Using their perceptions of the patient's health literacy and comfort, the NPs adjusted their approaches. For example, during a visit with an older patient who was diagnosed with prostate cancer and bone metaseries, Christine adapted her approach to determine his wishes for how he would want to be treated in the event of a cardiac arrest. Christine asked,

"Do you want chest compressions if your heart stops?" The patient responded, "I don't know if I would like that." Christine replied, "When people have cancer, if their heart stops, it is probably because of the cancer. I am going to give you some homework to talk to your friend who is your power of attorney about your wishes regarding CPR." In her discussion with the patient, she determined his health literacy was relatively basic. Christine used plain language and a direct approach to communicate what it actually means for a person's heart to stop when they have advancing cancer. In contrast, I have also seen how some of the NPs in this study engaged in an academic presentation style of resuscitation survival statistics with patients and families who responded better to a more scientific explanation.

The NPs in this study expressed that an important part of their role is facilitating the process of developing an understanding of the patient's wishes, which the NPs at times viewed as part of a broader team effort. Christine's comment exemplified this during a group meeting. She stated, "My role is to support the VN to have these difficult discussions." Nurse practitioners hope and expect the primary care physician, specialists, care coordinators, or VNs to have initiated EOL conversations. However, the NPs also recognized that this was not always possible, or that the situation might have changed and regularly tried to determine where conversations had left off and what required revisiting.

During conversations, the NPs negotiated an interplay of numerous patient factors including home and health situation, knowledge, emotion, and acceptance. In my fieldwork, I observed how the NPs made judgements about how to structure conversations based on how patients were responding, when to follow up, and how to build on previous discussions. For example, I drove with Nadine one afternoon for a follow-up visit. During the drive, she explained to me how she initially met the patient, Joan, a few weeks ago. Joan was a single

mother in her late 40s with two adult children in their mid-20s. Joan had recently been diagnosed with renal cancer after a year of unexplained symptoms and was essentially confined to a hospital bed in her living room. Joan described a desire to be cared for and die at home, and her children agreed they would support her. Her daughter, Alex, had recently moved home to assist. Despite Alex's deep resolve to take care of her mother, the rapid changes and demands of her mother's care (e.g., help with eating, bathing, toileting, and medication management) had overwhelmed her. Alex had recently gotten some of her mother's medications mixed up, causing confusion and sleepiness for Joan. This experience caused a great deal of family stress. Nadine shared with me that the VN had concerns because, to date, the family had refused outside help (from family, friends, and PSWs). Nadine also explained that, during her last visit, the family had expressed that they did not want CPR; however, they could not bring themselves to sign the forms that would formalize that decision. When we arrived at the home, the VN was sitting at the kitchen table reviewing Joan's medications. Nadine explored the symptoms, medications, side effects, supports, and revisited how the family still wanted Joan home for her EOL care. Nadine then returned to discussing CPR:

> I want to make sure we have all our ducks in a row. I don't want there to be any panic or crisis. If ever an ambulance was called, they would have to do CPR even if we know you don't want it, if the form is not signed. Would it be okay to sign the form? (Fieldnote)

In response to Nadine's question, Alex replied, "I want to do CPR until I can't do it anymore." Nadine clarified, "CPR won't help with your mom's breathing. We have medications that can help with breathing if we need them." Alex added, "I took a CPR course in high school. I know how to do it." At this point, I noted the NP sensed the daughter's resolve and nodded as she and the VN exchanged glances.

She moved on to the next discussion about the daughter's comfort with medication administration. Nadine asked, "Alex, if you need to do a medication by injection, do you think you could learn?" Alex replied, "Yeah. I am doing the Lantus now." In this interchange, Nadine noted Alex's perception of CPR as a way to take care of her mother if she were to have breathing difficulties, despite Nadine's attempts to help her understand otherwise in earlier discussions. Some families interpret the DNR as giving up, but CPR is conceptualized as an unproblematic rescue. The reality is that resuscitation success rates are poor for patients outside of hospital settings and for patients whose bodies are weakened by chronic disease and cancer. Families often do not understand that chest compressions can cause broken ribs in frail individuals. Nadine sensed the conversation was not progressing and shifted the conversation to discuss other tasks Alex would need to undertake to support Joan at home. Specifically, Nadine assessed Alex's comfort with medication administration; she recognized this might be an alternate way Alex could meaningfully enact caring for her mother. After the visit, Nadine and I reconvened in her car. In the car, Nadine turned to me and said, "Maybe part of a good death for them is doing CPR. I am just worried about the family and the trauma to the family and if the ambulance comes. I've done CPR on a dead body. It's not nice." I asked Nadine if the VN could continue to explore the desire for attempted resuscitation with the family. Nadine answered, "Yes, the VN knows and will follow up with the discussion."

During our next day together, Nadine and I discussed this visit again, and she elaborated on her view of the risks of the unsigned DNR. Specifically, she explained, "She could have a real peaceful death. I would have trouble having a service provider in the home with that expectation. It would be traumatic for them." Nadine balanced Alex's view of CPR as something she could do for her mother against her own views and experiences. Nadine reflected on her view that a

focus on CPR could adversely influence the dying experience for Joan and Alex. In addition, Nadine's own experiences of CPR (which include personally performing CPR and observing the experiences of nurses under her supervision in her previous roles as a supervisor) influenced her views. Nadine recognized an ongoing discussion was required; however, she needed to hand the discussion over to the VN who was in the home daily and better positioned to revisit the conversation as things changed.

Clarifying Resources and Realities: "…But Your Family is Going to Have to Do a Lot"

This subtheme addresses how, as part of EOL conversations, NPs strive to make what is possible at home and what can be expected from the available resources very clear. In this subtheme, the NPs balance the hopes of patients and FCGs with understanding the work involved in care and dying at home. For NPs, an important part of their EOL discussions is helping families understand the kind of support available, the limitations, and what is involved to support dying at home. Alternately, they seek to help patients understand the transitions to other more supportive care settings. For example, Grace explained:

> We do talk about the realities of dying at home. There is support. It's not 24 hours a day. There is a limit to the hours that are available. You can have overnight shift nursing. You can have visit nursing. You have the personal support workers, but your family is going to have to do a lot. And if they live by themselves, I don't even bring that up unless I know there's a family member that can take compassionate leave and come visit with them. Right. Like I ask, "Would your son or daughter be able to come and stay with you when you're not able to care for yourself?" And if they say no, well, then hospice is our next step. So, we go through all that and discuss that means. (Interview)

In her explanation of her approach to planning for EOL care, Grace outlined how she discusses EOL planning with patients and the importance of family involvement in care for patients who wish to remain in their homes.

While many patients and families express a desire to be cared for and die at home, this is often based on an incomplete or romanticized understanding of what is really involved in caring for a family member. Erica explained her experience with helping her patients and their families understand what to expect and what would be required:

> That's where it counts for patients. They all want to die at home. But when you ask them, "Well, what else?" that looks different for different people. Families say, "Yeah. I want to keep him at home as long as humanly possible." I reply, "Okay, what does that mean for you if your parents were no longer able to go to the bathroom?" Then they say, "Oh, no, no, no, we couldn't do that." So already you know that once the PPS is at 30, he has to go into hospice. So, you're planning ahead of time, and he's on a priority list. And, he's going to get offered a bed even a few times before they're even ready to take it. So, a lot of coordination of that. (Interview)

The NPs in this study recognized that not all patients had the same breadth of choices. Choices were seen as highly dependent on wishes and the resolve and hard work of family or friends, financial resources, and available community resources (e.g., VN, PSW, hospice, and in-patient palliative care). Furthermore, the NPs appreciated that patients and families reach their "readiness" for transitions to different levels of care at different times. As Erica explained, even though a patient would like to stay home "as long as possible," what that means can be different for every patient and family. Also, to plan for resources—in this example, hospice—an application may need to be submitted before families are ready to make that transition

emotionally, knowing it may take time for a bed to become available. As a result, a bed may become available before the patient and family are emotionally ready to make a move. Alternatively, the patient's situation may change rapidly (e.g., unbearable symptoms, exhausted caregivers, and insufficient home support), which may require the patient to wait for a bed to become available. In their work, the NPs use their knowledge and skill to gauge patient readiness along with their understanding of local resources to be able to facilitate timelier access. For example, they communicate with care coordinators to understand the availability of hospice beds. Aligning patient readiness with available resources can be challenging, particularly with limited available resources and the unpredictable nature of EOL experiences.

In conversations with the NPs, I learned how they worked to ensure their patients understood the possibilities and limitations of resources or the risks of their decisions. For example, Christine described working with one of her bed-bound patients who had a diagnosis of lung cancer with spinal and brain metastases. The patient was resolute to stay and die at home but lived alone. Christine learned that the patient valued her privacy and was not fearful of being alone, which influenced her desire to remain at home for EOL care. Christine assessed the resources available to her, including a son who lived nearby, two friends who took turns staying with her at night, and twice-a-day PSW visits. Christine also knew the patient's physician did not do home visits. Christine described how the patient encountered some challenges with her medications, highlighting how she perceived the patient's vulnerability: "She had a full delirium last week and she did not tell anyone. I pulled back on her opioids, and her delirium lifted." Christine helped the patient better understand the risks of being alone, such as the risk of falling or having trouble with her medication infusion that could result in unnecessary pain and suffering. With this information, the patient agreed to hire private nursing help so she could

remain safely at home. After describing this situation to her colleagues in a team meeting, Christine commented, “I am just worried about her. She is on her own.” While NPs aim to help patients achieve an EOL experience that is consistent with their values and choices, they also struggle when they perceive patients are making choices that put them at risk of what they view as unnecessary pain and suffering.

The NPs in this study engaged in situations that were constantly evolving and, in repose, they continuously reassessed how their families were managing, evaluated if the available supports were sufficient to meet their needs, and reassured them of available options (or the lack thereof). Through ongoing conversations about coping, exploring caregiver fatigue, and formulating back-up plans, the NPs helped families reassess their own situation to support them.

For example, during the visit with Joan and Alex discussed earlier, I observed how Nadine revisited plans with Joan and learned that Alex had moved home to be Joan’s primary caregiver. To date, Joan had not allowed any outside help in the home (i.e., PSWs) despite others having offered this help. Nadine knew from her previous visits that this was a tremendous responsibility for Alex to assume and could be more than she could manage:

> Joan was in the hospital bed in her living room. She was very sleepy, and her responses were slow and brief because of her breathlessness. All the questions easily tired her. Alex sat on the floor with her legs curled up. Despite being in her mid-20s, Alex appeared childlike, and her responses were brief. Nadine followed up with Joan and Alex about plans moving forward because she must ensure staying at home for EOL care was still what everyone wanted. Nadine asked Joan, “Joan, what’s the plan for the future, do you still want to stay at home?” Joan responded, “Mmhmm.” Nadine asked Alex if that was okay, and Alex agreed. Nadine then asked, “Alex, do you get out?” Alex confirmed that

> she did. Nadine asked her, "Do you need someone to come and give you a break?" Alex confirmed she did. Nadine asked Joan if this was okay with her. Joan responded it was. Then, the VN turned to Joan and remarked, "It's a bit of a different conversation from last time when you gave Alex the hairy eyeball when we talked about help." They all laughed. (Fieldnote)

The exchange in this excerpt illustrated how NPs at times have to navigate the realities of EOL situations. Often, patients have very little energy or their medications may make them feel sedated; therefore, fulsome conversations are impossible. Joan was unable to answer in full sentences. Alex's youth also became apparent in her brief responses. While a seemingly unimpressive interchange, it created opportunities to voice commitment or concerns and established some important understandings. First and most importantly, Nadine had given Alex and Joan an opportunity to revisit commitments to care at home. These were questions posed previously that needed to be reaffirmed, as things were rapidly changing for Joan. Nadine revisited previous decisions and learned that Joan had recently agreed to accept PSW help in the home. Joan added that her son would be staying with her during the day. Nadine also learned that Alex was receiving emotional support from a fellow parishioner who had recently lost a family member, which she found helpful.

This situation had evolved over weeks as the family was adjusting to new realities. Nadine used this information to determine that the family was managing well and seemed to have adequate support for now, despite the challenges. The check-in was important, given the often rapidly-evolving nature of palliative care for patients who require a recalibration of understanding and acceptable solutions. Families may be coping fine one day and then quickly become overwhelmed with escalating symptoms, emotions, or responsibilities. Conversely,

struggling families can find new strength in their personal resolve and from external supports. This revisiting of discussions and decisions helped NPs re-evaluate established and anticipated points of tension. The NPs worked with families to formulate alternate plans or simply reassure them so they felt supported. Without the opportunity to do these check-ins, there is a risk patients and families will unnecessarily struggle to manage on their own without opportunities to explore feasible solutions, like respite, volunteer help, symptom management, or hospice help.

I observed how the NPs in this study worked to help families understand the different forms of help, like PSWs, VN visits, or adaptive equipment, and how these resources could support their capacity to care for their loved ones at home. One challenge NPs experienced was families who were not always eager for external help. The reasons for hesitancy might include a fear of losing privacy, the need to change their routines, or the inability to appreciate the possible benefit. Equipment like hospital beds or commodes might symbolize decline, despite their potential to improve quality of life and safety. As a result, patients and families who are not emotionally ready to accept death might refuse the help that can potentially improve their experience.

For example, Andrea described a situation where an exhausted wife and her daughter were reluctant to accept a shift nurse overnight to help monitor her rapidly declining husband. Andrea recalled how they felt uncomfortable with the idea of a “stranger” in their house overnight and initially refused the help. She explained that when she called the family back the next day to reassess how they were managing, they reconsidered and accepted the nursing support for overnight care. They were happy with the help and relieved to get some rest. She further elaborated on her experience with patient and family access to services: “In the city, it is not a matter of a lack of access to services but getting used to the idea of allowing services to

happen." Introducing services requires the intrusion of people, equipment, and changes to routines. Families are under immense strain and experience all sorts of disruption, causing them to become protective of their intimate home spaces. In this study, NPs engaged in conversations to help them understand how such disruptions had the potential benefits for families. Furthermore, the NPs recognized that some people needed more time to process the change and adjust to the new realities.

I also observed how the NPs gauged what patients and family members wanted, to better understand their situation. I watched and listened to how Erica worked with an elderly couple in which the husband was dying from cancer. Erica discerned that each spouse had differing desires and a need to know what to expect at the EOL, and she used that understanding to shape her approach. We sat at the kitchen table with the wife while her husband was in the bedroom. Erica and the wife discussed the experience of the illness and diagnosis, how they were managing, and their family supports. Erica asked the wife, "Are you wondering what to expect?" She replied, "Yes, I am, I would like to know." Erica responded to the wife's many questions about how long she thought the husband had and his appetite and energy. Erica explained the patient's diagnosis and how things would possibly evolve, along with what symptoms to expect and how to most effectively manage the symptoms, including his appetite and energy. The wife listened attentively and interjected with additional questions. The wife was wondering about hospice and how to arrange for that when the time came. Erica explained this. The wife thanked her and appeared content with the information. Erica concluded the discussion with the wife, and we transitioned to the bedroom, where she found the patient. He was dressed but lying in bed. He was smiling and alert. Erica introduced herself and explained the purpose of her visit. Erica said to the patient, "Some people want to know what to expect." The patient responded, "I don't

really want to know how long I have." Erica replied, "Okay, I respect that." In this situation, Erica recognized the different knowledge needs and preferences and sought to meet each of these needs.

Christine took on a similar task assessing the EOL wishes of her patient, whom she met for the first time during the following exchange, and tried to develop an understanding of his situation. Christine asked the patient, "What did they tell you?" The patient replied, "I'm going to die." Christine asked, "How do you feel about it?" The patient said, "What can you do? I don't want to be resuscitated." Christine then asked, "Where do you want your last few days to be?" The patient answered, "Right here." Throughout the visit, I observed how Christine worked to learn about the patient's situation, daily routines, family involvement, and support, as well as how he was managing symptoms and medications and the practical planning for EOL. Through dialogue with the patient, Christine was able to develop a deeper understanding of the patient's current and future needs and formulate a shared plan with the patient, his physician, and the care coordinator who attended the visit with her. On another occasion, I observed how Christine addressed her patient's questions about what to expect as her condition declined. Christine asked this patient, "Is there anything you are afraid of?" The patient replied, "No, not afraid. I am just not sure what to expect." Christine then explained to the patient how she would slowly experience reduced appetite, lowered energy, would spend more time in bed, and would sleep more. The patient responded in a reassured manner, "That's good to know."

Conversations About MAiD: "Are You Talking About Medical Assistance in Dying?"

As part of EOL conversations with patients, NPs address questions and fears about the last days, which can also include discussions about MAiD. This subtheme presents how NPs navigate those conversations. As presented in Chapter 2, NPs in Canada have legislated authority

to assess patient eligibility for MAiD and to administer MAiD. In this setting, because of their consultant role and because other resources were generally available to patients, the NPs did not administer MAiD; however, they often engaged in conversations about MAiD and assessed patient eligibility. The NPs in this study expressed a common belief that access to assisted dying was a patient's right, but they also recognized that such inquiries are sometimes based on fears of suffering or being a burden and prioritized these discussions along with discussions about MAiD. The NPs felt that they played a role in helping patients understand how they could be supported with good symptom management. At times, the NPs addressed family questions about where MAiD fit in the overall EOL care plan. For example, after assessing a patient, a patient's daughter, who was concerned about what would happen if her father was suffering, approached Grace to understand where assisted dying fit in. Specifically, the daughter of this patient took Grace aside and asked her, "What happens if he is declining? We don't want him to suffer. What about MAiD?" Grace explained MAiD to the daughter. She noted the daughter's concern about suffering. Grace explained pain control and how she felt confident that, with medications, they could effectively address a broad range of symptoms at the EOL. Grace tried to reassure the daughter: "Our goal is to prevent suffering."

In this interchange, a well-meaning daughter who was worried about her father's potential uncontrolled symptoms at the end of his life sought to understand how assisted dying fit into her father's care. Grace reflected back on her visit with the patient and noted she did not sense the patient was at all interested in prematurely ending his life. Based on her knowledge of the patient's condition and her experience, Grace was confident he could be kept comfortable. Months later, I further explored how the NPs determined if patients wanted to discuss assisted dying during an interview with Grace. Grace explained:

> People sometimes often dance around it and I will finally say are you talking about medical assistance in dying? And if they say yes, then we will proceed. If they say no, I will say, "Okay, that's fine." I usually say, "How do you see the future?" and if they've thought about MAiD, they bring that up pretty quickly.

The NPs addressed patient questions directly if asked or if they learned that patients had been asking questions from care coordinators, physicians, or VNs. The NPs seemed sensitized to patients' expressions of distress and responded to patient cues by confirming whether they were referring to assisted dying or something else. If patients indicated that they wanted to know more, the NPs provided information. The NPs highlighted how they reassured patients that they would continue to receive care and management of symptoms regardless of their EOL choices. This response was related to sensitivity about patients' possible concerns of being abandoned if they chose MAiD.

While the NPs mostly described being sensitive to patient cues about assisted dying, contemporary medical discourses have suggested that patients should be informed about it early in their EOL care, and it should be presented as an option. Until recently, clinicians were cautioned not to initiate a discussion about MAiD with patients, as patients could view this as promoting MAiD. Christine described how she is challenging her own perspective on this and refining her practice:

> You know, I think historically, we've always deliberately not brought it up. You know, if they're putting out some feelers and dropping some hints, then you bring it up. But if the patient doesn't bring it up themselves, do we have an obligation to do so? And I'm still not sure where I sit on that. So, I've had a couple of patients recently where I have brought it up. And in both of those cases, neither of them has been interested in it. And

> so, a part of me wonders if we are pretty good at identifying when it's something they might be interested in. (Interview)

The NPs generally felt that MAiD was an important option for some patients and felt confident in their ability to attend to cues that signaled that the patient would like to explore the topic.

Although NPs in this province can legally assess, prescribe, and administer the medication to provide a medically assisted death, the NPs in this study tended to have a narrower role. In this study, the NPs engaged in counselling patients about what MAiD is, which in some instances included assessing patient eligibility and then referring to other providers for the actual procedure. Two NPs mentioned their conscientious objection with their involvement in MAiD, but they also supported the patients' choices and advocated for their access to the procedure. One of the two NPs indicated that she would consider providing MAiD assessments if they were not available elsewhere in the community, separating her own values and beliefs from those of the patients. Primary responsibilities around assisted dying included educating patients and families about what it entails legally and logistically, and attending to the fears and worries that often precipitate the exploration of MAiD. Grace described her interaction with patients who make it clear to her that they have made decisions in advance of their diagnosis and are resolute in their choice of MAiD: "I say, 'That's fine. I am not here to convince you otherwise, but let's work on the symptoms you have right now.'" The NPs viewed addressing fears about the future and suffering as an important part of the MAiD discussion.

Addressing patient concerns and fears that precipitate inquiries about MAiD was a common response from the NPs, in addition to reassuring patients that their symptoms could be addressed and increasing their willingness to address uncontrolled symptoms. The NPs followed patients more closely and communicated with other care providers to ensure the symptoms were

managed. Andrea described her response to requests for assisted dying and how support and symptom management are central to responding to such requests, particularly when they seem based in the fear of uncontrolled symptoms:

> So, they think, "Oh my God, this is awful, and it will never be better." And so, I try to reassure them that we're starting it at step one. There are, I don't know, 15 steps. There's so much more that we can do. Don't be discouraged if round one doesn't meet your quality of life or what you're looking for in pain or nausea management…there's so much more we can do. So, I really think, at least from my experience with my patients who've gone through with MAiD, none of them was because of uncontrolled symptoms. It was more the existential suffering by the fact that this (dying) is taking too long; for example, "I can't possibly go through another bowel obstruction." (Interview)

Nadine described a similar approach when discussing her conversation with a patient who was requesting MAiD. Her patient heard about how other patients with pancreatic cancer endured horrible symptoms. The patient was fearful his experience would be the same. Nadine described her response to the patient's concerns:

> I told him, "No, this is what it will be like." And I have been with him for a month and a half now and each time he calls with a symptom, I respond, and we manage it. And I don't think he is going to pursue MAiD. (Fieldnote)

When I asked why patients may change their minds, Nadine explained that she thought the process of "actively responding to patients' questions and concerns" probably had a role in alleviating their fears. While the NPs respected decisions about and facilitated MAiD requests, they were also sensitive to how these requests could represent fears about the future or becoming a burden. Responding to patient concerns was an important element to responding to inquiries

about ending life prematurely, more broadly, and the NPs generally responded by being even more attentive and responsive to communicate their support and commitment to their patients.

The relationships that the NPs built, along with their approach to understanding patients, provided the NPs with access to patient values and priorities. While the NPs in this study did not provide MAiD, they expressed that facilitating a good MAiD experience is important. A good MAiD experience could include pursuing access to timelier procedures for patients or coordinating procedures in hospitals when patients desired organ donations. Christine described her experience and response to one patient's request for MAiD. Christine explained how her role involved more than simply facilitating MAiD by connecting her patient with a MAiD provider; it also involved responding to her patient's specific needs and finding someone with whom her patient could have a connection with and a better EOL experience. Christine shared this exchange in an interview:

> I had a lady. She wanted medically assisted dying. She asked me to do it. I had to say no because we couldn't do it. And then she went through an assessment with a physician from [redacted] who's notorious for not being overly compassionate, and being a bit odd, and it's a mess when he's involved. And she really did not want him doing her assisted death. They didn't connect. I guess he talked about all the dollars and cents during the visit, and she was really put off. And so, I reached out to [the patient's physician]: "Could you do it?" No, she didn't feel she had the skill, you know, to do it. And then I ended up bringing it to my manager and saying, "They've asked me now three times if I could do it." Anyway, so they asked me again, "Could I do it?" And I said, "You know, we need to find this lady somebody different. She's not going to have this doctor who is not overly

> compassionate." So, we found a hospital physician who agreed to drive out and gave her the procedure. (Interview)

Through her knowledge of the patient and understanding what was meaningful to her, Christine understood the importance of finding someone who could perform the procedure and connect with the patient. This understanding of the patient's needs compelled her to work to find a solution that was going to meet the needs of the patient. Without this intervention, the patient might either have refused the procedure she desired or risked a poor EOL experience.

Chapter Summary

In this chapter, I presented the theme of "having conversations" as a way that the NPs enacted their role in this setting. This main theme had five subthemes that supported different aspects of how the NPs approached these conversations and the nature of these exchanges. In this chapter, I aimed to present how the NPs engaged in this prominent part of their role and what it meant to them and their work with their patients. Working around patient readiness in the context of changing patient conditions and the notion that conversational skills are developed over time became evident. In addition, the NPs addressed a broad range of concerns and either initiated conversations or built on conversations that had already been started to ensure a shared and current understanding of future plans. Through conversations, the NPs also tried to make clear the possibilities and limitations of care and dying at home. Finally, I ended this chapter with how the NPs engaged in conversations specifically about MAiD, which showed how, for the NPs, this is a broader conversation than just MAiD. In Chapter 6, I present the third main theme of my research, building capacity, and how the NPs worked with their patients and FCGs as well as their community colleagues toward this goal.

Chapter 6: Building Capacity for Palliative Care

In this chapter, I present the findings of how NPs aim to build capacity for palliative caregiving. In their work, NPs enact their role to a great extent by engaging with patients and family caregivers, along with community colleagues, to enhance their capacities for care. For patients and FCGs, NPs work with them to build their knowledge and ability to identify problematic symptoms, and to be able to manage these situations. In their work, NPs also engage with community colleagues, namely, nurses and physicians, to build their capacity to meet the palliative care needs of their shared patients. This capacity building may occur through education, clinical advice, or sharing of patient care when needed. This chapter addresses two main subthemes, each of which is further divided into more specific subthemes. The first subtheme of engaging with patients and families is further sub-divided into two subthemes: facilitating understanding about therapeutic choices, and tailoring emergency medication. The second theme here is engaging with community colleagues, and it is further sub-divided into four subthemes: creating and building collegial relationships, teaching and mentoring, clinical support, and sharing the work.

Engaging with Patients and Families: "I Just Want to Know What to Do for the Pain Because I Am the One Who is Getting Him to Take His Pills"

The NPs in this study worked to build the capacity of their patients and FCGs to better understand and manage their symptoms and make future decisions about accepting or declining therapies. While certainly not the only concern of patients and families, understanding, managing and access to medications is a critical element of managing treatments well at home. Patient medications and administration schedules can become overwhelming and confusing for patients and families. Family involvement is critical in supporting dying patients at home, and family

members often assume duties that trained professionals in other settings, like LTC, would otherwise carry out. The NPs continuously assess patient and FCG understandings of their symptom self-management and were actively involved in supporting patients with their medication needs and challenges. Furthermore, NPs also ensure that patients can be well supported by nurses at EOL by ensuring the availability of appropriate medication to relieve distressing symptoms.

Facilitating Understanding about Therapeutic Choices

During visits with patients, I noted how the NPs in my study evaluated the presence of symptoms as well as the patients' and FCG interpretation and management of these symptoms. This ranged from simple things like teaching patients and FCGs about managing oral yeast infections, to more serious concerns, like managing their shortness of breath or fatigue or how to do injections using special ports. The NPs engaged in dispelling myths, answering questions, and helping patients and FCGs understand and recognize changes and what to do or who to reach out to. I also observed how the NPs in this study evaluated patient perceptions of benefit, burden, or fearfulness about potentially helpful therapies. In this study the NPs also helped patients and FCGs by reviewing worrisome and bothersome symptoms and suggesting dose changes, timing changes, packaging changes, discontinuations, or replacements. Some families and patients managed their medications without difficulty (e.g., for simple regimes, low symptom burden, or high health literacy). However, I also saw how the NPs were frequently called in to help when patients encountered difficulties (e.g., feeling overwhelmed by their disease, fatigued, experiencing pill burden, misunderstanding dosing or use, having difficulty coordinating, or fearing medications that could otherwise greatly improve comfort). The NPs expressed that their role included understanding patient difficulties related to managing their symptoms and

addressing side effects. I observed how NPs engaged with patients and FCGs to promote a more robust understanding of therapies (purpose, potential benefits, and burdens) and what patients and families were willing to accept as important parts of their work. The NPs in this study aimed to understand how involved FCGs wanted to be as part of the caregiving team. For example, the NPs supported the FCGs, who were highly motivated to take on as much as possible (e.g. injections and colostomy bag changes), while helping others navigate their fears around simple management and decision-making. The NPs engaged in teaching and modifying medication regimes according to patient acceptance, which they also recognized could change in any direction over the course of time.

A common occurrence is reflected in an example from Grace's experience. During my fieldwork, Grace described her involvement with a family in which a medication misunderstanding threatened both the patient's and daughter's wellbeing. If not detected and rectified, the patient would have likely sought hospitalization for help. In Grace's words:

> The daughter was hysterical. She was giving her mom Hydromorph Contin 8 times a day. I reviewed the medications. Her mom was confused [delirious]. I set the pills up to BID [twice daily]. I counseled and reassured the daughter that it could be increased but to be cautious because of risk of confusion if too much. Now all the confusion has cleared. I think the patient mixed the meds. There was Hydromorphone and Hydromorph Contin all in the same bottle. Often, patients don't understand the difference. The instructions on the bottle were too confusing, so I just scribbled them out and wrote new ones—one in a.m., one in p.m. (Fieldnote)

By sitting down and discussing with the patient and her daughter and carefully reviewing the medications being used, the patient's history, and symptoms, Grace was able to determine the

patient's delirium was a result of the medication mix-up. The daughter was trying her best to help her mother manage her pain, but instead inadvertently precipitated a delirium. Seeing her mother suffer caused the daughter great stress. After Grace reorganized the medication and provided simpler instructions, the patient's delirium cleared in a few days, which in turn reduced the daughter's stress. Patients and families are often tasked with complex medication regimes, and with medications that can have serious effects if not taken as prescribed. Furthermore, medications can look similar or have similar names with instructions on bottles that are small and confusing to users. The NPs in this study drew on their in-depth knowledge to sort these situations out and ensure the patients understood their medications, and to identify and resolve any arising issues. Patients and families are often expected to manage medications that can cause harm if misunderstood, and they require support to fulfill their care duties safely. NPs play an important role in sorting out complicated situations and helping patients and families better manage complicated care routines.

The NPs in this study also helped patients and FCGs develop an understanding of therapeutic interventions and their options for future treatment. For example, one day during my fieldwork, I observed Nadine work with a patient to review decision points related to her therapy. This patient had several recent repeated hospitalizations for draining abscesses and was undergoing multiple cycles of intravenous antibiotics, which she acknowledged had significantly affected her quality of life. Knowing this, Nadine engaged in a discussion about the potential benefits and drawbacks of continuing antibiotics. During the visit, Nadine asked the patient:

> "Do you think you will continue with the antibiotics? You have been on years of antibiotics now. An option may be to forgo antibiotics in the future if you are not able to get a PICC line in place. Your abscess would get bigger. You would get an infection and,

> eventually, death. But as long as you tolerate your antibiotics, they can be part of your palliative care." The patient responded to Nadine's inquiry: "I have often said if I couldn't handle antibiotics, I would stop." The patient's husband interjected: "She has had her moments where she was fed up and didn't want to do this anymore." Nadine continued, "There may be a tipping point where that will happen, and we will be here to support you." (Fieldnote)

This type of discussion, while not requiring immediate decisions, was aimed at introducing future considerations, decision points, and possible outcomes for patients and families to begin contemplating. NPs in this study facilitated this proactive contemplation to help patients and FCGs prepare for the difficult decisions they would need to make in the future.

Understanding the timing and potency of medications can be confusing to patients, particularly when medications come in multiple formulations and have unfamiliar names. The NPs educated their patients and families about how to take medications to address their specific patterns of pain. For example, I observed how Andrea responded to a patient who reported having a pain crisis on the weekend. The patient and his wife shared their story of panic and crisis over the weekend when the patient's pain escalated quickly and dramatically, and how he and his wife were quite distraught and couldn't reach their PCP, despite leaving multiple messages at his office. Finally, on Monday morning the clinic picked up his message and a locum physician did a home visit and increased some medication. The couple described that they still did not understand their medication and had questions, particularly about what to do if this happened again. They were experiencing a significant amount of anxiety anticipating this may happen again and not knowing how best to manage the situation. The patient and his wife did not

understand how to address future pain escalation pain or the role of different kinds of pain medication (e.g., long- and short-acting opioids or acetaminophen):

> The wife reviews her notebook and says to Andrea in a frustrated tone, I just want to know what to do for the pain because I am the one who is getting him to take his pills. She said this with a mixture of worry and frustration. Andrea reviewed a suggested pain care regime: "Keep the long-acting hydromorphone at 6 mg twice a day. If there is more breakthrough pain, we can increase this later. Then use 1 mg hydromorphone plus one extra-strength Tylenol in the morning before getting out of bed and wait half an hour for it to start working." At the same time, the NP drew a graphic of how the long-acting and short-acting hydrophone are released into the body to explain why both need to be taken at the same time in the morning to best manage pain initially and through the day. The patient seemed satisfied with the explanation and showed his wife. The wife stopped her note taking and confirmed that she understood. (Fieldnote)

During this visit, the patient's wife expressed the weight of *her* responsibility for ensuring she gives her husband the appropriate medication, which was magnified by her limited knowledge of which medications to use. Andrea was able to provide the patient and his wife with a shared understanding of how to better manage and even prevent his pain moving forward, and clarified the roles of long-and short-acting medication. This information was important in building the wife's confidence that she could adequately manage her husband's pain, which in turn served to reduce her stress. NPs were seen drawing on advanced knowledge and translating this to practical ways for patients and families.

In shadowing the NPs during their daily work, I also observed how they taught patients and families about how to better manage symptoms, balancing their own knowledge with their

patients' values and fears. For example, Christine described her visit with an elderly male patient with end-stage lung disease who was struggling with shortness of breath. Based on her knowledge and experience with these symptoms, Christine felt he would experience relief of his dyspnea with regular use of an opioid medication: "I tried to talk him into some morphine, but that didn't go well." Christine described how the patient and family were opposed to using this kind of medication. Upon further exploration of Christine's understanding of this resistance, she indicated, "they think it's an EOL thing." Christine recognized these medications hold potential symbolism about EOL or represent fears related to effects or side effects of sedation. Christine further explained how, during a follow-up visit, the patient's wife accepted the medication after reflection and further discussions with family:

> She came back and said, "I talked to my kids, and they feel it's okay to give it—only when needed and not all the time. That would be okay." And they wanted only the injectable so it would kick in right away. (Fieldnote)

Patients and FCGs often had reservations and fears about medications that could enhance comfort. In response to patient understandings and reservations, the NPs in this study sought solutions that were considered acceptable to patients and FCGs. The NPs identified exploring and arriving at acceptable solutions as a process that required time and repeated visits to gain trust and an understanding of patient fears and values. Patient/FCG views may or may not change with reflection, after discussion, or as the patient's situation changes. At times, the NPs in this study enlisted help from the rest of their ad-hoc "team" (i.e., VNs, physicians, and specialists) to continue conversations with patients to reduce fear, build trust, support decision-making, or even just stand by in the event that decisions changed or symptoms escalated.

Tailoring Emergency Medications

The NPs in this study underscored the need to ensure that appropriate emergency medications were available in the patient's home for VNs to be able to address rapidly escalating and problematic patient symptoms (i.e., nausea, pain, dyspnea, and agitation). In this region, VNs can request that a patient's PCP order a symptom management kit (SMK).[7] Sometimes, physicians may not realize when they should order a kit, and VNs may not think to request one from physicians. Physicians who engage in palliative care may be unfamiliar with appropriate dosing for these special EOL medications, particularly if they use them infrequently. For example, this can be seen in the "day in the life" story presented in the previous chapter. When Margaret arranged for medications for her patient, who was likely experiencing a terminal delirium, she discussed the recommended medications with the patient's physician. The physician requested that Margaret order these medications because he was unfamiliar with them. Furthermore, if physicians are not doing home visits, they may not realize the kinds of symptoms patients are experiencing or the severity of these symptoms. I observed how the NPs prompted physicians to order such kits and recommended medications and dosages tailored specifically for a patient's anticipated symptoms.

I also observed how the NPs reviewed the PCPs' orders and, based on their knowledge of the patient and how their symptoms were progressing, modified the orders to ensure the patients received the most appropriate medication. Christine explained her approach during an observation: "I will often send in a modified prescription for the symptom management kit." NPs will typically review the order and correct or customize the dosing in anticipation of the patient's specific needs. This customization helps ensure symptoms are addressed without over- or under-

[7] A symptom management kit (SMK) is a box of medication that is kept in the patient's home and available to the VN to address common EOL symptoms like nausea, pain, dyspnea, or agitation.

medicating patients. During a home visit with Donna, I observed her review of the SMK medications ordered by the PCP and how she modified the medication order for the VNs to be able to better address the needs of a patient who was declining: “She reviewed the SMK kit and noted that there is far too much medication ordered: Haldol, Nozinan, Morphine, Dilaudid… She indicated to me that the M.D. should have chosen one or the other, Morphine or Dilaudid.” (Fieldnote)

The benefit to the symptom management kits is that standardized order forms have been made available to simplify ordering medication for PCPs. Because PCP may not know what patient symptoms might look like at the EOL, PCPs will often order multiple medications, as in the example above. While this practice provides a breadth of options, it can also be confusing for VNs, who may not have enough experience to choose the most appropriate medication. During her assessment of the patient’s situation, Donna chose medication based on her knowledge and understanding of the patient’s current situation to ensure the patient was not overly sedated and her symptoms were well controlled. A symptom management kit is of no use if it is not ordered or if the medications and administration orders are not tailored to the patient’s situation. This may not be a concern if VNs have experience or knowledge about these medications or if they call for help. However, if VNs are unable to reach the physician for guidance and do not call the NP, this can be stressful for the VN, but also catastrophic for the patient whose symptoms may be rapidly escalating and for the family who witnesses the patient’s distress. Uncontrolled patient symptoms can result in a distressing EOL experience for patients and FCGs and result in emergency transfer to a setting where symptoms can be managed. When involved, the NPs in this study ensured the patients and their nurses had access to medications that suited their specific needs. In these situations, NPs drew on advanced knowledge of therapeutic medications

and aligned it with their advanced assessment of the patient and anticipated illness trajectory, as well as with the patient and family wishes. Furthermore, their practice was facilitated by a broad prescriptive authority for therapeutic drugs and controlled substances.

Engaging with Community Colleagues: "So, I Find Often That It Is Our Role… to Create That Relationship"

In this study, the NPs viewed a significant part of their role as enhancing and supporting the capabilities of their colleagues in the community, namely, physicians and nurses, to be better able to meet the needs of their patients. This theme of engaging with community colleagues is divided into the subthemes of creating and building relationships, teaching and mentoring, providing clinical support, and sharing the work, which further describe *how* NPs engage with colleagues to build capacity for palliative caregiving. As a result, NPs engage in activities and use approaches that encourage relationship formation between themselves and others and to establish their ad hoc teams. Furthermore, the NPs in this study enacted teaching and mentoring and provided clinical advice and support within the relationships they worked to build. Lastly, though labeled and positioned as consultants, the NPs in this study took steps to share the work and make the responsibility of palliative care more manageable for their physician colleagues.

Creating and Building Collegial Relationships: "I don't ever want them to feel like they can't call"

The NPs who participated in this study emphasized that assisting their peers to be better prepared to address the needs of their patients is highly reliant on creating, engaging, and building relationships with these peers. In shadowing the NPs, I saw how they continuously reached out to community colleagues to create these relationships. The NPs were constantly reaching out and trying to forge connections with community providers (physicians and nurses),

directors of care at retirement and LTC homes, to set up teaching and chart review opportunities, and with specialists, to problem-solve patient concerns. I observed that the NPs regarded their relationships with their colleagues as central to making their work both possible and meaningful. However, relationships are rarely effortless. For relationships to be formed, the NPs in this study described first needing to reach out and connect and then to establish patterns of communicating and working together. In comparison to settings where all health care providers are collocated, the community setting offers challenges to establishing and maintaining relationships. In particular, challenges arise because care is delivered in patients' homes where chance meetings are unlikely. Different agencies often employ the nurses involved in the patients' care, and it is difficult for NPs to know all the nurses involved. Phone and text are the primary ways NPs initiate and maintain their relationships. For example, Andrea described how connecting verbally with physicians she does not know is necessary in establishing the working relationship:

> They may not even know how we work, that when we put it in the consult note, we mean for them to carry out the recommendations, if it's a new doctor. So, I find there's value in having at least one conversation if you don't need to have any others. I have one doctor—I have not spoken to him on the phone in years—because everything is either by text or fax. (Interview)

In this excerpt, a conversation sets the stage for the terms of the ongoing relationship. This conversation sets the expectations for who is responsible for what, and the conventions for communication. In enacting their role, NPs evaluated the needs of the individuals involved (from loosely connected in order to share information to tightly interactive for the purpose of ongoing patient care and problem-solving) to shape the nature of the established relationships.

When the NPs in this study reached out to make connections with their colleagues, I observed how they constantly managed their perceived approachability. In reaching out, their demeanor was professional and welcoming. I observed how the NPs worked to put their colleagues at ease by always acknowledging their efforts, thanking them for calling, and encouraging them to reach out if they needed support. The NPs viewed managing their approachability as a key way to foster relationships with their colleagues. Nadine explained her approach, which I perceived was common to all the NPs in this study:

> It's a positive interaction, which I always am very positive. I want them to call me so I am nice, and I encourage them, and I compliment them in their care. Like, I give feedback, for sure, just because I want them to be rewarded for a good job and for calling. I don't ever want them to feel like they can't call. And the way that they show their appreciation is to say thanks. Or they'll call you for positive things, too. Or they'll text you and say, 'So and so's pain is so much better, I think we've done a great job,' or something like that. So, it becomes a bit of a relationship. (Interview)

The NPs viewed getting to know their colleagues and building relationships with them as important from both a practical perspective and from that of personal satisfaction. As highlighted in this interview excerpt, NPs view their approachability as a way to increase the possibility for their colleagues to feel welcome to reach out and maintain communication. The challenge for the NPs in this role as consultants in the community setting is that they are physically removed from their patients and colleagues. As a result, the NPs in this setting are highly dependent on CNs and physicians, who might have more frequent connections with patients, to reach out and connect if they need support. The NPs in this study expressed that developing a relationship offers insights to the practice patterns and capacities of their colleagues. An awareness of both

physician and CN practice patterns, strengths, and limitations influences how the NPs shape their own work. For example, Nadine explained,

> If you know the nurse (who) is going in, you know exactly how much involvement I would need to have, you know if that nurse is going to not call you, call you too much, call you for inappropriate things, or just take it and run and not need us... (Interview)

It is through relationships with colleagues that the NPs in this study gained insight into the practice patterns, knowledge, and confidence of their peers. When the NPs perceived that a nurse or physician was new to palliative care or less likely to reach out for help, they adapted their own practice pattern. In these instances, the NPs indicated that they were often compelled to follow a patient more closely if they were worried about continuity or communication about the patient's condition. This relational insight helped the NPs anticipate who might require more support and mentoring and, in parallel, patients who might benefit from more frequent contact.

The NPs viewed having a relationship with CNs as an essential facilitator of communication. The NPs tried to coordinate a joint visit if they knew the VN involved with a patient or if they could determine who the VN was from the chart in the home. For example, Erica described how she works with VNs: "I send a notification to visit nurses for visits. The nurses that know me will schedule a joint visit." Erica and the VNs have established their own joint way of working together in their relationships. Grace provided further insight into how established relationships facilitated working jointly with CNs:

> Those that know me, we do great visits, and I value what they have to say to me. And I'm often saying to the nurse, "What have you observed? What are your impressions? How do you see this happening? Because I'm just more of a sporadic visitor and you're more regular." (Interview)

This interview excerpt is typical of the approaches I witnessed the NPs engaging in. I noted how NPs in this study reached out to CNs, when possible, to connect about patients when there were concerns (i.e., exploring nurses' views, highlighting their concerns and identifying what to watch for, or increasing and coordinating visits where possible). Joint visits were a central strategy the NPs employed to help foster a shared understanding of the patients' needs and plans of care. The NPs frequently expressed how they valued these visits both as opportunities to learn about patients from the CNs and as good teaching opportunities. However, coordinating joint visits posed challenges for the NPs. To the dismay of the NPs, the VNs would often cancel their visits when they learned that the NP would be seeing the patient. The NPs speculated this might be because VNs feel it is redundant to have both the NP and VN with the patient simultaneously. The NPs acknowledged that better communication about the benefits of joint visits is required at an organizational level, particularly because the staffing turnover for nurses is so high and there are many new individuals who may be unaccustomed to this way of working.

The NPs believe that getting to know CNs can provide insight into their capacities and way of working. The reality in the community is that there is a broad range of knowledge, skills, and experience. Very few nurses have received palliative care education, and for many who were provided with initial LEAP training, there is often rapid turnover. During one team meeting, the NPs shared with me how in one agency, 25 nurses who were trained a year ago, left the agency. New nurses may be hired but they may be novice or new to the field of palliative care. Working with an experienced, knowledgeable nurse has different implications than working with a novice nurse or a nurse who has no palliative care experience. Novices may need more support, and the NP may need increased vigilance when interpreting their assessments.

For the NPs in this study, having an established relationship enhanced communication with their physician and nurse colleagues. It also contributed to feeling that there was a team approach to patient care, even if those teams were temporary. Where there were established relationships, calls or texts were exchanged freely and easily with advice, to provide updates, or to coordinate visit schedules.

In my observations, it was evident that, where there was familiarity, it most often engendered an enjoyable, effortless interaction that was not only patient-focused but social and supportive. While there were some differences between participants, I could see that more established relationships occurred more frequently when there was stability and continuity in community staffing. The NPs found relationships easier to establish when they were able to work with the same nurses and physicians over time. Andrea described her approach to establishing relationships and how this has evolved with experience:

> "Sometimes I've shown up when I know the doctor's going to be there. Those are the times where the uptake is even better. It's hard to say 'no' to the individual versus to the consult note." I followed up, "So it sounds like you make a bit more of a connection with a human face?" Andrea replied, "Yes. On those good weeks where I'm not feeling too lazy or busy to do that." I asked, "So that seems like an important part of your role, to make space for that?" Andrea responded, "Yes, and I do think that's something that's evolved over time as well, that we have, all of us have learned how to schedule our days to make sure there's time to do that. And also learning the schedules of the PCPs you work with, like Thursday is the best day to reach this person, or they work evenings on this day. So, you do start to get used to those. Originally, we did not have set geographies so it was hard to build that relationship but now that we have a very structured

> geography, I have a fairly good knowledge of the regular physicians I work with." I responded, "Okay. So how you communicate, meaning how you reach out?" Andrea confirmed, "Right, it varies based on the primary care provider. And you even hear that in rounds: 'Oh so and so responds best to text.'" (Interview)

Andrea highlighted how critical it is to establish the relationship in that first meeting and how face-to-face introductions can facilitate meetings with new physicians who might not understand the role of the NP. This kind of work is time-consuming but important in building an alliance. By building relationships, the NPs in this study established trust and a shared understanding of each other and their patients. These kinds of relationships enabled the NPs to feel reassured in their team approach and to have confidence that the CNs and physicians would reach out if there were problematic situations. This connection also allowed the NPs to feel comfortable reaching out as well. The connection alone contributes to capacity. Nadine expressed the value of relationships by specifically reflecting on the value of professional relationships:

> If I can text and get a check-in on somebody, it may be the difference between having to go and do a visit, or having them say, "No, everything is good," or "We've done this and we're good to go." You've done that because you're building capacity. So, it's good. It's good. (Interview)

The NPs viewed capacity-building as including something as simple as opening the lines of communication through relationships. Established relationships enabled short and episodic communications that easily conveyed current challenges or provided peace of mind. The NPs valued this kind of communication as it reassured them about patients for whom they might otherwise be concerned and allowed them to focus more on others in need. These relationships take time to develop and are also challenging to establish when there is high staffing turnover. A

more recently hired NP explained to me how she was just getting to know the nurses in her area and needed to develop her own database of contact information. This work takes time and can be difficult when trying to juggle patient visits. The community care environment involves multiple agencies that struggle with consistent staffing. This constantly evolving environment differs from work in one large organization where there are lists of stable employee contacts. The NPs in this study learned about which nurse was caring for a patient only if the nurse had included his or her name on the patient's home chart or by calling the agency to find the nurse.

When the NPs had established relationships and knew their work colleagues, communication and information transfer seemed easier. The NPs valued the mutual sharing of information and work highly, as Grace noted:

> We work with multiple physicians, nurses, care coordinators, and personal support workers who are our colleagues. I think the good relationships are those with a lot of communication and open relationships, either with physicians, care coordinators, or nurses. It's a shared relationship, it's not all on one person or the other. So, I have a lot of relationships with physicians where maybe they'll do the assessment in the home one week and I'll do one in a couple weeks. So, we alternate. And then after the appointment, it's not only me sharing information; they share with me, which is fantastic. (Interview)

In many cases, the NPs in this study viewed their role as bringing colleagues together and facilitating relationships as part of temporary teams to provide the care patients need. Christine described this notion of creating relationships best:

> Sometimes, I find that, actually, our role is to be almost the glue that holds everyone together. So, I find often that is our role, to bring the physician, the nurse, ourselves, and

> the patient together and bridge that relationship or create that relationship. Sometimes, I find if we do nothing else, we do that in our role. (Interview)

This function of bringing people together, even if a virtual manner, was seen as important to developing a shared understanding of patients, their anticipated needs, and the clarification of roles and patterns of working. Without this "bridging" activity, information is partitioned and can lead everyone to feel they have to solve problems on their own in which case problems may escalate without the benefit of the team being able to problem-solve. The NPs in this study enacted their role by trying to encourage the development of professional alliances by initiating communication and fostering interprofessional exchanges that invited participation by others. Particularly important in an environment that is relatively unstructured.

Teaching and Mentoring: "What I Try and Do is Try and Visit with Those Nurses so That They Can Hear Me Doing the Counseling"

The NPs in this study perceived teaching and mentoring as an important way of building capacity in their community colleagues. During my fieldwork, I heard the NPs talk enthusiastically about helping their colleagues improve their knowledge and skills in palliative care. Their comments suggested that they regarded teaching not only as an expectation, but as a role they valued as a part of their identity. Moreover, they viewed the idea of helping a colleague feel more confident in their ability to recognize or address patient concerns as rewarding.

The NPs mentored physicians informally through their consultation notes, which both outline their understanding of patient situations and provide instruction on how to approach complex patient symptoms. I heard how the NPs expressed enthusiasm about more interactive teaching modalities, like joint visits or group sessions, where they could customize the teaching. The NPs provided guest lectures on EOL care for NP students, supervised medical residents, and

provided tailored educational sessions for staff in LTC homes. I also observed teaching sessions in the LEAP palliative care course for newly hired agency nurses. The NPs in my study viewed these occasions not only as opportunities to build capacity by increasing care providers' knowledge, but also as opportunities to meet other care providers and initiate relationships that would help them become more comfortable reaching out, as discussed in the previous section.

The NPs were constantly trying to devise ways they could build capacity in the community. During an NP meeting, I listened to discussions about the strategies the NPs were using in their individual areas to enhance the abilities of staff in retirement and LTC homes. Andrea shared her strategy with the group, and the pride in her voice was clear: "I am meeting with the care home staff. They were struggling to know when to refer. Since I started doing this, the referrals have decreased! They don't need help with uncomplicated patients!" Andrea further explained to the team:

> I was there every week before we started these sessions. Now the nurse brings in other cases for input to decide if the patients are appropriate for referral to me. They review the caseload and see who can be discharged from my roster. It is the best half hour that I think I spend per month. We schedule 1 hour and use only 30 minutes, then spend 30 minutes talking about other educational topics. I am now thinking about where to go next. (Fieldnote)

As identified in this fieldnote excerpt, the NPs reflected on the specific needs of their colleagues and were able to tailor their teaching. As opposed to a generic teaching session, discussing actual patients with nurses helped them build theoretical and practical knowledge on how to recognize and address relevant changes in their existing patients. Andrea has helped the nurses in this setting build confidence and independence. This further developed Andrea's ability to offer

similar support in other settings. Without this kind of capacity building, nurses might be unable to recognize patients who are experiencing difficulties, or might be intimidated by situations they could easily resolve on their own. Andrea's comment about CN uncertainty over when to refer suggests an inability to recognize subtle but problematic changes, which may result in a delay in reaching out for help. Such challenges can result in patients who experience an undetected decline and rapid deterioration in their condition.

Formal and informal teaching for CNs is as an important part of the NP role in this study. In many settings, PSWs often deliver the majority of primary care, and are also important recipients of teaching. Grace describes one teaching strategy at a LTC home with the primary PSWs and nurses:

> When we first started, I kept running after the nurses. I could not find them. Now, they bring the chart and we sit and do the review. We also roleplay what to say in situations where the patient is dying. (Interview)

During my fieldwork, I often heard the NPs expressing fear about nurses who fail to call them about their patients, so the NPs viewed teaching nurses about situations when they should call for help as important. Grace explained her perspective: "The main point often is teaching the nurses when to call and when not to call. With 30 new nurses hired on to one agency, knowing when to call is a number one priority." In the fieldnote excerpt, Grace indicated that, because of the high rate of staff turnover in the community, knowledge and skills have been lost. New or novice nurses who are learning how to navigate their role in the community are at risk of not knowing when they should contact someone for help about patients. While Grace described teaching about "when not to call," this was born out of frustration when nurses call the NPs about procedural matters that their employer should equip them for. Nurses should receive instruction on

procedures, such as programming infusion pumps, from their agencies. In their day-to-day practice, the NPs encouraged and welcomed CNs to call if they needed help interpreting patient findings and address symptoms. A larger concern to the NPs was to not get calls when there was a problem they could help with.

The NPs in this study also viewed mentoring nurses as important. At times, the NPs were compelled to mentor when they noticed nurses who needed support in their skill development. During an interview, Nadine described her approach when she sensed a nurse might benefit from some support, based on what she noted about having shared patients:

> So, you have to sort of step in, and what I try and do is try and visit with those nurses so that they can hear me doing the counseling. Or addressing it with them outside of the home if I've seen something. (Interview)

While the NPs viewed mentoring and teaching as important, they also aimed to use an approach that was respectful and not intimidating. During an interview, Grace described scheduling joint visits as her preferred standard practice, whenever possible, to optimize joint learning: "I want it to be a joint visit where we both learn from each other." In the case of learning, the NPs valued the professional or patient-related insights other health care professionals offered. Such situations also provided the NPs with an understanding of the knowledge, skills, and comfort of their peers in providing care and their particular patient insights. By getting to know their peers, NPs also gained an understanding of how to better support them.

Grace responded to my inquiry about a joint visit with a VN for a patient who had concerns of escalating abdominal pain. The VN had reported these concerns to Grace. Grace described how she saw this as an opportunity to help the VN develop her assessment and critical thinking skills:

> I recently went to visit with a nurse. She just did sort of the blood pressure and listened to the lungs, and I said, "Well, you know, he's talking about constipation." She's doing the exam and I said, "Can you check his abdomen? Let's really look at his legs." What we ended up finding out was he was so—which he hadn't noticed—he was so edematous, like his abdomen. Because she'd never looked at his abdomen. And yes, he had a few crackles, but it's just putting together all those things, plus the crackles. I said, "And look at his arms. His arms are swollen. Like, why are his arms swollen?" When we are together, I could say, "Well listen, these are the reasons this could be happening, and this is what we need to look at, and this is what we need to monitor. Is it possible for the nurses to come in more often than once a week? Because we obviously have an issue here with this." And then hopefully, just sort of a little spark to say, "Hey, you know, this is important, just to remind you to look at that." (Interview)

In this interview excerpt, Grace identified how she hoped to model and mentor the VN to develop this same knowledge and skill by talking through her own assessment and critical thinking out loud. During a day I spent observing Christine, we discussed her experiences with a physician who was new to palliative care and whom she mentored: "We used to do a lot of joint visits but now she is a champion in the practice." In these examples, the NPs regarded joint visits as an important opportunity to not only develop a shared understanding of the patient, but to build a shared understanding of each other's knowledge and model an approach to advanced assessment skills. For NPs in this study, the long-term goal was to foster independence, and even interdependence.

The NPs also coached VNs to more effectively carry out their role of communicating with physician colleagues. During one day of observation, Erica received a call from a VN for

advice. Erica helped the VN by coaching her about the kind of information that would be important for the physician to know: “vital signs, lung sounds, and assessment information.” This coaching was intended to increase the VN’s confidence to communicate directly with physicians in the future. In an interview, Andrea clarified her role in enhancing nurses’ abilities by enhancing their ability to communicate about patient concerns:

> We try. So, we try in the sense that we go to the agencies, we do education. Every time I do education with an agency, I talk about when you’re calling someone on call and that is not just us, that it is the family doctor. It is the specialist. What a proper report looks like, I don’t know if we learn that in school. I can’t remember that far back, and I suspect I’ve probably done a crappy job in my nursing career. It’s not until you’re on the receiving end that you start to realize there’s so much more information you need. (Interview)

Andrea reflected on how her experiences as a novice nurse and NP shaped her understanding of the nurses she works with and teaches. Andrea further explained how she drew on this information to influence her teaching and capacity building for new nurses. The NPs in this study expressed pride about being instrumental in supporting CNs to become more confident and knowledgeable. Grace provided her perspective:

> Yeah, lots of role modeling so they see that, and then they’ll hopefully do that in the future. And then, if they don’t need me, that’s fine. I’m happy. And the patient’s good and they’re managing it and they’re calling the physician. I’m okay with that. I’m busy. I’ve got lots to do. It’s not going hurt my ego at all. I’m good. And some of them do that. They’re phenomenal. Phenomenal. And I love it. I love those nurses who do that. They’ve grown, and I’ve seen a lot of growth when they’ve done that, and it’s wonderful! Wonderful! (Interview)

I also observed how the NPs often became the preferred contacts for VNs who needed support. Nurses in the community encountered their own challenges contacting physicians about patients and often called the NPs for medication orders and advice because they knew the NPs would respond. Meanwhile, the physician might be unable to return their call that day. On one occasion, during fieldwork with Erica, as we were leaving a retirement home, and she turned to me and said, "So many nurses would want us to take over care because it is easy to get a hold of us and talk to us." I further explored the reason for VN preference to communicate with the NPs with Christine during an interview where she shared her understanding:

> I think, probably, it's because it's nurse to nurse. I think there's a bit more comfort. I think there's still in medicine this perception that the physician is on a rung above us and that there's a status difference. So, I think that's part of it. I think we're easier to get a hold of. They have our direct cell numbers. We're often on the road, so we're easier to get a hold of by text or by phone. We're approachable. Somebody told me once there's no meanies in palliative care, we are all nice people. And I think as a nurse, I think back to when I was first a nurse, I was working in the ICU so we had to do a lot of communicating with physicians. But, at first, I was so uncomfortable and intimidated and afraid that if they asked a question, I wouldn't have the answer. And so, I have to remind myself what that felt like because I think, that's probably what some of those nurses feel like when they are calling docs. (Interview)

Drawing on their experiences, the NPs appreciated the inter-professional and logistical challenges CNs face in their work. During a busy day, the ability to reach out and receive timely advice would significantly impact CN work. In some instances, the NPs viewed some CNs as more comfortable approaching NPs, because they may feel intimidated to call physicians. While

the NPs appreciated supporting VNs, they also acknowledged their role in reorienting and supporting VNs to call patient physicians directly to consult on patients. This is important, particularly from a logistical perspective, because PCPs need to be involved in the clinical decisions about their patients, and NPs cannot manage the workload if VNs continue to rely solely on NPs only. I observed how the NPs tried to be supportive when responding to nurses but also redirected them to call the patient's physicians directly to resolve patient concerns.

Clinical Support: "You Know, We Have the Symptom Management Kit"

The NPs regarded providing clinical and professional support to other clinicians as an important part of their work. In shadowing the NPs in their day-to-day work, I observed how they engaged in helping physicians and nurses who reached the limits of their comfort and ability to address patient symptoms. The NPs in this study described how they provided support to others who were overwhelmed by patients who were struggling with uncontrolled symptoms at EOL. I observed how the NPs provided guidance to nurses and physicians who had reached their knowledge limits on how to best address patients' symptoms. The NPs worked with physicians and nurses to interpret patient symptoms and provided advice about the next steps. These next steps sometimes included initiating medications, changing doses, or assessing the benefit of short-term admission for symptom control and a transfer home.

The NPs described the opportunity to provide support to nurses and physicians who reached out for help as a rewarding experience. For example, Christine described a situation in which a nurse found the patient was declining and struggling to breathe during a home visit. Christine knew the patient well and had already discussed EOL plans with the family. The patient and family were well prepared, knew what to expect, and had planned a transfer to

hospice in a few days. This plan was clearly documented in the patient's chart. However, the nurse was new to the patient, and the patient's breathing difficulties disturbed her:

> The nurse called me one day and said, "What are we doing here? I think this man needs to go to the hospital" (because he looked poor and his O2 saturation was in the 70s on oxygen). And I said, "no, that's not the goals of care." So, she was kind of panicking and I had to explain to her, "You know, we have the symptom management kit. You can give some midazolam or morphine." She calmed down. She increased his visits to daily over the weekend and I reinforced she could call our team for advice. (Fieldnote)

For the VN who was new to the patient (and possibly had limited palliative care experience), seeing a patient in respiratory distress was alarming. This response likely occurred because this level of distress is most often managed in hospital settings. Also, a lack of familiarity with the patient's condition and the established goals of care risked unsettling the patient and his wife, who had established plans to manage care at home until transfer to hospice in the next few days. Christine knew the wife and patient were still in agreement with this plan. Christine also assessed that the symptoms reported by the VN could likely be adequately managed with the medications available to the nurse. With Christine's clinical and emotional support in an otherwise stressful scenario, the VN was able to manage this patient comfortably at home until transferred to hospice as the family had planned. Without such support, there is a risk that the patient and family's plans to remain home might have be uprooted.

Sharing the Work: "I Also Think We Build Capacity in a Different Way"

During my fieldwork, the NPs also described how they shared the work of patient care with their ad hoc team when needed. These ad hoc teams were informal and temporary links between the VN, physician, and NP, who all shared the patient in common. This informal team

linking seemed to extend everyone's capabilities and capacities when members communicated appropriately. Andrea provided an example of working with her nurse and physician colleagues to support a patient and his wife:

> I knew the patient for quite a long period of time, probably about 2 years. And the physician and I alternated visits for that period of time. He had immensely skilled visit nursing. He had an incredibly supportive spouse who really was capable of caregiving at home and wanted to meet his wish of staying at home, which he did. And so, I think the success of that situation came from having a cohesive team that never physically met in person once. But there was always communication going on behind the scenes. And a spouse who was able to maintain the care at home. But I do think a really important piece is the skilled visit nurse, dedicated and skilled. They're the constant. They're frequent and constant. (Interview)

In this way of working together, there is a shared care approach where the NP coordinates and alternates visits with the physician and the VN. Communication among these colleagues enhanced the capacity of the team and enabled them to care for this patient so he could spend his final days comfortably at home.

Capacity-building, while an understood mandate of the NP's role in this setting, is also well aligned with what the NPs in this study identified as important. However, while the NPs recognized this mandate as important and as a valued way of working, they also often described that, at times, capacity-building entailed a more active role beyond their consultant role. Christine's response captures how NPs commonly adapt their role to help their "team" and extend care to patients and FCGs:

> As far as our role as consultants, I mean the mandate of our team is to build capacity in palliative care among primary care teams, which I think we do through mentorship and through our consultations. But I also think we build capacity in a different way, by helping reduce the workload. Palliative patients can be demanding. So, I think we help reduce some of the workload on the primary care team by being able to do some of the home visiting if they can't get out there. And sometimes I do prescribe medications or manage a crisis. If I can't reach a doctor in their office, rather than pulling them away from their busy day, I'll manage the crisis and then we just connect afterwards. So, I think we do build capacity in that way as well, by lowering the rates of physician burnout. When we first started, a lot of people would say, "No, I can't do palliative care," because they're getting burned out. (Interview)

This interview excerpt highlights how NPs modify their role to address patient care needs when needed and share more of the burden of care with their colleagues, despite their role description as consultants. Capacity-building, in this sense, is about enhancing the system capacity to ensure that patients receive the care they when some situations require a more relevant approach.

Chapter Summary

In this chapter I presented how the NPs engaged with patients and FCGs and their community peers (nurses and physicians) with the ultimate goal of building capacity for palliative caregiving. In working with patients and FCGs, the NPs worked to build capacity to monitor, detect, interpret, and manage symptoms independently and to understand their choices for interventions. The NPs also worked to build the capacity of their peers to provide better palliative care, which was fundamentally linked to strong collegial relationships, which ultimately broadly enabled health care providers to meet the needs of their patients by drawing

together otherwise disconnected health care providers. In Chapter 7, I then present how NP work is impacted by system constraints, particularly the under-resourcing of CNs and physicians. This under-resourcing is seen to manifest as a poorly integrated system.

Chapter 7: Navigating an Imperfect System and Local Challenges

In the previous chapter, I outlined how NPs in this study engaged with patients and families to better understand their needs and support them to have a better EOL experience. To support patients and families, the NPs engaged in ongoing conversations as situations evolved to understand the needs of patients and their families. I also highlighted how the NPs valued their community colleagues and understood their role in bringing the informal team together and sharing patient information to strengthen the quality of care. To be able to engage in this kind of relational work, the NPs in this study needed to first undertake the work of creating and building relationships. Furthermore, I discussed how the NPs embraced their role in teaching, mentoring, and supporting their peers to enhance capacities as palliative care providers.

In this chapter, I will revisit the role elements the NPs valued and viewed as an essential part of what they do and situate them within the context of a broader system of health care delivery. While the NPs undertook their day-to-day work, challenges arose because of existing structures of care delivery, communication, and resource allocation. In this chapter, I identify how NP work is shaped and how the NPs navigate through and against the organization of community palliative care. In particular, I show how NPs are highly reliant on the engagement and participation of nurses and physicians to provide the best level of care to their patients. However, systemic constraints restrict this engagement.

I begin this chapter by introducing the systemic constraints, characterized by the NPs as "an imperfect system." The main theme, navigating an imperfect system and local challenges, is further subdivided into three subthemes that highlight the different systemic challenges. The main theme represents how NPs reflect on their work environment and its structural shortcomings. The subthemes reflect how the NPs are affected by and respond to the systemic

influences. These subthemes include: communication and information, trust, and teamwork and navigating responsibilities. I begin with an introduction to how the NPs perceived the limitations of their working environment.

As I spent more and more time with the NPs in my fieldwork, I began to see patterns not only in how they approached their work but also how they encountered and negotiated challenges rooted in the broader structure of how community care is delivered. These challenges were commonly identified as arising from the structural environment that shapes how palliative care is organized, resourced, and delivered. Grace offered insight into the day-to-day challenges this study's NPs encountered:

> If the system was perfect, let's just say the system was perfect. That the nurses were calling me whenever there were changes, there was enough staff in the community to ensure that there were visits, and they had enough time to see the patients and do a thorough assessment. That we *had* nurses. That they could guarantee they would have shift nursing. That we could guarantee that this person would get the personal support workers that they need. And that the family members weren't hurting themselves, or not recognizing that they couldn't provide care any longer. If it was a perfect system and the physicians did their visits and all that, and that the nurses were going to call me, I could be purely a consultant. But, as I would say, the reality is that is not true. (Interview)

Grace's reflection highlights the common challenges that the NPs encountered in their day to day work. These included problems with communication between health care providers about patients, insufficient human resources, nurses who are not provided with adequate time to conduct patient assessments, and physicians who do not fulfill their expected patient care roles.

As a result, NPs are required to navigate these systemic challenges to ensure patients and families are well supported at the EOL.

As highlighted in Chapter 6, the NPs felt invested in helping their peers in the community to develop the knowledge, skills, and comfort to provide the care that patients need in the last months, weeks, days, and hours of life. What became evident in my fieldwork with the NPs was that a high rate of staff turnover constrained their ability to build capacity across settings, including LTC, community care, and in retirement homes. Andrea provided an example of how an unstable staffing environment influenced her work to support her peers in the community:

> I have a really crappy long-term care facility, and crappy doesn't even begin to describe it. So, it's been over a year. I've been slowly working with them to try to set up a team of palliative care champion nurses who feel comfortable giving feedback to the doctors. And it falls apart, and we piece it back together because people leave. So, I would say that would be an example of one that it's never really getting where I wanted to go because of life, I guess. There's a lot of heart, but people are struggling because of whether it's staffing issues or lots of turnover. (Interview)

While committed to sharing expertise, I saw the NPs in this study regularly strategize on how to more effectively meet the needs of the community and invest in the time-consuming activity of ongoing teaching in light of the constant turnover of nurses from both LTC homes and VNs employed by the nursing agencies who do the home visits. Christine expressed this notion during a group meeting: "Our time is better spent doing joint teaching with the care coordinators and the director of nursing because you could go in every month and see new nurses." In such unstable staffing environments, building capacity hardly seems possible. While recognizing their role of educating others, the NPs also identified feeling uneasy with how for-profit organizations

benefited from their teaching and did not seem to invest in supporting nurses as much as they should.

As patients become more unwell and homebound, CNs and PSWs have the most frequent contact with patients and families as they provide home support and monitoring. Early in their disease trajectory, while still mobile and independent, patients tend to have more contact with their primary care physicians. During my shadowing with NPs I learned how some physicians remain very involved with their patients through to the EOL, many struggled with balancing patient needs against busy practices and others more regularly reached out for support in providing palliative care. The commitment to providing palliative care is significant, requiring physicians to be accessible after traditional office hours and weekends. Physicians may see this responsibility as overwhelming and beyond what they are prepared to take on. The system is fragmented. Many physicians work in individual practices or groups without an established mechanism to offer evening, weekend, or vacation support to patients and CNs. Christine shared how she understands the stresses placed on community physicians to meet their patient obligations: “Because some of the payment models to physicians aren’t set up to encourage them to do home care or to have their phone on 24 hours a day for us or nurses.” As a result of the way their compensation is structured, physicians may be reluctant to make themselves available to support patients and nurses outside of typical office hours. Some physicians reject requests for a palliative care consultation from care coordinators because they feel they can manage patient care independently. Some physicians rationalize that they will transfer care to the palliative care physician groups in the area; however, coordinating the timing of this can place patients at risk because these specialists will only accept patients in the final few weeks of their life. These physician groups provide service within defined geographical areas and rarely travel outside of

these boundaries. Managing the timing of referrals can be a challenge, because there is often a 3-week minimum waiting list to be seen. These groups only accept patients at the very EOL when they are essentially bed-bound. In this study, NPs were often seen in such instances to step in to assume a role beyond that expected from a consultant. As presented in the previous chapters, NPs worked with physicians to enable them to still remain involved by "sharing the work" and providing nurses with the clinical support they would have expected from primary care providers.

The inequitable distribution of community services is another systemic challenge. There is geographical variability with inadequate coverage in some rural areas for both VNs and PSWs. Patients may live far from their PCPs, making it difficult for those who would have done a home visit to do so. Unstable staffing with high employee turnover, with nursing and PSWs in both agencies and LTC settings, also pose challenges. The constant state of change in personnel threatens patient care continuity. Continuity is essential when interpreting changes in patients' conditions is a responsibility. During an interview with Christine, she offered insight into her understanding of how fundamentally flawed nursing services organizations are:

> I feel like this is off-topic, but I feel like we have a real system issue here. I don't know if you've heard, but the nurses are paid per visit, no travel time, or very minimal for their travel time. So, it's enticing for them to see 12-15 patients in a day, whereas with a palliative patient, you could spend an hour and a half, 2 hours in the visit if they're really in a crisis. So, I find we have a system where the nurses don't get benefits. They work after hours. All their ordering of supplies and equipment, that's all done on their own time. They don't get paid for that. So, we have a system that sets us up to fail because

> we're not going to attract good nurses or those that we do attract, as soon as something is more enticing with permanent full time, benefits, and better pay, they're gone.

Christine's understanding of systemic shortfalls can provide some potential insights into the challenges represented and discussed.

The NPs in this study occupy a position within the context of community care between CNs and physicians, who have closer, ongoing contact with palliative care patients. As presented in Chapter 6, the NPs in this study value working with nurses and physicians because of their shared goals of patient care. The patients' needs, how rapidly their conditions are changing, and the capacities of CNs and physicians primarily influence the ways NPs work with and between CNs and physicians. When physicians and nurses are communicating well with each other and the family, their roles complement each other and the patients' needs are more likely to be met. The NPs in this study also viewed their role as bringing loosely connected care team members (e.g., nurses, physicians, patients, and family) together when required to establish a shared understanding of patient needs and roles as patients' conditions change. Their removed positioning becomes problematic for NPs, as they rely on receiving timely and accurate information and communications to most effectively care for patients. The three subthemes presented in this chapter represent the tension between NP values and how NPs seek to enact their role and this imperfect system. The three subthemes include: communication and information, trust, and teamwork and navigating responsibilities.

Communication and Information: "I Really Need an Update, and I'm Not Receiving That Update"

Communication and information refer specifically to the timely sharing of patient specific information either through phone, text, or documentation, and, in particular, information

that would direct or inform NP action. In this study, the NPs regarded communication (both giving and receiving timely information) as critical for completing their work and supporting their nurse and physician colleagues and patients. Because of the organization of home care, phone and text are core methods of communicating about patients. This method of communication offers a quick way to exchange patient information. The information exchanged has the potential to streamline the coordination of care, such as by communicating that a nursing or NP visit is not required, may be delayed or hastened, or will remain on schedule. As a result, all collaborators could optimize visits while ensuring the patients receive the appropriate amount of attention.

The NPs in this study struggled to connect with CNs who work in challenging environments. Such environments are often under-resourced. More specifically, they often do not have enough nurses to provide the care required, or call for care requirements beyond what nurses can realistically meet. The NPs experienced that nurses in these kinds of settings find it difficult to prioritize time for communication. During a group meeting, Grace described her experience trying to communicate by phone with nurses in a LTC home: “I call and the phone rings and rings and rings. I leave a message, and 2 days later no one has called me back. I don’t even try to connect by phone anymore. I just go in person.” The NPs in this study often needed to modify their approach to include an in-person visit when otherwise their questions and concerns could otherwise have be easily addressed in a phone conversation.

During an interview, Erica described her experience when trying to connect by phone with a VN about a patient: “The VN told me, I’m not paid to talk to you. The time it takes to talk to you, I don’t have. I have many visits to do, and I don’t have time.” While potentially interpreted as reluctance, the reality is that many nurses in the community have tightly scheduled

days and see many patients. These nurses have little time for travel between patient visits. In such situations, communicating has implications for their entire day, putting them off schedule or reducing their time with patients.

The NPs in this study depended on communication and feedback from nurses to best facilitate care; however, CN work environments can obstruct communication. In home care and LTC homes, nurses are often assigned more patients than they can manage. Also, as highlighted in the earlier interview comment by Christine, nurses do not stay in these jobs for long, or there is a high reliance on part-time employees. Inconsistent staffing (i.e., a patient has a different nurse every day) poses a challenge to effective communication. In one group meeting, Grace described how a lack of continuity in staffing affected her ability to follow up with patients. Grace's voice was strained, and she appeared tense as she shared her sentiment: "If I couldn't talk to a visit nurse about a patient because it was their first time with a patient, I wouldn't be able to talk to anyone! It's so frustrating!" To check-in on how patients are doing, NPs will often reach out to CNs. Grace's statement is reflective of the staffing and resulting continuity of care problem in home care. Grace's comment provides insight to the fact that that continuity in CNs for patient care poses an issue. This is problematic for many reasons. It is suboptimal for patients because they are constantly seeing new faces and needing to repeat their stories, which is more than inconvenient, it consumes the little energy they have. This is problematic for the NPs because they are reliant on the insights of the CNs who have come to know their patients and able to detect changes from visit to visit. Grace's experience highlights a lack of continuity in nursing care and even a lack of a system for nursing staff to communicate among themselves about how patients are doing. This lack of continuity also poses challenges for nurses who are simply trying to get to know their patients. A team or collaborative approach is often identified

as an important part of palliative care. The inability of CNs to speak to their patients' status further hinders this approach to team care. When CNs are unable to respond to inquiries from the NPs, this hinders the capacity to collaborate and address patient care needs. What might have been resolved in a quick phone conversation now necessitates an in-person visit for the NP.

I also observed how the lack of communication regarding patients who are having difficulty also weighs on the NPs' minds and affects their practice. As consultants, they depend on others to reach out to them and let them know that patients are having difficulty so they can advise on changes that might help. Because they know they can help in most situations, not receiving updates and then hearing about a patient who experienced problems was upsetting for the NPs when this became known to them. Grace described how she felt responsible for patient suffering despite her best efforts to work around communication challenges:

> Now with nurses, too, sometimes it's not a good relationship. I'll call the agency or the care coordinator as I really need an update, and I'm not receiving that update. And then I'm finding 2 days later that my colleagues are getting calls because there's a crisis. So, then I feel a little responsible for that. But really, it's because I couldn't get the communication and the information. (Interview)

The lack of responsivity from CN colleagues is distressing to NPs, given their reliance on nurses' assessments to determine how the patients are managing. The NPs in this study were reliant on input from nurses to determine if therapies or plans needed to change. This anticipatory approach can keep patients comfortable, but the lack of communication and information risks leaving sub-optimally managed symptoms to worsen. Furthermore, the NPs in this study recognized how challenging it can be for on-call colleagues who have no knowledge of the patient to be able to address needs when CNs call and feel that they would have been better positioned to address the

patient and CN needs. The NPs in this study valued ongoing assessment and interventions to prevent crises but were highly reliant on their nurse colleagues to support this approach. Grace further clarified her perception of the impact of these situations, both personally and for patients:

> It's also emotionally draining and exhausting in that way because you feel that something could have been prevented. That's what bothers me, patient suffering that could be prevented. And whether it's emotional or physical, if I can prevent that. I'm a planner; I'd rather prevent that rather than wait to the last second, and then they're in crisis. (Interview)

As illustrated in these examples, the NP role is interdependent with, if not dependent on CNs who are more proximal to patients and generally have more frequent contact. Without timely and accurate communication from these health care providers, the NP role is restricted from having optimal impact on the lives of patients, their families and even health care providers who might benefit from additional clinical support.

Communication, as an important part of palliative care in the community, occurs not only through direct exchanges, phone, or text, but also through written documentation. During my fieldwork, I observed how the NPs reviewed nurses' and PSWs' chart documentation in the home, learning from their nursing colleagues' insights about their patients and basing their actions on notations (e.g., pain control and questions about MAiD). While reviewing the chart in the home, Christine turned to me and commented in a frustrated tone, "See this? This is a problem, the nurse's chart only by exception. Look at this chart. There is nothing here, it's annoying. August, me; September, me; October, me. There is no narrative, only vitals." Christine's "annoyance" is based on the belief that the interactions VNs have with patients extend beyond vital signs. Christine (and other NPs) believe nurses have or should have

important conversations with patients and gain critical insights that would be valuable to share. In this case, it is true that this patient was leading a relatively active life despite his tumor, ongoing pain, and feeding through a stomach tube. However, this same patient had also been contemplating MAiD and at times had uncontrolled pain. Christine expected that the VN would have had some conversations that could provide insight into how the patient was managing.

Furthermore, Christine felt she would benefit from the nursing insights and could address any outstanding concerns the VNs identified through their interactions with the patients, including concerns the patients might not have shared with her because the patient might have a closer relationship with the VN. Sometimes patients share concerns with one care provider and not another. Multiple organizations are often involved with patient care, requiring multiple sites of documentation. In this example, it was not clear whether an assessment had occurred but had not been documented, had been documented elsewhere, or if no assessment beyond vital signs had been done. In a follow-up interview with Christine, she shared her perception of systemic structures that posed challenges for sharing information through documentation:

> "I think the problem is we do a lot of double documenting." I responded, "Okay." Christine added, "agencies have their own electronic charts. Oh, and then we have the chart in the home. And then we have the CHRIS record. So, there's sometimes double and triple documentation." I asked, "And if the agencies have their own documentation, who has access to that?" Christine replied, "Not me!" (Interview)

As Christine explained, multiple agencies and multiple documentation systems and a lack of a shared communication system hinders communication across organizations.

Trust: "Those Are the Ones That I'm Inclined to Follow Up with the Patient a Bit More Closely"

NPs in this study believe a core part of their role includes providing support to their physician and nurse colleagues in the community. NPs value the opportunity to offer clinical guidance and advice to their peers who encounter challenging situations. This theme of trust represents how the NPs, to be able to do their work, needed to feel they could trust that others would fulfill their responsibilities. This means that the NPs could trust that others would detect patient changes, would reach out when they perceived the patients' conditions were changing, that the information provided was accurate and readily available, or that others would follow through as negotiated. The NPs expressed how their ability to help nurses who contacted them about patient concerns was constrained or rendered impossible when nurses were unable to provide relevant and accurate patient information. Furthermore, the NPs altered their practice patterns when they felt they could not trust others so they could more closely monitor the patients.

In the local organization of home care, CNs are expected to liaise and communicate directly with the patient's PCP to address medical concerns they have about the patients. For example, this could include problems with existing symptoms or new symptoms that signal a change in their health or symptom management. The PCPs has access to and maintains the patient record, often knows the patient's history, and can provide appropriate clinical guidance. However, as previously identified, PCPs may not be easily reachable or able to promptly return calls for VNs who are doing home visits and have limited time with patients. Furthermore, the nurses might be familiar with the NPs and feel more comfortable communicating with them.

As a result, the NPs shared how some VNs would call the NPs for help when they noticed new or escalating symptoms and were unsure of how to interpret or manage them. However, to help nurses, the NPs required specific and accurate patient information to make a sound clinical judgment and provide guidance and a therapeutic plan. On several occasions during my fieldwork, the NPs commented on how nurses called them with only a vague patient concern without relevant details critical to informing an assessment. In many instances, the VNs were no longer at the patient's home and therefore could not be coached to collect the appropriate information. Critical information needed to guide the NPs' advisement could include a pain history and assessment, current medications, vital signs, chest sounds, abdominal exam, or pedal edema. The NPs spoke about feeling compelled to help but struggled when providing guidance based on incomplete information. Christine described her experience:

> Sometimes when we're on call, we get these calls: "Oh hi, I'm calling because Mr. X is in pain." "Okay, well, where's his pain?" "I don't know." "Well, what's he using for his pain?" "Oh, I'm not in the home anymore." Those are the nurses that you don't trust. They haven't done their assessment and they're already calling you, versus a nurse that I trust is going to call me and say, "Mr. X is in pain. It's located here, he's taken X number of opioids. I've checked his bowels. I've checked his chest. I've done this, I've done that." (Interview)

Christine highlighted how reliant the NPs are on the information from CNs, and this information has significant implications for how the NPs can support the nurse and patient. When nurses call NPs for assistance, the NPs try to provide the best advice possible but rely on the nurse's ability to accurately assess and communicate their findings. Andrea shared an example of how partial and even incorrect information impacts her work:

> A patient of mine who fortunately I knew fairly well… His nurse calls me to tell me that he's hypotensive, like significantly, 70 over 40. And I said, "Okay, what anti-hypertensive is he on?" And she said, "None." And I'm driving in the car, and I think to myself, I'm pretty sure he's on metoprolol. So, I said to her, "Okay, I want you to grab the blister pack and read through to me what he's on." He wasn't *just* on the metoprolol; he was on another anti-hypertensive. And I was like, "He should not be taking these." So, I think it's feeling that the information they give you is accurate. And also, it was a good reminder that when I'm on call, and I'm getting calls about all kinds of people I don't know about, I can't always trust when they tell me that somebody is not on something. Or when I ask, that the information actually is true. Unless it's a nurse that I feel very comfortable with their skills. (Interview)

The NPs highlighted the need to trust that the information they were given was accurate, or else they could not provide advice safely. The accuracy of information is always important, but this is even more true when the NPs do not have easy access to the patient's file, as shown in the interview excerpt. In this situation, Andrea's remote recollection of the patient enabled her to talk the nurse through the information required to inform her recommendations. Nurses commonly call for assistance about patients when no longer in the home. The nurse's proximity to the patient is not a problem if they have completed an accurate assessment and can provide the required information. However, the NPs highlighted how, in many instances, the nurses did not have this information. Nadine described her experience to me as we waited for a group meeting to begin:

> When the VN does not provide a history or physical, I find it frustrating. I used to work with them. Now I tell them I can't. For example, I ask, "What are his symptoms?" They

> answer, “I don’t know.” “What are his physical exam findings?” “I don’t know.” Now I just tell them, “I can’t help you based on the information you have. You need to go back to the home and do an assessment.” (Fieldnote)

While there was frustration in Nadine’s voice, I sensed she regretted being unable to help. She appreciated that the nurse had recognized and shared the concern but felt tethered in her ability to help in any meaningful and safe way. She also understood the patient might continue to have unmet needs in the interim.

The NPs genuinely desired to support the nurses and welcomed nursing inquiries about patient concerns. However, the NPs also frequently described being unable to help due to unavailable and insufficient assessment information from nurses. The NPs recognized the challenging and complex nature of palliative care and understood that the VNs were reaching out because they had identified a problem or were having difficulty with a patient. Without the NPs’ advice, VNs may not be able to make patients comfortable, putting them at risk for unnecessary suffering or driving them to seek relief in a hospital setting. To be able to help, however, the NPs rely on VNs to either collect the required information or, at the very least, to remain with the patient so they can be coached to collect the required information. In the previous fieldnote excerpt, Nadine’s ability to help is reliant on her trust that others will be able to provide the required basic information. While potentially interpreted as a minor inconvenience, closer examination of what the NPs actually experience in these instances suggests emotions beyond frustration. In their description of such situations, I often noted their expressions became more focused and serious, communicating a significant level of concern about the situation. The NPs’ reactions were not based on the premise of inconvenience but on the impression that the nurses and patients were encountering a difficulty the NPs could likely help remedy. The NPs

understood that when nurses called, it was because they were worried about a patient. While the NPs perceived redirecting the nurse to return to complete an assessment as the only acceptable option, they also understood that there would be a delay in resolving patient issues by perhaps a day or more. The NPs perceived such delays as prolonging patient suffering and potentially escalating into a more significant problem.

The reason CNs called without assessment information to support their claims and their inability to provide accurate information is not clear. However, these patterns suggest either a lack of knowledge or a lack of time to complete an appropriate assessment. The NPs recognized that the CNs required significant knowledge and skill to carry out their work. As one NP commented to me, “It’s not easy to be a visit nurse. It takes a lot of knowledge.” The NPs try to help nurses develop knowledge through group and individual teaching; however, their contact is relatively limited. While NPs can provide advice, CNs need to be supported with adequate time for assessment and communication to do the work required. Support in skill-building regarding assessment and communication is also essential. The level of knowledge and skill needed to support patients and families through to the EOL at home is not well acknowledged from a systems perspective.

In my fieldwork, I noted how the NPs became visibly upset when they encountered patients with advanced and uncontrolled symptoms despite regular and recent nursing visits. Such experiences were based on their shared values of preventing unnecessary suffering. The NPs understood these instances as VNs not detecting or communicating changes in the patient’s condition. In many instances, the NPs perceived that the patient’s symptoms would have been easily preventable or manageable had they been contacted for guidance. However; the NPs also continuously reflected on their understanding of the challenging work of VNs.

In this setting, as part of a palliative consultation team, the NPs participated in weekly rounds with other team members (i.e., nurses and physician). The purpose of these rounds was to inform the team members who would be on-call about patients who might be anticipated to have difficult symptoms or who were actively dying. These rounds also provided team members with a forum to discuss challenging situations. Commonly, during these rounds, the NPs shared experiences about their patients, where patients were found experiencing unaddressed concerns (e.g., pain, delirium, oral candidiasis, constipation, and medication mismanagement) despite regular, even daily nursing visits. Grace described her recent experience during a team meeting. Her concern was about the poor state in which she found the patient despite daily nursing visits. Grace perceived that this patient's condition had obviously deteriorated, and she felt the nurses should have both noticed the changes and notified someone about this patient's deterioration, given their daily interactions with the patient. While sharing her experience, Grace was visibly upset, and the tone of her voice alerted me to her emotional state of concern: "The nurses are going in there every day, and there are no calls. He is in fluid overload, black diarrhea everywhere." Grace's distress was based in the fact that she perceived visible signs of decline and concerning symptoms and knew that the patient would have benefited from earlier attention to better manage his symptoms, keep him more comfortable and helping with future planning.

I frequently heard the NPs debate whether a lack of knowledge or other factors contributed to the lack of detection of patient decline. For patients nearing the EOL, symptoms can evolve very quickly. Social contexts can be complicated, in that patients and family may conceal or downplay symptoms or concerns, not wanting to trouble their health care provider or worry their FCG. Furthermore, patients may even misinterpret or dismiss symptoms that seem minor but that actually represent the early stages of more serious problems. The organization of

community care with weak lines of communication and a lack of consistency in nurses assigned to patients may also contribute to challenges in discriminating patient changes. When there is a new nurse every day, it may be difficult to note incremental changes in a patient's condition. Furthermore, it is common for symptoms in palliative care patients to be insidious, requiring vigilance and skill for detection. These factors highlight the importance of VNs with the knowledge and skill to detect concerns and the time to communicate concerns that could be easily addressed with the right support before they escalate and cause patient and family distress. Once again, it is evident how NPs in this study are in many ways dependent on CNs. Without CNs who can detect changes and know they can reach out, the capacity of NPs is restricted. Without knowing there is a potential problem, NPs are not able to become more involved, assess a situation and work with CNs, patients and families to either prevent escalation of problematic situations.

In my fieldwork, I have also often heard how the NPs, troubled by their perceptions of missed care/rationed care, also recognized the challenging working conditions for nurses. During a meeting, the NPs discussed their troubling experiences. The NPs perceptions and acknowledgment of difficult working conditions tempered their expressions of outrage about missed symptoms. Nadine described a recent incident where she found a patient who had signs of delirium, abdominal discomfort, and no bowel movement for 10 days. Nadine characterized this situation to a fellow NP as avoidable given the regularity of nursing visits, the presence of necessary medication in the home, and the availability of the physician for a phone consultation. Nadine and Grace discussed the situation trying to understand how such situations could occur:

> Nadine asked, "How can the VN not notice? And they had access to everything. Or, just call! The doctor is so available and willing." Grace added, "That's the scary part. Visit

> nurses are supposed to advocate for patients. What are you doing as a visit nurse?" Nadine remarked, "You have to wonder what the working conditions are." Grace contributed, "They don't want to notice because then they have to deal with it, and it will take time." Nadine inquired, "But why do we all have to take that on, and why, how do agencies get away with this?" (Fieldnote)

This interchange highlights how the NPs recognized that there are systemic and organizational issues that contribute to the challenge of patient care. While the NPs encountered situations where they felt nurses should have noticed and communicated changes to patient conditions, they also recognized the influence of systemic challenges. The NPs commonly identified that the working conditions for VNs acted as disincentives for a holistic approach to patient care and contributed to missed or rationed care. During a team meeting, Nadine described an episode where she was consulted to help manage a patient's escalating symptoms. By discussing with the family, she discovered that the patient's symptoms seemed to have been escalating over the previous week, but, despite daily nursing visits, neither the physician nor she, as the NP on the patient's chart, had been notified. Nadine shared her experience with her colleagues and, as she spoke, her general lighthearted demeanor shifted to a more serious one as she communicated both her disbelief and frustration with the situation:

> There are lots of meds in the home, and I am a phone call away. My number is there, and the physician is answering his phone. The agency says maybe they need more education. Yeah, they do, but maybe you need to have them not seeing 10 patients a day or value these palliative visits more… I think there is a system-wide problem. (Fieldnote)

Nadine recognized a problem that involved nursing but that is further rooted in the broader system that underestimates the level of education and the amount of time CNs need to attend to

the needs of palliative patients. The NPs experienced a tension between encountering patients with whom VNs have missed or rationed care yet understood the challenging work conditions to which their colleagues are subjected. At the same time, the NPs recognized the importance of VNs to a quality patient and family EOL experience, both in their direct care and their capacity to work as part of a team. Andrea shared her view on the importance of the role of nursing in supporting palliative care patients: “But I do think a really important piece is the skilled visit nurse, dedicated and skilled. Because when we don’t have skilled visit nursing in place, then things fall apart.”

The NPs understood that CNs are key for patients and families to feel safe and recognize subtle changes and that nurses need be provided with the time to reach out for support when they perceive they need help to support patients at home. The NPs also identified success stories of patients who were appropriately supported at home when their nursing colleagues were well resourced to do the work they needed to do. However, the NPs in this study recognized the challenges of how community care is structured and resourced in this study setting. This organization of care directly impacts how CNs are able to carry out their work. This is particularly true when the required education is unsupportive of nurses or when nurses are not given the necessary time to properly assess and manage patients at home. Nadine provided her perspective on how the experiences of patients and families relied on how CNs are supported in their work:

> It makes me feel badly for the patient because their experience could be so much better with an experienced nurse or a nurse who’s engaged. Yeah, or a nurse who comes from an agency that allows them to be engaged. So, I feel badly because it’s such a big part of

> the puzzle. And when it goes right, it really goes right, and when it goes wrong, it can be a barrier for people being at home and being well managed. (Interview)

Nadine highlighted how the broader structure of the health care system has the ability to either potentiate or constrain her nursing colleagues in their work. As a result, the NPs' efforts are similarly constrained or potentiated. Health care agencies employ CNs but have their own values and structures; for example, they restrict flexibility, time spent with patients, or even the educational and professional support they provide. These values and structures shape the CNs' capacities. Furthermore, the agencies are also embedded in broader systems that actively and passively impose values the agencies can reproduce. Active imposition may be the manner in which programs are funded, while passive imposition may include not addressing system inadequacies through restructuring.

The NPs frequently try to connect with CNs to inform them that they can reach back to encourage nurses to call with concerns. This strategy is not always successful, primarily because of how care in the community is organized. Andrea described her experience:

> When I find out there's a visit nurse in the home that I don't know, I try to get their numbers so I can reach out to them and say, "Call me if something changes. Don't let it be a disaster. If you're seeing subtle changes, let us know earlier." It doesn't always work. I think, unfortunately, we're moving away from the model of primary nursing where one nurse is predominantly in the home, and now the patient may see a different nurse every day. (Interview)

Despite strategies to establish relationships and initiate lines of communication, a disjointed system that creates the lack of continuity of care ultimately works against the NPs' efforts. In this interview excerpt from Christine, even reaching out proactively can be rendered

ineffective because of a revolving door effect in staffing. When the NPs in this study perceived that the communication from either the nurses or physicians about the patients was unreliable, they tended to modify their practice pattern, fearing the patient might otherwise "fall through the cracks." In my interview with Christine, I probed further to explore the impact of unreliable communication on the work of the NPs:

> I think some of them, they're not as knowledgeable, but you know they're going to call you if there's a change. And you can build on that. It's the ones that kind of go rogue and, every time you walk in, there is a crisis because they haven't managed things well. Those are the ones that I'm inclined to follow up with the patient a bit more closely.

In this instance, going "rogue" represents a lack of help-seeking by CNs. This lack of help-seeking when needed results in reduced trust regarding the CN's judgment in relation to knowing when to reach out for additional clinical assessment and guidance. When communication or consultation seems to be inadequate, the NPs often adjusted their work to schedule more frequent visits to check in on patients. The difficulty with this approach is that it reduces the capacity of the NPs.

Teamwork and Navigating Responsibilities: "Can You Order It or Do You Want Me to Order It Right Now?"

In this setting, PCPs and CNs are responsible for the medical and nursing needs of patients who require palliative care in the community setting. The NPs rely on PCPs and CNs to communicate and maintain their care responsibilities as part of the "team." When nurses and physicians are not reliably available to play their part in patient care, this becomes problematic not only for the NPs but also for the patients who depend on them. Furthermore, timely responses are essential when patients' conditions change and they experience uncontrolled

symptoms. In such instances, NPs find themselves shifting their energy to take on broader roles to compensate for the absence of these important collaborators instead of potentiating the work of CNs and PCPs. This theme of teamwork and navigating responsibilities refers to how the NPs are seen to strive for a teamwork approach. However, when team members are not responsive or available to play their part in the team, this poses a challenge. The lack of team work compels the NPs to modify their role, ideally by negotiating responsibilities or doing what needs to be done to ensure the patients' needs are met. In this setting, the NP role is labelled as a consultant role; however, when situations are rapidly changing and clinical and resource decisions need to be made immediately, they are frequently seen to adapt their role to become more involved in care-coordination, securing resources and, clinical decision-making.

Because of their established relationships and knowledge of the patient's medical history, PCPs are generally considered the main contact for patient medical concerns. The extent to which physicians are engaged or involved with their patients with palliative care needs ranges from highly involved with participation in home visits, to available for consultation by phone any time, to consultation between regular office hours, to not readily available. This variable availability poses a challenge for patients who are nearing EOL and experiencing problematic EOL symptoms. PCP availability is also problematic for VNs who might detect a patient problem and need advice. As highlighted previously, the NPs have identified how they value communication and the coordination of patient care. The NPs viewed this as increasing their ability to meet patient needs and as a satisfying way to work. However, working in this manner was highly dependent on the values and commitments of their community colleagues and ability to overcome the system constraints.

The NPs in this study encountered difficulties when physicians were not readily available, did not respond, or did not follow through as expected or negotiated. When physicians were not engaged, the NPs felt that their lack of engagement jeopardized the quality of patient care and balance of responsibility. In my fieldwork, I observed and heard about how the NPs encountered challenges when PCPs were absent or unavailable to fulfill their expected duties to patients. This absence was perceived as placing the CNs, patients, and NPs in difficult positions. As a result, the NPs were compelled to take on a broader role in patient management beyond that of a consultant who provides clinical advice and informational support. Grace explained how she is affected when her physician colleagues do not honor negotiated working or communication patterns, or are unresponsive:

> My difficult and challenging relationships are those that don't do that. There's not a good communication. They don't follow up with patients, or they'll say, "Grace, I'm going to go do a home visit," they confirm that with the patient, and they haven't shown up multiple times. And so, then what happens is, then the patient and family start looking to me to be their primary [care provider] because it seems like the physician is not reachable and is not reachable by the nurse, and the nurses start thinking that I'm the primary. So, because they can't reach [them], they leave messages, and nobody calls back. Those kind of communication breakdowns happen, and they know I will call back. (Interview)

While Grace identified this experience as poor communication, what has actually occurred is that the physician has disappeared from the care context. Availability is part of the PCP role, so poor availability is a failure of role expectations. I often observed the NPs trying to balance their consulting role, where they were expected to mentor physicians and provide advice on how to address patient needs, with needing to make time-sensitive clinical decisions and actions. In their

consultant role, there is an understanding that the NPs will provide guidance and physicians will manage the implementation, such that they will address the prescribing and follow-up.

When the PCPs were unreachable and unresponsive, the NPs found that they were compelled to take over managing the patient's needs. This shift in responsibility can potentially pose difficulties moving forward. While the NPs are fully capable of "assuming" this responsibility, confusion may arise as to who is responsible for ongoing patient needs moving forward, such as the ongoing assessment of response to treatments and renewal of medications. The NPs try to keep physicians involved so they can continue to carry out their primary care duties. However, when their physician colleagues are nonresponsive or unavailable, the NPs make decisions about what is more important in that moment to prevent delays in meeting the patient's needs. The need for the NPs to engage in this level of intervention highlights the gaps in how the broader system is organized. The consultant role is not intended to address the system "gaps", however the NPs in this study at times are compelled to work beyond their consultant label and shift their role to fill in these gaps.

Christine provided a typical example of what the NPs experience when a patient's physician is unreachable and the patient's condition is changing rapidly, requiring advanced support:

> I went and saw the patient, and in fairness to the physician, things evolved really quickly. I ordered the symptom management kit. I tuned up a bunch of medications. He was in acute respiratory distress. I tried to reach the physician, I didn't hear back, so then the following day, I wanted to drop off an educational booklet for the family, and so I went out to see them again, and I was so glad I did because he was really in distress. We ended up putting him on palliative sedation. Again, I couldn't reach the physician. So, for the

> patient, I ended up totally taking over. And then he died the next day. So, in that case, when you know there is an absentee doctor, we often do end up taking over. (Interview)

If patient comfort is at risk and physicians are unresponsive or unable to address patient needs in time, the NPs will often take on a broader role of therapeutic management and care coordination. Physicians may not have the required time to meet the patient's needs at the moment they arise. There may be logistical constraints on physicians who may be unable to disengage themselves from a busy schedule of a primary care practice. Time is critical when acute needs arise, particularly if patients are very symptomatic and drugs and equipment need to be ordered and delivered. The NPs engaged in discussions to support physicians to be involved. However, when able, the NPs preferred to engage in a dialogue first to determine the physician capacity and then negotiate who was responsible for immediate and follow-up elements in care. Grace provided an example of her negotiation process:

> If I can get the physician, then I'll say, "Can you order it or do you want me to order it right now?" And if they can't order it right now, then I'm doing it in my car, ordering these things. I'm ordering oxygen, I'm ordering the symptom management kit, I'm ordering the morphine, I'm sending those over urgently and getting the nurses involved. So, it all depends on the urgency of the patient and their level of distress. And that's what determines how I respond. (Interview)

In observations, I noted how the NPs engaged in flexible practices when needed, trying to keep the PCPs involved but intervening when patient needs were acute and needing timely attention.

The NPs in this study are employed as consultants. That is, their primary objective is to support physicians and nurses to provide better patient care. What is not accounted for is how demanding this role is, primarily because of the "in-between" locale they occupy. When seeing

patients, they have the knowledge and skill to decide and intervene to help patients. As a consultant, this means tracking down the patient's care provider and advising them of findings and recommendations. This is problematic in that physicians may not respond in a timely manner. During fieldwork, I often heard the NPs describing the dilemma they face between adhering to their "mandate" as opposed to taking immediate action. Andrea provided insight into her experience:

> I have to say, and I think it completely depends on what kind of day I'm having, which is very not concrete. If it's really busy, I am more likely to "do" than to "mentor." And if I'm having a reasonable week, I'm much more likely to take the time to reach out to their physician colleague to mentor versus do and send/fax a note to the doctor to say, "This is what I've done, please follow up." Which I fully recognize that that is not good consultation, particularly with a doctor that I've never worked with before who I need to set some expectations. But sometimes, in busy weeks, I just get lazy. (Interview)

While Andrea describes herself as getting lazy, what this really meant is that mentoring is far more exhausting and time-consuming than making decisions and acting as needed. The idea of mentoring and teaching is based on the goal of long-term capacity building. The reality is that decisions often have to be made quickly to ensure time-sensitive interventions, such as changes to medication regimes. As a result, how NPs approach this overarching expectation to act as a consultant is very much shaped by the nature and timeliness of required interventions balanced against the cumbersome process of mentoring where energy and time are limiting factors.

The NPs often acted to make their work manageable and ensure patients got what they needed in a timely manner to manage heavy caseloads. While within the NP's professional scope, assuming these extra activities can be problematic in this setting. The NPs' position

mandates mentoring, and the NPs feel a professional responsibility to this. The NPs expressed concern that taking on primary responsibility for patient palliative care needs could set a precedent and allow physicians to feel minimal urgency to act quickly or respond to CNs or NPs because they knew that NPs would just take care of the situation. Lastly, as consultants, NPs do not have the capacity to provide the close follow-up that many patients need. Grace provided insight into how these situations affect NPs:

> First of all, the caseload that I have, then my other patients, I only have so many hours in the day. So, then what happens is I end up focusing more on these patients and neglecting my others. And then you know, a crisis has happened, and so it becomes very demanding. The other thing that happens is that I don't mind, if physicians are away on vacation, taking over for a short period, but I would rather give recommendations and have them follow through as the primary provider. When I become the primary provider, then I'm renewing all the medications and doing all the things and checking the labs and doing all that on top of my other work. So, it's an added workload. If I was going to do that, I would have to have a much smaller caseload than what I'm carrying right now because that wasn't the way the system was set up, you know the way we're doing that. I think that those are the frustrations with the workload. I think the time commitment, the charting, the increased communications, then when the physician comes back. Additionally, trying to get them on board, a lot of energy is spent. (Interview)

In this excerpt, Grace explained the dilemma that the NPs face when assuming more involvement. The NPs often find themselves taking on more patient care when physicians are unavailable. Physicians, while entitled to vacations, have been seen to essentially disappear for weeks without arranging alternate coverage for their patients. While I have seen the NPs in this

study agree to "cover" for physicians while they are away for short periods to maintain a relationship, their role is not intended to be a physician vacation coverage service. While physicians are expected to arrange their own medical coverage, "disappearance" without alternate coverage occurs frequently. This lack of system infrastructure represented by physician "disappearance" influences NPs to enact a broader role than consultant, but when this happens, NPs can find it challenging to meet their consultant responsibilities.

Chapter Summary

In this chapter, I presented how the context of community palliative care in this setting is problematic because of structural deficiencies. Structural deficiencies, like unstable staffing for community nurses, inadequate support for community nurses, and poorly integrated systems of responsibility and communication, negatively affect the extent to which the NPs can positively support their peers and patients. The NPs highlighted their experience of working within this context, including the challenges for timely and accurate information-sharing. These challenge the NPs to have a lack of trust and impaired abilities to work as a team, which is essential to ensuring patients and FCG palliative care needs are well supported.

The NPs work to support CNs and PCPs, yet they can encounter difficulty when CNs or PCPs are less engaged in patient care than they are expected to be. The home care and health care system under-resourcing places strains on health care providers that limit their involvement in patient care. While valuing the concept of teamwork and collaboration, the NPs in this study encountered challenges to bring their colleagues together. Furthermore, the fragile nature of palliative care patients requires a nimble system that responds quickly to rapidly changing circumstances. The NPs are an important part of improving the responsiveness of this system; however, improvements to broader organizational issues are required to ensure patients receive

the care they need. To begin, nurses require support to develop the required skills and knowledge and need the appropriate time allocation to be able to provide holistic patient care and communicate with other team members when they require help. PCPs need to be appropriately compensated for after-hours support and be forthright in their commitments and availability to support patients and their CNs. Good intentions are not sufficient. A single electronic charting system would support communication about shared patients. Until such changes are implemented, the NPs will continue to experience constraints in their capacity to fully support their patients and colleagues.

In the next chapter, I present a synthesized discussion of my study findings and situate these within the current literature. I also highlight the strengths of this study, the practical and policy implications, and the study limitations.

Chapter 8: Discussion

This study aims to better understand how NPs enact their role as community palliative care consultants in one distinct geographical region of Ontario. In Chapter 2, my literature review, I contextualized the community as a caregiving landscape. I also presented the challenges patients and FCGs face in receiving the care they need in the context of community-based palliative care. In Chapter 2, I also underscored how NPs continue to be added to diverse health care settings to improve health care quality and address diverse populations' unmet health care needs. In keeping with this global and national strategic approach, NPs have been systematically added to each of the health regions of Ontario to enhance the quality and access to palliative care in community settings. Because NPs tailor their roles to local needs, with different regions adopting different models of care provision, it is a challenge to develop a comprehensive understanding of the NP role. Before we can fully appreciate how NPs impact their care environments, it is imperative to understand how they enact their role in this setting. In this discussion, I present a synthesis of my findings to answer my research question, "how do NPs enact their role in community palliative care?" In my discussion, I draw on the findings presented in the four findings chapters and integrate them with the literature. As I move through my discussion, I also add narrative detail about the specifics of the findings at times.

I begin this chapter by presenting a summary of this study's key findings and strengths. I then follow with a discussion of my findings in greater detail. To organize the discussion, I draw on the WHO (2020) definition of palliative care, introduced in Chapter 2. I then discuss the findings related to MAiD and situate them within the relevant MAiD literature. I have chosen to dedicate a separate section to MAiD in my discussion because of its recent introduction to the health care landscape and associated significant implications for nursing practice. Historically

MAiD has not been considered a part of palliative care. However, the recent legislative changes have shaped the palliative care landscape in such a way that compels nurses to confront how they situate themselves personally and professionally regarding MAiD. In the third part of this discussion, I present RI as an approach for contextualizing and interpreting the role enactment of NPs. I offer a reflection that integrates my findings into the theoretical landscape of RI. I conclude this chapter with a discussion of practical, educational, policy, and study limitations.

Summary of Key Findings

This study showed that NPs engaged in a broad range of activities that were grounded in relationships to best support the unique needs of patients and families. NPs used information gathered through conversations with patients and families to inform how best to support patients and families in their particular situations. NPs drew on acquired understandings of patients and families in their approaches to anticipatory planning, symptom management and transitions across care sites to provide a better palliative care experience. This study also showed that NPs used their advanced knowledge and skill to enhance the knowledge, skill and clinical support of CNs and PSWs in an unstable service environment affected by high levels of attrition.

NPs in this study also supported FPs with an overall picture of the patient's situation and guidance on managing current and anticipated difficult symptoms. At times, NPs found that a more appropriate way to build capacity was to share patient management responsibility with PCPs through negotiating involvement and close communication. In this study, NPs also brought together disparate health care providers in a poorly integrated environment to facilitate a mutual understanding of patient and family needs.

Finally, in this study, NPs were labelled as consultants, a role traditionally characterized as being removed from patients and families and offering expert advice. While enacting a

consultation-like role, NPs in this study, empowered by their in-depth knowledge and broad legislative scope of practice, flexibly expanded and contracted their involvement based on their evaluation of situational needs. The primary example of such situations includes the management of rapidly escalating symptoms where no primary care provider was available, taking on advanced assessment of the patient, resource allocation and symptom management.

Study Strengths

This study contributes to the limited national and international literature about NP role enactment in community palliative care. Nearly 500 hours of observing NPs in their day-to-day work interacting with various actors and in a broad range of situations contribute to the strength of this study and the findings. I believe that my background as an NP facilitated access to the field and interactions with study participants. My background as an NP also positively influenced access to the research setting, data collection, analysis, and interpretation processes. My pre-understanding of general NP practice in other settings informed the study. At the same time, my limited knowledge of the specific context of community palliative care enabled me to challenge the taken-for-granted aspects of the setting. The use of FE to answer the research question resulted in a contextualized understanding of how NPs enact their role and how their shared attitudes, values, and beliefs underpin the role enactment in community palliative care. The strength of FE studies is that they support the development of a contextualized understanding (Higginbottom et al., 2013; Knoblauch, 2005). In presenting the findings of this study, I aimed to present the data using thick description, as advocated by Geertz (1973), to help readers judge how transferable these findings are to other health care settings and nursing populations. With this contextualization, others might identify similar patterns in nursing practices in similar and even dissimilar settings.

Role Enactment

A fundamental expectation of the NP role is engagement in a patient-centred and holistic approach to patient care while enacting the domains of advanced nursing practice related to clinical practice, collaboration, consultation, and referral. Furthermore, NPs use their advanced knowledge to conduct comprehensive patient assessments, diagnose and provide therapeutic interventions, promote health, and contribute to preventing illness and injury (CNA, 2010). While these are fundamental expectations of NP practice, knowledge of how NPs draw on and enact these competencies in the little-understood environment of community palliative care was lacking, which underpinned the motivation for my study.

In this study, I found that NPs engaged in a broad range of professional activities to improve the care experiences of patients, FCGs, and other health care providers. For instance, the NPs in this study enabled patients and families to make their needs and desires known and ensured the patients' immediate caregiving teams understood these. The NPs also facilitated theoretical and practical knowledge and capacity-building with their peers (physicians and nurses). This capacity-building further enabled nurses and physicians to continue to meet the needs of their patients relatively independently. Where the system showed gaps in care through PCP inaccessibility or a lack of CN reliability, the NPs expanded their reach by assuming physician and community nursing roles. In this act, the NPs met patient needs by assessing, monitoring, prescribing, and teaching to enhance patient symptom management and reassurance for families. Where able, the NPs in this study brought together otherwise disconnected community physicians and nurses and families to establish the plan of care that would best suit the patient and family's needs. Ultimately the NPs worked to keep patients comfortable in their

homes and improve their EOL experience. The following section provides a synthesized discussion of how the NPs enacted their role in this setting.

Palliative Care

In brief review, palliative care is an approach to improving the quality of life for patients and FCGs who face life-threatening illnesses. The WHO definition maintains the importance of 1) a person-centred approach; 2) early identification and the treatment of pain and other physical, psychosocial, or spiritual concerns; 3) a team-based approach. The WHO (2020) promotes person-centred care as central to the philosophy of palliative care. The WHO does not explicitly provide a specific definition of person-centred care, but it refers to elements of this care, suggesting a holistic approach. A recent synthesis of reviews conducted by Hakansson et al. (2018) identified that person-centred care involves nine themes, including 1) empathy, 2) respect, 3) engagement, 4) relationship, 5) communication, 6) shared decision-making, 7) a holistic focus, and 8) individualized and 9) coordinated care (Hakansson et al., 2018, p. 6).

A Person-Centered Approach

While not explicitly analyzed using these discrete themes, the findings illustrate that NPs frequently engage in a person-centred approach with patients and families. The fundamental underpinnings for NP practice in Canada include person-centred care (CNA, 2010; CNO, 2016). The person-centred approach enabled the NPs to appreciate patient and FGC perspectives and concerns in this study. The findings of this study reveal that NPs enlist a person-centred approach with their patients, prioritizing a trusting relationship that is integral to encouraging patients to share their situations. In this study, the NPs enacted their role with patients primarily through conversations. They used conversations to learn about patients and enable them to share their stories. This process allowed the NPs to develop a broader understanding of the patient,

including their fears, hopes, challenges, available resources, and what they considered important now and for the future. The NPs also directed conversations to review how the patients saw their current situation, which health care providers were involved, and in what capacity. Other studies about NPs in community palliative care showed similar findings in that NP work centred on constructing a broader understanding of patients through discussions (Deitrick et al., 2011; Pesut, Thorne, Schiller, Greig, Roussel & Tishelman, 2020). Deitrick et al. (2011) characterized NPs in their study as assembling an "overall picture" (p. E26), an approach implemented to achieve a holistic understanding of the situation. This approach enabled NPs to further re-tell the patient's story to others so that patient-centred care goals could be understood, made explicit, and better supported (Deitrick et al., 2011).

Similar to other studies that examine nursing communication, the NPs in my study engaged in open communication through listening and addressing questions and fears, identified as essential elements of emotional and psychosocial care (Johnston & Smith, 2006; Richardson, 2002). Johnston and Smith (2006) investigated nurse and patient perceptions of expert palliative nursing care. These authors found that nurses and patients alike valued communication, with patients articulating needing to feel heard and nurses recognizing the importance of talking and listening to patients. Richardson (2002) investigated patients' perceptions of interaction with community palliative care nurses that enhanced feelings of health and well-being. Patients identified key nursing actions to include allocating adequate time for the discussion, listening attentively, and remembering what they said (Richardson, 2002). Patients further reported that feeling heard when nurses openly addressed their fears and questions, explained medical details, and recognized and addressed their fears further enhanced their coping ability (Richardson, 2002).

Addressing the spiritual needs of individuals has been identified as an essential aspect of palliative care. Murray et al. (2004) advocated that spiritual care is "about helping people whose sense of meaning, purpose and worth is challenged by illness" (p. 40). In their study about the spiritual needs of people dying of lung cancer or heart failure, Murray et al. (2004) found that patients expressed spiritual needs by articulating distress and fears about an uncertain future. Murray et al. (2004) also found that worry about uncontrolled symptoms disrupted the illness work required, equally distressing to patients and FCGs. In my study, the NPs similarly addressed spiritual needs by addressing patient and FCG fears and uncertainties about their future. The NPs in my study also explored religious and spiritual beliefs with patients and linked patients and FCGs to local religious or spiritual resources (local chaplains, ministers, volunteers, religious services) when they desired this connection.

In my study, I saw how the NPs worked to weave a person-centred approach into the fabric of their day-to-day work. For example, in Christine's account from my findings section, she described arranging a second assessor for MAiD (who would administer the MAiD). Christine later learned that her patient had a poor interpersonal experience with the clinician who had provided a second assessment. Christine understood how the poor personal connection with the assessor jeopardized a meaningful MAiD experience for her patient. This understanding compelled Christine to find another MAiD provider that the patient would find more acceptable. Finding an alternate MAiD provider was not a simple task, as there were not yet many MAiD providers. Furthermore, at that time, MAiD providers in the region kept their identities protected to avoid public and professional criticism in the early days of MAiD implementation. Christine recognized the importance of the quality of her patient's MAiD experience and searched to find a better fit resulting in a better EOL experience for the patient and family. There is limited

research about providing high-quality patient-centred MAiD experiences in Canada. A recent study by Oczkowski, Crawshaw, Austin, Versluis, Kalles-Chan, Kekewich, Curan, Miller, Kelly, Wiebe, & Frolic (2021) explored patient and FCG experiences regarding their MAiD experience. Oczokowski and colleagues found that a patient-centred approach was considered an essential part of high-quality care, including supporting the details around the choice of location, route and timing of death, selecting who would be present. The study by Oczkowski, Crawshaw, Austin, Versluis, Kalles-Chan, Kekewich, Curan, Miller, Kelly, Wiebe, & Frolic highlighted the importance placed by family members on the human connection and compassionate care during the process. Additional research is required to learn more about how NPs and other health care providers in other settings facilitate a person-centred approach to MAiD from NP and patient/FCG perspectives.

End-of-Life Conversations

The NPs in my study engaged in a broad range of discussions with patients and FCGs to understand patient and FCG priorities and concerns and adjust plans as conditions changed. Conversations involved learning about patients, their values, desires, and hopes, contributing to important EOL planning. However, one expectation of the NP role in this setting is to establish specific decisions about EOL care. Goals of care and advance care planning have been identified as key to ensuring that patients receive the care they want and reducing patient and FCG anxiety, and increasing the sense of support (Detering et al., 2010). The NPs in my study described that part of their expected role was to address decisions about the desire for CPR and place of care for EOL. As patients' condition declined, care became more demanding, or symptoms became more challenging to manage. While many patients and FCGs had often given some thought to EOL planning or had started conversations with others (e.g., specialists, care coordinators), the NPs in

my study engaged patients in discussions to reassess their understandings and decisions. The NPs expressed their reliance on judgement and patient cues about readiness to discuss these topics. These NPs highlighted the need to assess patient readiness for conversations; however, they also balanced this against their perception of the patient's illness trajectory.

When the NPs felt that additional time was required to build trust in the relationship, they described delaying conversations to their next visit and, sometimes, after clear discussions about patient preferences, leaving patients in control of revisiting these conversations. Broaching these sensitive topics required skills that the NPs had learned from each other, and their techniques refined over time with experience. The NPs in this study highlighted the importance of having the time and opportunity to return to revisit discussions with patients. Researchers have underscored the goals of care and EOL discussions as essential activities for NPs in other palliative care settings (Deitrick et al., 2011; Mitchell et al., 2016). Other research has similarly identified the importance of tailoring the timing and content of these conversations to when patients are ready and willing (Abdul-Razzak et al., 2014; Friedrichsen et al., 2011; Parker et al., 2007). Additional research regarding patient perceptions of NP approaches and interventions around EOL conversations would provide a more wholesome understanding of NP contributions, such as how patients experience EOL discussions and if they recognize the NP's patient-centred approach and its perceived impact.

Early Identification, the Correct Assessment and Treatment of Pain, and Other Problems

The capacity to diagnose and effectively address pain and other physical, psychosocial, and emotional concerns is a core component of palliative care and the NP role (CNA, 2010; WHO, 2020). As presented in the findings, the NPs in my study enlisted their advanced knowledge and skill base to assess a wide range of patient concerns confidently. Besides

providing psychosocial and emotional support during visits, the NPs referred patients and families to social work for families with complex bereavement, occupational and physical therapy for mobility assessment, and nutritionists for dietary consultation. The NPs in my study also linked patients to local spiritual leaders/chaplains/volunteers when the patients and families desired additional support. To mitigate limited resources offered by the provincial health plan, the NPs in my study developed an understanding of local resources they could link patients with (i.e., volunteer, hospice, community counselling). The NPs also identified benefits from supplementary insurance plans (e.g., veterans' benefits, private insurance) that could be useful for patients.

As consultants, the NPs in my study assessed and intervened in difficult patient situations that CNs and physicians had difficulty resolving on their own. They diagnosed and managed acute and subacute concerns and anticipated and planned for future problems, keeping in mind their patient's values and wishes whenever possible. For example, the NPs assessed and treated complex and problematic symptoms of pain, dyspnea, constipation, weakness, fatigue, and bowel obstruction while working with patients, families, and nurses to reassess treatment responses. The NPs in my study were vigilant for the subtlest symptoms that were difficult for other care providers to detect. For example, conditions like oral candidiasis, which impairs taste and comfort, and opioid toxicity, which begins subtly and can escalate, causing significant patient and family distress. Sarmento et al. (2017) conducted a meta-ethnography to investigate the critical components of home palliative care that shape the experiences of patients and FCGs. They found that when physical and psychological symptoms were well managed, patients and FCGs reported enhanced feelings of security, trusted the team, and hoped for future symptom control. As a result, patients achieved other family goals, like living life and preparing for death

(Sarmento et al., 2017). Additional research about patient and FCG perceptions of NP involvement is required. Such research would help illuminate potential NP contributions in this setting. For instance, to gauge patients' experience of symptom management and feelings of safety and security knowing the NPs' involvement in their care. For example, a phenomenological approach like that undertaken by Dusseldorp et al. (2018) would be a beneficial approach to this area of research. Dusseldorp et al. studied patient experiences with NPs in palliative care and found that patients reported experiencing trust, gaining knowledge and empowerment and feeling respected, listened to and understood. A similar research approach would provide insight into patient and FCG experience with NPs.

In my study, the NPs also worked with patients and FCGs to identify medication regimes that patients experienced as problematic, such as those that caused drowsiness, sub-optimal timing, and control of symptoms. Individuals who require palliative care are frequently reliant on potent medications that can cause significant side effects that need requisite knowledge to monitor and manage (Lau, Berman et al., 2010). The NPs in my study provided patients and FCGs with opportunities to discuss and resolve problematic medication regimes. They also taught patients and families about medications and symptom management to build confidence and capacity.

Studies examining NPs' roles in other palliative care settings have also found that NPs used advanced assessment, diagnosis, and management skills to understand patient concerns, diagnose problems, and help identify solutions. For example, in LTC (Kaasalainen et al., 2013), NPs used their advanced skill set to assess and address bothersome patient symptoms, sort out problematic medications for patients (behavioural impact or excessive sedation), and optimize pain management. Research about NPs providing palliative care in other settings (outpatient

oncology, hybrid inpatient and home care, and other LTC settings) has shown similar findings. For example, NPs assess and manage problematic symptoms and provide anticipatory medications when symptoms (Deitrick et al., 2011; O'Connor et al., 2018; Vellani et al., 2021; Williams & Sidani, 2001).

Evidence suggests that good symptom management relieves the stress perceived by FCGs (Andrews, 2001; Given et al., 2004) and has implications for supporting care and dying at home for FCGs and patients who desire it (Bell et al., 2010). The NPs in my study also helped patients understand the benefits and burdens (for example, too many pills, difficulty swallowing, and minimal therapeutic advantages). Deitrick et al. found similar results in their study about NPs in specialized palliative care. In the study by Deitrick et al., NPs helped identify when patients were in their last days of life and who would benefit from discontinuing medications that impart more burden than a benefit.

Anticipation, Prevention, and Facilitating Early Intervention

In my study, the NPs saw the anticipation, prevention, and planning for early intervention of problems as a significant part of their role. Problems might take the form of symptoms related to the illness or involve the need for a change in the place of care for EOL and later for dying. Prevention involved reviewing potential problems with families, planning for these problems, and laying out a contingency plan. One NP in this study commented, "I like to have a plan A, Plan B, and Plan C." Anticipating problems and planning to mitigate these problems featured prominently in the work of NPs in my study. NPs facilitated this understanding by asking patients and families to imagine the future and identify their priorities in specific scenarios. Studies show that this is an approach used by other community palliative nurse specialists in a

Canadian study that examined specialist palliative teams (Seow et al., 2020) and NPs (Mitchell et al., 2016).

The NPs in my study engaged in teaching families how to manage medications and symptoms. They also ordered anticipatory emergency medications and customized medication orders for nurses when physicians had authorized generic emergency medication packages. Furthermore, the NPs in my study selected specific medications and regimes for patients and provided written orders for nurses to have available to them when patients could no longer take oral medications. The NPs saw this intervention as a critical activity needed to support the patient, FCG, and the nurses in the home to better attend to problematic and distressing symptoms. Other research has identified similar practices for supporting patients, FCGs, and nurses in community palliative care (Payne et al., 2015; Staats et al., 2018; Wilson et al., 2015). Bowers et al. (2019) conducted a systematic review of evidence concerning anticipatory prescribing of medications for adults at the EOL in the community. Bowers et al. found that nurses generally perceived that anticipatory prescribing offers reassurance to patients, FCGs, and health care professionals and provides the opportunity for timely and adequate symptom control along with the reduction of crisis hospital admissions. Besides anticipating symptoms, the NPs in my study customized medication formulations (for example, from a tablet to suspension or subcutaneous routes), suggested custom delivery devices (blister packs or pill organizers) and started subcutaneous infusions when oral medications became ineffective. Wilson et al., 2018 found that prescribers in their study also engaged in similar strategies when supporting patients and FCGs. Recent research about prescriber experiences related to prescribing during the COVID-19 pandemic (Antunes et al., 2020) showed that anticipatory prescribing for community-dwelling patients involved changing medications used and routes of administration. Prescribers

initiated these changes in anticipatory prescribing practices to enable FCGs to administer EOL medications with greater ease. For example, prescribers chose medications that FCGs could administer buccally, sublingually and transdermally. Additional research is required to examine NP experiences and prescribing modifications during the pandemic. Research is also required to examine FCG experiences related to how they perceived and navigated their role in symptom management and how NP involvement might have influenced this.

The NPs in my study enlisted a patient-centred approach in ongoing conversations about the goals of care. NPs helped patients establish their care goals with knowledge about medication effects, such as maintaining alertness and managing anxiety, pain, and dyspnea. NPs acknowledged that patient and FCG goals could change as the situation evolved. I draw an example from the findings where Christine counselled a patient and his wife on pain management. Initially, the patient and FCGs refused the suggested opioid based on their fear of opioids. At the next NP visit, the patient's wife communicated that the family had discussed and accepted a particular opioid regime. The NPs in my study sometimes found it difficult when patients were resistant to medication solutions that NPs "knew" would address concerning symptoms. However, the NPs also understood that patients and families had personal preferences and individual fears and meanings they attached to specific therapies, particularly opioids. The NPs in my study responded to these situations by offering to enhance their understandings and, through their ongoing support, by being available should the circumstances and perspectives change. Recognizing fears and supporting patients in their choices is regarded as a patient-centred approach to medication and symptom management by other research (Bowers & While, 2019; Wilson et al., 2018).

The NPs in my study also altered medication regimes to ensure patients received the medication they required, at times erring on the side of comfort. For example, in nursing homes, staff are often afraid of opioids and reluctant to administer PRN medication because of lacking the time and possibly knowledge to assess pain levels. As a result of these local practice limitations, the NPs in my study prescribed opioids on regular schedules to ensure the patients did not unnecessarily suffer from uncontrolled symptoms. Other research showed that hospice physicians servicing nursing homes also adopted similar strategies (Lau, Masin-Peters et al., 2010).

In my study, the NPs engaged in ongoing assessments of patient and family goals of care and EOL plans through conversations. When needed, the NPs facilitated transfer to residential hospice, urgent placement in LTC, or a brief stay in the palliative inpatient unit to address complex symptoms in a controlled environment before being discharged back home. Alternately, the NPs in my study worked closely with care coordinators to maximize resource availability (visit nursing, shift nursing, home support, respite). The NPs in this study were often better positioned to assess the patient's decline than care coordinators who infrequently saw the patients. As a result, the NPs often advocated for the increased allocation of resources available to the patients and FCGs in their last days. The challenge with such resources is that they are finite and unrenewable. As a result, there is a reluctance by community health care providers to initiate this level of service until there is a clear sense of patient decline. When the NPs in this study were in the home at critical turning points in patient conditions, drawing on expert assessment, they often advised the timing and use of home care resources to better support patients and FCGs. While the focus of my study was to elucidate NP role enactment in this setting, it is unclear how patients and FCGs experienced the involvement of NPs. Further

research is recommended to understand how the interactions with NPs are perceived, received, and valued by patients and FCGs and their experience of NP caregiving. For example, did explanations of medication help them manage better and have more control of their symptoms?

Teamwork, Collaboration, and Communication

Teamwork and collaboration are concepts central to palliative care and NP practice (CNA, 2010; WHO, 2020). The WHO (2020) advocates for a team approach yet does not specify what this means. Xyrichis and Ream (2008) defined teamwork as "a dynamic process involving two or more health professionals with complementary backgrounds and skills, sharing common goals and exercising concerted physical and mental effort in assessing, planning or evaluating patient care" (p. 238). Studies often promote teamwork and collaboration as the reasons for specialist palliative care team success; however, in research on groups of health care providers who work together, there is heterogeneity in team composition and structure (Centeno et al., 2016; García-Pérez et al., 2009). Studies promoting teamwork rarely make evident how the collaboration unfolds among the related actors (Seow et al., 2020). Other researchers (Mertens et al., 2019; Walshe et al., 2008; Woodward et al., 2004) have identified that community palliative care teams most often are generally not formalized teams but a network of services constantly formed and re-formed around patients, much like the broader organization of care demonstrated in this study.

Research shows that CNs and physicians often need to collaborate with specialist palliative care nurses to best respond to patient symptoms and needs (Beernaert et al., 2015; Dahlhaus et al., 2013; Pype et al., 2013). In my study, the NPs became involved in situations in which patients already had PCPs, a VN (or, in many cases, a variety of nurses), a care coordinator, and possibly a specialist (cancer care or chronic disease management). However, the

level of cohesion and communication of that group was never guaranteed. Physicians may have a close and longstanding relationship with their patients or barely be familiar with the patient. The nurse and physician may be known to each other, or there may be a revolving door of nurses involved with the patient. The NPs in my study continuously sought to bring disparate caregivers together to form temporary and ad hoc teams (Roberts et al., 2014) to improve the continuity and quality of care for patients. Other researchers have reported this type of teaming and changing team composition (Beernaert et al., 2015; Mertens et al., 2019) in community settings.

In my study, the NPs, where possible, tried to facilitate a joint home visit between the patient and FCGs, physician, VN, and home care coordinator. The goal was to develop a shared understanding of the patient-centred goals of care and facilitate practical connections between physicians and nurses. The NPs also used joint visits to clarify the terms of communication (e.g., determining the physician's availability during and after regular office hours, sharing personal cell phone numbers for after-hours). Joint home visits supported a shared plan and PCP availability in a study about home palliative care nurses in Norway (Danielsen et al., 2018). Deitrick et al. (2011) also discussed joint visits employed by NPs in palliative home care and identified that in their work, NPs "synthesize fragmented care" (p. E27). In my study, the NPs also worked to build relationships with PCPs and CNs to enhance the professional cohesion of the temporary team, reaching out and making themselves known and available. The NPs in my study aimed to create conditions that allowed for synergies and enhanced continuity. Continuity is a concern, particularly in home care. It is a challenge because health care providers may not know each other, may not have a sense of each other's skills, and do not benefit from the co-location of working or a shared medical record (Woodward et al., 2004). How this approachability, communication, and cohesion function to enhance continuity of care is essential

in community palliative care (Mertens et al., 2019). In my study, higher collaborative and communicative relationships resulted in synergies in ad hoc teams, a finding also reported in another study regarding NP work in community palliative care (Deitrick et al., 2011).

For NPs in my study, understanding the contextual situation also involved integrating knowledge about how particular PCP and CNs practiced, including their communication styles and comfort and skill with palliative care and involvement. This understanding also extended to appreciate the strengths and limitations of settings like retirement and LTC homes. In my study, knowledge of the capacities and participation of others in the circle of care often influenced the NPs' level of involvement. For example, if the NPs knew physicians were less involved, if the nurse was a novice, or if staffing was less stable, they followed the patients more closely. In this way, they sought to ensure the patients and families received the attention they needed. In addition, the NPs in my study tried to overlap their visits with nurses to promote familiarity. Knowledge of "what people do and what people do well" was also identified as necessary in research regarding collaborative practices among physicians, home care nurses, and specialist palliative care nurses (Walshe et al., 2008, p. 267). This understanding often compelled the NPs in my study to expand their involvement when they perceived that patients were not well supported. The NPs in my study contented themselves to be more removed when others were adequately meeting the patients' needs. Without this flexing of roles in response to local strengths and weaknesses, there is a risk that patients would suffer from unaddressed needs when situations are less resourced or less stable.

Support to Nurses and Physicians

The NPs in my study provided support to nurses and physicians through formal and informal education and clinical advice. For example, the NPs supported nurses in the community

by teaching courses to newly hired nurses, using teachable moments during joint visits, and offering telephone advice when physicians were unreachable. To maintain continuity of care, home care nurses are expected to contact the patient's PCPs for any arising concerns. Rapid changes in the patient's condition require nurses to secure timely advice from the PCPs. If the PCP is unreachable (not responding, on vacation), the nurse and patient are left in a difficult position. For instance, if a nurse cannot reach a physician on a Friday afternoon to renew a pain medication, this may create an emergency room visit to obtain a medication renewal. In my study, NPs supported nurses when they could not reach the family physician. In this manner, they prevented emergency room visits or, the alternate outcome, the unnecessary suffering of patients because of uncontrolled symptoms. In a study by Danielsen et al. (2018), home care nurses indicated that if patients' conditions and symptoms escalated and they could not reach the physician for support, there was a risk that the patients would require transfer to the hospital.

The NPs in my study worked to make themselves known to CNs through instructions in the home charts, inter-personal connection, and offerings of support through clinical advice or, when needed, emergency clinical advice and prescribing. In other studies, specialist palliative care nurses were essential resources for CNs when they could not reach physicians for advice or direction and needed time-sensitive guidance or solutions to address urgent patient needs (Mertens et al., 2019). NPs in other palliative care settings acted as resources for CNs. For example, O'Connor et al. (2018) found that NPs helped nurses with urgent advice or prescriptions when physicians were unavailable, especially on Friday afternoons or holidays, saving nurses time and frustration. In their study, Osborn and Townsend (1997) found that NPs provided hospice nurses with telephone support for pain management, sorting out medical problems, and prescriptions for patients too weak to travel for primary care (the role was limited

to telephone support). In a study of NPs in LTC, NPs supported nurses by being available and responding in time-sensitive situations and applying an advanced skillset to assist with problem-solving (Kaasalainen et al., 2013). While the context of these studies differed from my study, the similarities include that the NPs provided support to nurses through their approachability, availability, and advanced skillsets to assess, problem-solve, and provide nurses with what they needed to better care for the patients.

Research about physicians who provide palliative care has highlighted that some physicians encounter difficulty retaining advanced EOL care knowledge. For example, Selman et al. (2017) surveyed family physicians in the United Kingdom who identified problems that stemmed from the difficulty of keeping up to date regarding rapidly evolving therapies and the lack of a community-based focus in undergraduate education. As a result, physicians' skills were underdeveloped and declined because of infrequent use. Selman et al. (2017) found that physicians appreciated face-to-face mentorship and learning in joint visits. While the physicians in my study consulted the NPs either when patients were experiencing difficult symptoms or in anticipation of difficult symptoms, the NPs offered more than symptom management advice. In their holistic assessment and looking at the larger picture, they reconciled medications and suggested discontinuation of superfluous medications. The NPs in my study also, in their consultation, painted the larger picture of patient and family challenges and resources and revisited care goals and advanced care planning to build shared knowledge of the patient and the family's plan for the future and negotiate follow-up. The NPs offered a broader understanding of the patient and family. At the same time, the NPs in my study worked to make physicians feel comfortable with reaching out and working together. Deitrick et al. (2011) also found

interprofessional relationship-building part of NP work. Similarly, Kennedy (2002) found interprofessional relationship-building paramount in home care nursing.

While my study sought to identify how NPs enacted their role in community palliative care, it did not consider the perspectives of CNs and physicians. Research pursuing the views of family physicians and nurses in the community would provide a broader understanding of how they perceive interactions with NPs and how NPs influence their abilities to meet the palliative care needs of patients and families. Furthermore, exploring how NPs impact their work, work satisfaction, and stress would provide a broader view of how NPs influence the work of their colleagues.

Nurse Practitioners and MAiD

Because of their profession and the clinical context of palliative care, NPs in my study were seen to engage conceptually, morally, professionally, and practically with the notion of MAiD. MAiD is now a legal right for Canadians who meet particular criteria. NPs must now take part, at the very least, by ensuring patient referral to a professional or service that can fulfill this right. Facilitating access to MAiD is a legal and professional obligation for NPs (Bill C-14, 2016; CNO, 2021).

As a group, the NPs described ongoing conversations and deliberations to determine their role regarding MAiD as palliative care consultants. Such conversations involved consideration of existing community resources, ease of access, and the consumption of limited resources that would limit consultant availability for other patients and clinicians. As a result of group consensus, engagement with MAiD by study participants involved only assessing patient eligibility and not administering MAiD. Over the past few years, the provincial MAiD program has established MAiD coordinators and identified regional MAiD providers. The NPs in my

study identified that taking these existing resources into account has factored into their decisions about levels of participation. Brown et al. (2021) reported similar findings in interviews with physicians and NPs when exploring reasons for non-participation in MAiD. They found that, among other reasons, consideration of local resources factored into decisions about participation. For example, where there were local teams for MAiD, participants felt less compelled to actively engage, knowing that their patients had alternate ways to access this option for EOL care.

The NPs in my study identified their participation in MAiD across the continuum, from conscientious objectors who do not participate in any MAiD assessment to providing assessments for current patients. Because of the mutually agreed-upon role, the NPs in this study did not administer MAiD. However, a sub-set reported that they would provide MAiD for patients in the future, perhaps even outside of their current role, endorsing it as an important choice for some patients and challenging to access, particularly in rural areas. Regardless of degrees of professional participation, the NPs in my study generally regarded MAiD as part of holistic care. They maintained that MAiD was a patient choice and supported patients to have an EOL experience aligned with their needs and beliefs. Other recent Canadian research about nursing experiences with MAiD showed that nurses often considered MAiD as part of offering holistic care (Beuthin et al., 2018).

The NPs in my study who provided assessments asserted that, because they were already engaging with their patients at a comprehensive, holistic level, the formal assessment required only a minimal additional amount of time and effort. They saw the formal MAiD assessment as overlapping their work to provide good palliative care. However, the associated documentation required more effort. The study participants felt that holistically engaging with their patients allowed them to accurately understand the patients' situations and needs, the nature of their

suffering, and the basis of their intentions. Pesult, Thorne, Schiller, Greig, Roussel, and Tishelman (2020) studied how nurses construct excellent nursing practice in MAiD. Pesult, Thorne, Schiller, Greig, Roussel and Tishelman reported that NPs described having to rapidly establish rapport and intimacy while determining eligibility for MAiD, doing this by enlisting a nursing approach of caring and encouraging people to tell their stories (Pesult, Thorne, Schiller, Greig, Roussel & Tishelman, 2020). Like my study, the NPs constantly worked to establish rapport and trust by listening to patient experiences and stories (Pesult, Thorne, Schiller, Greig, Roussel & Tishelman, 2020). In my study, however, patients were already known to the NP or the consultation team, and the NPs could often schedule a follow-up visit for the formal assessment if time permitted. Early referral to the team enabled thorough assessments and support to patients requesting MAiD.

The NPs in my study recognized that, for some patients, assessment and approval for MAiD was part of a therapeutic process. NPs shared their perceptions of how patients seemed to find these discussions reassuring, addressing their fears about the future. Recent studies report how some patients experience discussing MAiD as therapeutic and reassuring (Oczkowski, Crawshaw, Austin, Versluis, Kalles-Chan, Kekewich, Curan, Miller, Kelly, Wiebe, & Frolic, 2021; Pesut et al., 2020). In a study by Pesut et al. (2020), nurses reported a similar therapeutic impact for patients who learned they were eligible for MAiD. Similarly, in a study by Oczkowski, Crawshaw, Austin, Versluis, Kalles-Chan, Kekewich, Curan, Miller, Kelly, Wiebe, & Frolic (2021) that examined patient and FCG experiences with the MAiD process, participants reported feeling that in the MAiD assessment process, they felt that early conversations addressing MAiD could also be a source of reassurance. For NPs in my study, inquiries about MAiD prompted further exploration to determine the root cause of the request. When the NPs

determined MAiD inquiries to be grounded in fears about the future, they aimed to reassure the patients about how their anticipated and feared symptoms could be managed and accompanied these patients step by step as their illnesses progressed to ease fears. The NPs in my study were attentive to patients' concerns and established an acceptable plan to address developing symptoms, reassuring patients with their presence. The NPs did this by reassuring the patient that they were readily available to provide consultation to the patient's nurse or physician should any difficulty be encountered. Research about nurses' roles in communication around euthanasia revealed similar findings. Nurses who received requests for euthanasia, where it was legal, also ensured that patients knew that there were other ways to address particular symptoms adequately (Denier et al., 2010).

NPs in this study navigated professional expectations to uphold patient rights to be aware of MAiD as a choice (CAMAP, 2020; Downie, 2018) yet not to appear as promoting it (CNO, 2021). Advocates of raising the option of MAiD with patients who do not initiate the inquiry maintain that such practices will empower patients who may feel intimidated or judged about their inquiry (Brassfield & Buchbinder, 2021). Alternately, those that oppose open discussions of MAiD as an option maintain that this practice may harm the patient-clinician relationship. Offence to those with strong religious beliefs or leading them to interpret their life as not worth living is premised to result in harm instead of empowerment (Brassfield & Buchbinder, 2021). In their role, the NPs in my study took more of a conservative approach and were highly sensitive to patient cues about ending suffering. Patient use of vague language was seen as an opportunity for study participants to engage with patients, searching for clarification, for example, by asking the patient, "do you mean assisted dying?" The NPs in my study favoured this conservative approach over offering MAiD as an option outright, fearing that they might alienate or offend

patients. The NPs viewed having a low threshold for cues as a better alternative for their patients. As a result, they relied on their ability to interpret situations to guide how they approached the conversation. The NPs in my study aimed to create a trusting and supportive relationship where patients could feel they could ask anything, much like that reported by Denier et al. (2010). MAiD is new to the Canadian context, and NP involvement with patients and FCG regarding MAiD is poorly understood. Early research about NPs and MAiD include NPs as part of a larger group, for example, NPs and RNs (Pesult et al. 2020) or NPs and MDs, nurses and social workers (Oczkowski, Crawshaw, Austin, Versluis, Kalles-Chan, Kekewich, Curan, Miller, Kelly, Wiebe, Dees & Frolic, 2021) which may obscure the unique perspectives and experiences held by NPs. Future research about NP role enactment and MAiD should include how NPs approach discussions around MAiD in other settings, with attention given to influences. Also, research should examine how patients and FCGs experience support from NPs around MAiD requests, both for those who choose MAiD and those who choose not to pursue MAiD. Furthermore, inquiry around NPs in palliative care who administer MAiD and their professional, emotional, moral, and practical experiences need to be elucidated through research to best understand implications for NP role enactment and patient and FCG experience at EOL.

Relational Inquiry and NP Role Enactment

In this section, I present a discussion of RI as a way to think about and explore NP role enactment. As explained in detail in Chapter 3, Doane and Varcoe (2021) posited RI as a way nurses should approach every interaction in their work. Doane and Varcoe (2021) proposed a relational conceptualization of people, families, and communities in their approach. The RI process assumes that nurses are situated and respond to nursing situations influenced by broader social, cultural, political, and historical. Each individual has a unique socio-historical location

that influences their experience, interpretations, and identity (Doane & Varcoe, 2007). RI involves two processes. The first process is engaging in the nursing understanding of individuals as being in relation to others. The second process is an inquiring action that involves constantly asking questions about oneself and others in a given situation (Doane & Varcoe, 2021). Doane and Varcoe (2007) posited that RI compels nurses to consider what it means to be a nurse in a complex world of personal/professional relationships, economics, history, politics, values, and normative ideologies. As a practice, RI involves a reflexive process of looking for ways in which people, situations, contexts, environments, and processes are integrally connected and shape each other, and the assumption that these elements shape each other (Doane & Varcoe, 2007). In this conceptualization, nursing care is an outcome of a multifaceted interplay of people in particular situations and contexts (Doane & Varcoe, 2021), where skill also involves navigating relational tensions and competing obligations.

Doane and Varcoe (2021) suggested two strategies to further focus the nursing gaze by using a hermeneutic phenomenological (HP) lens and a critical theory (CT) lens. Through an HP lens in RI, it is possible to understand people in relation to their world, "for it is only within those contexts that what people value and find significant is visible" (Doane & Varcoe, 2021, p. 93). Understanding what people value and find significant is an approach that is well-aligned with the philosophy of palliative care. The HP lens assists us to 1) identify that illness as associated with particular meaning and value for individuals; 2) inquire about what is most significant at a point in time; and 3) understand the uniqueness of patient and family concerns to help target nursing action (Doane & Varcoe, 2021).

RI provides nurses with a framework to think about how they engage, interpret, and act in response to situations that acknowledge the intricacies of decision-making. However, it also

provides a practical approach to examining how NPs enact their role because of its ability to highlight these situational intricacies. In this study, RI helped situate NPs in relationship with the patients/FCGs, other health care providers, and the broader health care system. This lens also helped highlight how NPs enacted their role, given this relational positioning and the inherent relational tensions. RI as a lens poses a good fit with FE, where the phenomenon of interest is how people interact in contextualized situations, such as within the giving and receiving contexts of health care. The RI process assumes attitudes, values, knowledge practices, and structures that comprise individuals' sociocultural world and are communicated through relational interaction (Doane & Varco, 2007). Relational interaction is also the phenomenon of interest in FE. RI provides a helpful way to see the tacit and taken-for-granted elements of everyday NP practice. RI acknowledges the dynamic and multidimensional nature of nursing care experiences for all participants of that experience, including nurses, patients, FCGs, other health care providers, and broader systems.

NPs, as they carry out their work, are inherently embedded in a web of relations. As a result, they need to reflect on these relations (intrapersonal, interpersonal, and contextual) and interpret how each influences the situation at hand to be best able to respond. NP work can only be understood as contextually embedded and influenced. Concerning patient encounters, the NPs in this study drew on their consideration and understanding of the multiple interpersonal, intrapersonal, and contextual elements and their influence on each other. RI involves the notions of assuming a relational consciousness and inquiry as action. The NPs in this study understood that their work with patients was relational and that there were also multiple overlapping relationships due to the contextual influence. The challenge for NPs is to understand the effects these relationships exert on the situation to determine the best nursing action.

The findings of this study highlight the merit of using RI and the HP lens to identify what is of particular meaning and concern to patients and families and how this might differ from our concerns. I refer to Chapter 4, which presents a scenario between Nadine, Joan, Alex, and the VN. Nadine was at a home visit with Joan, who was in the last weeks of life, her daughter, Alex, who had moved home to look after Joan, and the VN. Nadine attempted to revisit the care goals and plans if Alex were to find Joan unresponsive, opening a discussion about resuscitation and calling an ambulance. The discussion had started two weeks prior, at the initial visit, and the family showed a desire for CPR. Nadine understood the complexity of the situation. The diagnosis was relatively new after a year of illness. Joan was young, as was her family, and the comprehension of what CPR was and could achieve was, for Alex, like most of the public, a way to help her mother. During this interaction, Nadine considered her understanding of CPR's unfavourable success rate and her own experience engaging in CPR on frail patients who were unlikely to be revived when she had felt the crunching of ribs during chest compressions. In her past life as a manager, Nadine had supervised nurses who had had the same undesirable experience. She was aware of the almost non-existent chance of resuscitation and knew the last minutes together could be a peaceful experience for Alex and her mother. Nadine abandoned the CPR discussion again after feeling like the conversations were at a stalemate and enlisted Alex to help her mother administer her insulin. An unspoken understanding with the VN ensured that the conversation would continue over the following days. In reflecting on the situation, Nadine could see how, for Alex and Joan, committing to resuscitation at this point might have been how they perceived a good EOL experience.

RI brings attention to Nadine's perspective on the multidimensionality of the situation. Nadine spoke to the need to see through her own experience and knowledge of resuscitation

while considering the family's experience and what might be meaningful to them. At that moment, CPR represented a meaningful expression of love for Alex. Nadine knew that this perspective could change in the days and weeks following, as other expressions of love developed, considering the changing situation. Finally, having a collaborative relationship with the VN reassured Nadine that the VN would continue the conversation as she saw appropriate. In her role as a consultant, Nadine might not return for 1 or 2 weeks, whereas the VN would be in the home every day.

RI is helpful to make evident how NPs have to interpret the influences of multiple relationships between individuals, the context, and the available resources, with what is important to patients. For example, Christine engaged in an RI approach in caring for her patient, who had lung and brain cancer. The patient was bed-bound and living alone to facilitate her desire to die at home. In her conversations with the patient, it was clear to Nadine that the patient did not want to leave her home and wished to die at home. The complicating factor was that she lived alone, and Christine had to set aside her understanding that it was nearly impossible for individuals who lived alone to achieve a home death. In her conversations with the patient, Christine identified the limited allocation of home support services through twice-daily visits by PSWs. She also determined that the patient's family physician did not do home visits, which might have provided some support and reassurance. Christine further learned that two friends took turns spending the night with the patient and that her son lived nearby and could "check in" after work. Christine also reflected on her work mandate as a consultant, limiting her visiting capacity to only once weekly. While regular home visiting by Christine and the physician might have been helpful, this would not address the day-to-day unsafe living situation the patient was facing, which made Christine uncomfortable.

A care conversation helped identify that the patient wanted to stay home for the EOL more than anything else. Christine shared her concerns about staying alone for hours, including sitting in a soiled diaper all day, injury from a fall, or malfunctioning her analgesia infusion pump, which could escalate her shortness of breath and pain. These scenarios could result in escalated deterioration and a transfer to the hospital, which the patient wanted to avoid. After discussing the available resources, the patient decided she would use her limited resources to pay for extra caregiving support during the day. The literature commonly identifies that living with a family member is critical for patients to stay home at the EOL. However, Christine was able to engage in RI to explore the situation with the patient and support the patient to arrive at a creative and acceptable solution for the time being. In this situation, Christine reflected on her interpretation of safety and the patient's desire to remain at home, recognizing an under-resourced context of EOL at home for this patient. Christine acknowledged the inequitable allocation of home care resources. She also helped the patient decide how she wanted to live and the acceptable risks. Limited research identifies that family and friends can provide the support that some people require to remain at home for EOL, especially when combined with specialist palliative care services (Burns et al., 2013).

RI using the CT lens helps situate NP work with patients in a broader socio-political health care system that exerts power. The CT lens further helped identify how NPs viewed and interacted with the contextual factors of community service organizations and resource allocation. While they, as health care providers and collaborators, experienced this effect, they also saw the implication for patients. However, NPs understood the situation as relational. The work environment in home care and LTC was challenging and sub-optimal, restricting nurses from enacting their nursing role and impeding continuity of care and knowledge retention.

The NPs became most aware of these systemic influences when they encountered obvious patient symptoms that were not detected or consulted despite regular nursing visits. Doane and Varcoe (2021) advocated that nurses should conceptualize differences and difficulties relationally to foster collaborative practice. This approach promotes "responsibility rather than blame, understanding rather than defensiveness, connection rather than guilt or anger and responsiveness rather than powerlessness and frustration" (p. 652). While concerned for patient comfort, the NPs also voluntarily articulated understanding nurses as situated within an inadequately resourced system that limits their ability to engage with patients (be that through restricting visit length or lack of education) and collaborate with others. The NPs engaged in extra efforts to reach out and make connections to introduce themselves and make their availability known to their under-resourced colleagues. They wrote their cellphone numbers in communication books, called nurses directly to introduce themselves and even sought teaching opportunities to meet new nursing recruits and make personal and professional connections. The NPs expressed an awareness of the high nursing attrition rate, making it difficult to maintain professional relationships, communication, and quality of care. In this example, the NPs used a critical lens at an intrapersonal level to question their understanding and assumptions about what they were witnessing.

At the interpersonal level, the NPs reached out to individual colleagues directly and, at the contextual level, modified their practices to mitigate the negative influence of the system by becoming involved in educating and connecting with their community peers. The NPs recognized how broader structural and organizational factors contributed to many of their challenges. Because of the complexity of the organization and resource allocation of community palliative care, the NPs found it challenging, if not impossible, to influence the broader palliative

care landscape. However, awareness of the situation informed how they adapted their approach to supporting their community colleagues.

The nursing obligation to act at all levels requires recognizing and accepting the limitations of contexts yet seeking to exert influence (Doane & Varcoe, 2007). Doan and Varcoe (2007) further advocated that what happens in each nursing moment is shaped by individual nursing actions and the actions and responses of others and influences from all contexts. RI highlights how NPs act at different levels to meet their nursing obligations (intrapersonal, interpersonal, and contextual). Future research on NP role enactment would benefit from applying a RI approach as a theoretical framework. This framework would provide an opportunity to identify what NPs in a particular setting actually do and their analysis of complex situations that subsequently shape their action. RI would provide a helpful lens for researchers to collect, analyze, and interpret their findings to best understand the daily work of NPs and the tensions they navigate.

Study Implications and Limitations

Practice Implications

The findings of this study highlight NP work as situated within a broader system of CPC care delivery. NPs engage in a wide range of patient-centred care and teamwork activities to support their nurse and physician colleagues to meet the palliative care needs of patients and FCGs. The relational and interprofessional nature characterizing NP work in this setting should not be underestimated. NPs need to be supported to continue reaching out and making links with their community peers. In this study, the geographies, local resources, and relationships shaped how NPs enacted their role and their level of involvement. NPs need to be supported to be

flexible in their work structure and to be able to extend their involvement in various settings as they determine necessary.

Employers and supervisors need to protect NP autonomy by enabling flexibility in practice adaptation. NPs must be able to evaluate the needs of their colleagues across settings and freely decide how best to support their colleagues. NPs can then decide if formal teaching like the LEAP course, informal teaching, networking in meetings or scheduling joint visits will work best in the specific situation. Employers and managers need to ensure that NPs have time built into their schedule to reach out to CNs and PCPs to be able to build the alliances and relationships that will ultimately result in a better care experience for patients and families. Several reports on palliative care (Health Canada, 2018; Office of the Auditor General of Ontario, 2014, 2016) endorse that system-wide improvement in palliative care education of health care providers is key to improving quality access to palliative care. NPs are an integral part of the solution, and their positions need to be structured to facilitate their contribution to building a better system. There is also a solid argument for protecting the orientation and robust mentorship of newly hired NPs in this role to support learning specific to palliative care in this setting. The findings of this study highlight the value of such an orientation and mentorship as evidenced by NPs' notions of the strategic timing of sensitive conversations balanced against building trusting relationships.

Finally, NPs should be supported to participate in local, regional or national palliative care committees, working groups or educational programs. NPs can further influence meaningful palliative care policy and practice changes by participating in these groups. Inclusion of these expectations in NP competencies and job descriptions along with protected time for such participation is needed to support such involvement.

These practice implications should be evaluated in the future through research that examines how NPs' work is structured and whether NPs are experiencing the support and flexibility from their employers that they require. Further research should also examine the impact of these strategies, for example, on relationship and capacity building experienced by their community colleagues (physicians, nurses, PSWs). This kind of research would further justify and promote the value of NP work in community palliative care.

Educational Implications

This study highlights the importance of ensuring that NPs continue to build on their foundational nursing knowledge and values to develop advanced clinical and interprofessional skills. Graduate education programs also need to provide foundational knowledge about the philosophy and approach to palliative care. Continuing educational opportunities need to support NPs across settings, including palliative care, for example, certification in palliative care. Mentoring and communities of practice are needed for clinicians to be able to share their experiences and seek advice. Interprofessional educational opportunities need to support knowledge and skill-building and the development of collegial relationships with other nurses and physicians in the care community. Group meetings provide an essential source of peer support and learning and should be recognized as a critical complement to formal learning opportunities.

NP educational programs need to continue to ensure content about interprofessional collaboration and communication. The ability to reach out across organizational boundaries to create a temporary team may be underestimated in current NP educational curricula, despite the emphasis on collaborative practice. Given the prominent role of educators in supporting other professionals in the community, NPs need to be supported to build skills related to

interprofessional education. Furthermore, NPs need to be involved in the primary education of other professionals and continue to act as preceptors for NP and medical students and medical residents. Involvement as educators serves to consolidate NP knowledge and skills and that of others and establish collaborative relationships that can be drawn upon in the future. Finally, the content of NP continuing education might be equally important. Opportunities to learn alongside nurse and physician colleagues and even other community colleagues can facilitate collegial relationships and help establish shared understandings of each other's work.

Mentoring is a valuable approach that enhances clinical skills and practices while at the same time fostering professional relationships beyond the mentoring experience (Krishna et al., 2020). Previous provincial reports on the status of palliative care services highlight similar recommendations regarding education. Multiple provincial and national reports (Auditor General of Ontario 2014, 1016: Health Canada, 2018) have reported the lack of and need for basic palliative education for all palliative care providers. These reports also call for access to ongoing advanced palliative education for health care providers who specialize in palliative care (Health Canada, 2019).

In order to evaluate the specific education implications discussed here, future research regarding education should examine the curriculum in both undergraduate nursing and NP programs to ensure that programs address palliative care competencies. Furthermore, an environmental scan of available continuing education and post-graduate education would contribute to a broader understanding of education pathways to improve palliative care competencies. Research should also examine the experiences of those taught formally and informally by NPs and the impact of such experiences on learning and interpersonal and interprofessional relationships.

Policy Implications

Examining how NPs enact their role has highlighted the challenges posed by the current community palliative care organization. As seen in my findings, NPs can contribute to better palliative care experiences of patients/FCGs, CNs, and PCPs; however, without broader system changes, these contributions are constrained. Communication and information sharing processes need to improve through a shared documentation and communication system. Such a system should allow close to real-time updates in charting or instant messaging across organizational boundaries.

CN recruitment and retention need to be improved to stabilize nurse attrition from home care. Without these changes to nurse retention, expertise gained over time from NP teaching, mentoring, and clinical support is lost. Nurses in home care need to be supported to spend the time required to detect, communicate, and collaborate as necessary to meet the needs of their patients. NPs can help build capacity, but these capacities cannot be sustained and improved without changing broader health care policy and structure.

Health care organization requires examination to ensure better continuity of care for patients. For example, the commitments of community physicians and the role they agree to play in palliative care needs to be explicit. Details include knowledge and comfort, availability, mechanisms for contact after hours, and plans for vacation coverage while away. While some physicians coordinate this well, others do not, leaving a significant gap in palliative care support for nurses and patients. If these questions cannot be resolved, NPs should play a more integrated role in primary care settings to extend palliative care capacity. Alternately, more extensive NP integration would provide substantial clinical support for CNs. For example, NPs positioned within nursing agencies and LTC settings to support nurses with guidance and ongoing

knowledge and skill development. Such advanced integration is called for by provincial reports on community palliative care (Office of the Auditor General of Ontario, 2016).

The shifting of the location, responsibility and cost of care from institution to home needs to be acknowledged and supported by an equitable allocation of societal resources to support FCGs as part of the caregiving team and as bereaved family members with their own needs. Policy needs to change to offer greater flexibility to the system to support FCGs with expanded support and more hours of home and nursing time to eliminate the rationing of time when patients need them most. Nursing support at home must be sufficient to provide the care needed. There must be enough time allocated for nursing assessments, adequate staffing allowing for an urgent response, and the nursing knowledge and skill to assess and communicate assessment findings when needed for decision making.

Increasing the role and the number of palliative care NPs within the consultation service and in the general community in other models of care requires consideration. While, in many situations, physicians can have a well-developed relationship with CNs, this study shows that NPs experienced physicians as inaccessible or responsive to CNs. Nurses should never feel abandoned and unsupported when they face difficult patient situations. My findings show that NPs are well situated to give nurses the support they require to meet patient needs.

Recent reports at the provincial and national levels (Office of the Auditor General of Ontario, 2014, 2016; Health Canada, 2019) highlight the need to address similar previously identified shortfalls in the current system. These recommendations included strengthening communication through shared patient records, the equitable distribution of nurse practitioners to improve access to palliative care, increasing nursing availability and considering alternative modes of service delivery (Office of the Auditor General of Ontario, 2014, 2016; Health Canada,

2019). Future research needs to focus on evaluating the impact of integrated health records, novel models of NP involvement in palliative care and the influence of improvements in home-care staffing on patient and FCG experiences of care. This research can help shed light on the value and impact of such interventions and alternatives to consider in order for system improvement.

Research Implications

Targeted research implications have been provided earlier in the discussion section where relevant. In this section, I present additional research implications. Toward the end of my study, I had scheduled a few more days of participant observation with NPs to address a few remaining questions. These scheduled observations were cancelled as the COVID 19 pandemic was declared. I learned how NPs found this time challenging in my remaining follow-up telephone interviews. Because I was near the end of my data collection, I did not explore the impact of the pandemic on NP role enactment. Emerging research shows how health care providers experienced challenges in their work during the pandemic. Tavares et al. (2021) explored how health care providers at one inpatient palliative care unit (doctors, nurses, a psychologist, a physiotherapist and pharmacist) experienced and adapted their care practices during the pandemic. Tavares et al. found that these health care providers experienced altered relationships with patients and FCGs because of contact restrictions. Considering the relational nature of NP work, future research is required to examine the impact of the pandemic on NP role enactment. Future research should focus on how NPs build and maintain relationships, how NPs were affected, and how they adapted their role in the new practice reality.

Patient and FCGs experiences require an examination to shape future system improvements. Future research should also examine patient and FCG experiences with palliative

care in general, including experiences in unplanned transitions. This research should explore patient and FCG perspectives of why these transitions occurred to understand how to support these individuals better. Health Canada (2019) made similar recommendations in a report that calls for better research and data collection about the palliative care experiences of patients and families in community settings. Further research needs to understand whether patients are dying in their preferred place of death and how NPs influence these experiences. Recent provincial reports have called for a more accurate understanding of whether patients experience death in their preferred place (Health Quality Ontario, 2019). It is equally important to understand why patients may not have died in their preferred place. Research approaches must explore the spectrum of patient and family experiences. Such research would examine situations of adequate support and availability and adequacy of resources, how the needs of the patient and family were unmet at home leading up to a shift in the location of care.

NP roles in other models needs to be better understood. As mentioned earlier in this thesis, each region adopted a different model for NP practice in community palliative care with some selecting a consultation approach and others implementing a full transfer of patient care and others with some combination of these two approaches. However, these approaches are not well documented or explicated. Additional research would shed light on the models and roles in these different geographic regions.

Future researchers examining role enactment by NPs should consider adopting RI as a lens that will focus the researcher's gaze and contribute to a richer understanding of the intrapersonal, interpersonal, and contextual influences on nursing work. The use of RI, along with a broad conceptualization of role enactment, helped identify how NP role enactment has relational influences and influences at the individual, organizational and policy levels. This study

also revealed instances where NPs worked at the intersection of potential ethical issues posed by inadequate palliative care resources to meet patients' complex and rapidly evolving needs. Other potential ethical issues included the lack of availability of primary care physicians and inadequate palliative care knowledge and skill held by some health care providers. Ethics is seen in the everyday interactions of health care providers, patients and their families and situated within broader contexts and smaller moments. Future research using a relational ethics lens would help to highlight and explore these ethical moments in NP work and how NPs respond. Relational ethics is a modern approach to ethics where relationships are the context and influence of ethical action (Given, 2008). Relational ethics is a framework relevant to everyday interactions between health care providers, patients and FCGs in palliative care. The relational ethics framework proposes that the everyday ethical moments in health care are situated and interpreted within relationships, drawing on the foundational interdependent concepts of mutual respect, engagement, embodied knowledge, and the relational space of environment, with associated uncertainty and vulnerability (Bergum & Dossetor, 2005). Furthermore, influences on the macro (policy and funding), meso (organizational) and micro (interpersonal) play a role in creating the relational milieu. Using the lens of relational ethics can help further elucidate how NPs enact their role in community palliative care.

Study Limitations

Because this study focused on NPs in one geographical region, in a particular socio-political setting and in one type of health care service arrangement, the findings may not represent NP experiences or approaches in other palliative care service settings. This study drew from a convenience sample and relied on a few participants (seven); however, this number represents all the NPs employed in this setting. Interviewing only NPs about NP role enactment

may limit the findings to how NPs see themselves and not how others (nurse and physician colleagues, patients) perceive or experience their interactions with NPs. Including perspectives of other health care providers with whom NPs interact, like team nurses and physicians, patients, and CNs (VNs and LTC nurses), may provide insight about NP role enactment that is not available from the NPs themselves.

I must also consider how my presence as an observer might have influenced participant behaviour in my study. The observer effect on participants (otherwise known as the Hawthorne effect) is highlighted as an essential consideration for researchers, as it can potentially invalidate research findings (LeCompte & Goetz, 1982). Some critiques of ethnography argue that researchers need to identify and mitigate observer effects (LeCompte & Goetz, 1982). However, others, like Monahan and Fischer (2010), argued that, as opposed to a liability, the observer effect is a strength of the method, as it has the potential to reveal "profound truths about social and cultural phenomena" (p. 2). The argument is that if we assume that participants might adjust their behaviour, what we observe is significant. The conduct likely appeared a certain way for the researcher, or the observations represent behaviours that cannot be constrained.

While the participants may have changed their interactions, perhaps censoring opinions or presenting favourable interests, this does not invalidate the data. In my analysis, I could not appreciate constraint, censorship, or the presentation of adjusted behaviours. As suggested by LeCompte and Goetz (1982), I compared notes about observations and discussions that occurred in different compositions of groups, in private, and with patients/FCGs. NP behaviours and responses seemed consistent regardless of the setting. I would have made a methodological note if I perceived behaviour or conversation purposefully structured for my benefit. Often, the NPs were so preoccupied with the task at hand (sorting through a patient's concerns, driving,

responding to non-stop text and phone calls, documenting consultation notes and treatment modifications) that they hardly noticed my presence. Prolonged engagement in the field and the noted consistency of attitudes and behaviours across settings and situations reassured me that reactivity was minimal.

In my study strengths, I identified how my limited knowledge of the specific context of community palliative care enabled me to challenge the often taken-for-granted aspects of the setting. I believe this may have also limited the inquiry. As a clinician with no experience in palliative care, I tried to learn as much about palliative care as possible (I took a university course, attended conferences about palliative care and MAiD, and read countless articles). However, my insight may have been more limited than if I had had experience in this area. My lack of experience in palliative care may have limited what I was paying attention to and what I was privileging in my observations.

Conclusion

While I had a significant amount of experience as an NP in primary care, my general knowledge of palliative care was relatively limited prior to this research. My interactions and responsibility for the care of individuals with palliative care needs were limited to individuals with chronic illness and, most frequently, with a focus on disease management. My understanding of the palliative care environment in the community setting was also limited. My assumptions about NPs and community palliative care were based on what I knew about how NPs work in primary care and other settings. Reflecting on my knowledge and experience of NP work, adding NPs as palliative care consultants made sense, but I had no frame of reference outside of office-based primary care.

My experience with this research has changed how I view my work as an NP and the notion that we are all situated in relation to patients and others. I took for granted just how situated we are as nurses. This research sought to contribute to the understanding of how NPs enact their role as consultants in community palliative care. FE provided a practical research approach to examine NP work enacted in its local context. FE also offered a way to understand the experiences of NPs, their perceptions about their situations, and contextual tensions. This study revealed that NPs engage in a broad range of primarily patient-centred professional activities to help identify how best to respond to patient needs. The NPs also played an essential role in supporting their nurse and physician peers in the community, enhancing their capacities to meet patient needs through advanced assessments and advice and teaching. When patients' needs were not met, NPs adapted their role as consultants to assume broader responsibilities at times, working with overextended physicians and at times in place of absentee physicians. The study findings suggest that palliative care NPs would provide significant value in other community settings. While NPs show the potential of positive contributions to patient and health care provider experiences, this research also highlighted how broader systemic changes are needed to sustain the positive impact NPs can achieve.

References

Aestima Research. (2002). *The Ontario Nurse Practitioner in Long-Term Care Facilities Pilot Project*. https://www.health.gov.on.ca/en/common/ministry/publications/reports/nurseprac02/np_report_022302.pdf

Abdul-Razzak, You, J., Sherifali, D., Simon, J., & Brazil, K. (2014). "Conditional candour" and "knowing me": an interpretive description study on patient preferences for physician behaviours during end-of-life communication. *BMJ Open, 4*(10), e005653–e005653. https://doi.org/10.1136/bmjopen-2014-005653

Agar, M., Currow, D., Shelby-James, T., Plummer, J., Sanderson, C., & Abernethy, A. (2008). Preference for place of care and place of death in palliative care: Are these different questions? *Palliative Medicine*, *22*(7), 787–795. https://doi.org/10.1177/0269216308092287

Ali, M., Capel, M., Jones, G., & Gazi, T. (2019). The importance of identifying preferred place of death. *BMJ Supportive & Palliative Care*, *9*(1), 84–91. https://doi.org/10.1136/bmjspcare-2015-000878

Alvariza, A., Mjörnberg, M., & Goliath, I. (2020). Palliative care nurses' strategies when working in private homes—A photo-elicitation study. *Journal of Clinical Nursing*, *29*(1-2), 139–151. https://doi.org/10.1111/jocn.15072

American Nurses Association (ANA). (2015). *Nursing: Scope and standards of practice* (3rd ed.). Author.

Ampe, S.,Sevenants, A., Smets, T., Declercq, A., & Van Audenhove, C. (2016). Advance care planning for nursing home residents with dementia: Influence of "we DECide" on policy

and practice. *Patient Education and Counseling, 100*(1), 139–146. https://doi.org/10.1016/j.pec.2016.08.010

An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying), S.C. 2016, c. 3. http://laws-lois.justice.gc.ca/eng/AnnualStatutes/2016_3/FullText.html

Andrews, S. C. (2001). Caregiver burden and symptom distress in people with cancer receiving hospice care. *Oncology Nursing Forum*, *28*(9), 1469–1474. https://search-ebscohost-com.proxy.bib.uottawa.ca/login.aspx?direct=true&db=a9h&AN=107072076&site=ehost-live

Antunes, Bowers, B., Winterburn, I., Kelly, M. P., Brodrick, R., Pollock, K., Majumder, M., Spathis, A., Lawrie, I., George, R., Ryan, R., & Barclay, S. (2020). Anticipatory prescribing in community end-of-life care in the UK and Ireland during the COVID-19 pandemic: online survey. *BMJ Supportive & Palliative Care, 10*(3), 343–349. https://doi.org/10.1136/bmjspcare-2020-002394

Appleton, J. V., & King, L. (1997). Constructivism: A naturalistic methodology for nursing inquiry. *Advances in Nursing Science*, *20*(2), 13–22.

Armstrong, P., & Armstrong, H. (2018). Reforming health services in Ontario: Contradictions. In B. Evans, & G. Albo (Eds.), *Divided province: Ontario politics in the age of neoliberalism* (334-358). McGill-Queen's University Press.

Arnaert, A., Seller, R., & Wainwright, M. (2009). Homecare nurses' attitudes toward palliative care in a rural community in Western Quebec. *Journal of Hospice and Palliative Nursing*, *11*(4), 202–208. https://doi.org/10.1097/NJH.0b013e3181aad9c4

Atkinson, P. (2015). *For ethnography*. Sage.

Atkinson, P., Coffey, A., Delamont, S., Lofland, J., & Lofland, L. (Eds.). (2001). *Handbook of ethnography*. Sage.

Back, A., Arnold, R., & Tulsky, J. A. (2009). *Mastering communication with seriously ill patients: balancing honesty with empathy and hope*. Cambridge University Press.

Bacon, J. (2013). *The palliative approach: Improving care for Canadians with life limiting illnesses*. Canadian Hospice Palliative Care Association. http://hpcintegration.ca/media/38753/TWF-palliative-approach-report-English-final2.pdf

Bainbridge, D., Brazil, K., Krueger, P., Ploeg, J., & Taniguchi, A. (2010). A proposed systems approach to the evaluation of integrated palliative care. *BMC Palliative Care*, *9*(1), 1–12. https://doi.org/10.1186/1472-684X-9-8

Barbera, L., Paszat, L., & Chartier, C. (2006). Indicators of poor quality EOL cancer care in Ontario. *Journal of Palliative Care*, *22*(1), 12–17.

Barnabe, C., & Kirk, P. (2002). A needs assessment for southern Manitoba physicians for palliative care education. *Journal of Palliative Care*, *18*(3), 175–184. https://doi.org/10.1177/082585970201800306

Beernaert, K., Van den Block, L., Van Thienen, K., Devroey, D., Pardon, K., Deliens, L., & Cohen, J. (2015). Family physicians' role in palliative care throughout the care continuum: Stakeholder perspectives. *Family Practice*, *32*(6), 694–700. https://doi.org/10.1093/fampra/cmv072

Bell, C. L., Somogyi-Zalud, E., & Masaki, K. H. (2010). Factors associated with congruence between preferred and actual place of death. *Journal of Pain and Symptom Management*, *39*(3), 591–604. https://doi.org/10.1016/j.jpainsymman.2009.07.007

Benner, P., Tanner, C. A., & Chesla, C. A. (1996). The social embeddedness of knowledge.

In P. Benner, C. A. Tanner, & C. A. Chesla (Eds.), *Expertise in nursing practice* (pp. 193–231). Springer.

Bergum, & Dossetor, J. B. (2005). *Relational ethics: the full meaning of respect*. University Pub. Group.

Beuthin, R., Bruce, A., & Scaia, M. (2018). Medical assistance in dying (MAiD): Canadian nurses' experiences. *Nursing Forum*, *53*(4), 511–520.

Bhavsar, N. A., Bloom, K., Nicolla, J., Gable, C., Goodman, A., Olson, A., Harker, M., Bull, J., & Taylor, D. H. (2017). Delivery of community-based palliative care: Findings from a time and motion study. *Journal of Palliative Medicine*, *20*(10), 112–1126. https://doi.org/10.1089/jpm.2016.0433

Bill C-7, *An Act to Amend the Criminal Code (Medical Assistance in Dying),* 2nd Session, 43rd Parliament, 2021. https://parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent

Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, 1st Session, 42nd Parliament, 2016. https://www.parl.ca/LegisInfo/BillDetails.aspx?Language=E&billId=8177165

Bill 127*, Expanded Nursing Services for Patients Act*, 1rst Session, 36th Parliament, Ontario, 1997. https://www.ola.org/en/legislative-business/bills/parliament-36/session-1/bill-127

Billings, J. A. (2002). Vicissitudes of the clinician-patient relationship in end-of life care: Recognizing the role for teams. *Journal of Palliative Medicine, 5*(2), 295–299. https://doi.org/10.1089/109662102753641296.

Bjornsdottir, K. (2018). "I try to make a net around each patient": Home care nursing as relational practice. *Scandinavian Journal of Caring Sciences*, *32*(1), 177–185. https://doi.org/10.1111/scs.12443

Block, S. (2002). Medical education in EOL care: The status of reform. *Journal of Palliative Medicine*, *5*(2), 243–248.

Boadu. (2014). Using Malaria Rapid Diagnostic Tests in Ghana: Understanding Healthcare Providers' Compliance with Policy Guidelines for Malaria Diagnosis in Peripheral Facilities. ProQuest Dissertations Publishing.Borbasi, S., Jackson, D., & Wilkes, L. (2005). Fieldwork in nursing research: Positionality, practicalities and predicaments. *Journal of Advanced Nursing, 51*(5), 493–501. https://doi.org/10.1111/j.1365-2648.2005.03523.x

Borbasi, S., Jackson, D., & Wilkes, L. (2005). Fieldwork in nursing research: Positionality, practicalities and predicaments. *Journal of Advanced Nursing*, *51*(5), 493–501. https://doi.org/10.1111/j.1365-2648.2005.03523.x

Boudreau, T. (1972). *Report of the Committee on Nurse Practitioners*. Department of National Health and Welfare.

Bowers, B., Ryan, R., Kuhn, I., & Barclay, S. (2019). Anticipatory prescribing of injectable medications for adults at the end of life in the community: A systematic literature review and narrative synthesis. *Palliative Medicine*, *33*(2), 160–177. https://doi.org/10.1177/0269216318815796

Bowers, B., & While, A. (2019). Getting anticipatory prescribing right in EOL care. *British Journal of Community Nursing*, *24*(6), 274–277.

Brassfield, E. R., & Buchbinder, M. (2021). Clinical discussion of medical aid-in-dying: Minimizing harms and ensuring informed choice. *Patient Education and Counseling*, *104*(3), 671–674. https://doi.org/10.1016/j.pec.2020.08.029

Brazil, K., Howell, D., Marshal, D., Critchley, P., Van den, E., & Thomson, C. (2007). Building primary care capacity in palliative care: Proceedings of an interprofessional workshop. *Journal of Palliative Care, 23*(2), 113–116. https://doi.org/10.1177/082585970702300206

Brewer, J. (2000). *Ethnography*. McGraw-Hill Education (UK).

Brink, P. (2013). Traditional ethnography. In C. T. Beck (Ed.), *Routledge international handbook of qualitative nursing research* (pp. 203-212). Routledge. https://doi.org/10.4324/9780203409527

Broad, J., Gott, M., Kim, H., Boyd, M., Chen, H., & Connolly, M. J. (2012). Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *International Journal of Public Health, 58*(2), 257–267. https://doi.org/10.1007/s00038-012-0394-5

Broback, G., & Bertero, C. (2003). How next of kin experience palliative care of relatives at home. *European Journal of Cancer Care*, *12*(4), 339–346. https://doi.org/10.1046/j.1365-2354.2003.00436.x

Broom, A., & Willis, E. (2007). Competing paradigms in health research. In M. Saks & J. Allsop (Eds.), *Researching health: Qualitative, quantitative and mixed methods* (pp. 16–31). Sage.

Brown, J., Goodridge, D., Thorpe, L., & Crizzle, A. (2021). "What is right for me, is not necessarily right for you": The endogenous factors influencing nonparticipation in medical assistance in dying. *Qualitative Health Research*, *31*(10), 1786–1800. https://doi.org/10.1177/10497323211008843

Bruce, A., & Beuthin, R. (2020). Medically assisted dying in Canada: "Beautiful death" is transforming nurses' experiences of suffering. *Canadian Journal of Nursing Research*, *52*(4), 268–277. https://doi.org/10.1177/0844562119856234

Bryant-Lukosius, D., & Martin-Misener, R. (2015). *Advanced practice nursing: An essential component of country level human resources for health.* http://www.who.int/workforcealliance/knowledge/resources/ICN_PolicyBrief6AdvancedPracticeNursing.pdf

Bryman, A. (2004). *Social research methods*. Oxford University Press.

Buerhaus, P., Perloff, J., Clarke, S., O'Reilly-Jacob, M., Zolotusky, G., & DesRoches, C. M. (2018). Quality of primary care provided to Medicare beneficiaries by nurse practitioners and physicians. *Medical Care*, *56*(6), 484–490. https://doi.org/10.1097/MLR.0000000000000908

Bugge, E., & Higginson, I. (2006). Palliative care and the need for education: Do we know what makes a difference? A limited systematic review. *Health Education Journal*, *65*(2), 101–125.

Bull, R., & FitzGerald, M. (2006). Nursing in a technological environment: Nursing care in the operating room. *International Journal of Nursing Practice*, *12*(1), 3–7. https://doi.org/10.1111/j.1440-172X.2006.00542.x

Burns, C. M., Abernethy, A. P., Dal Grande, E., & Currow, D. C. (2013). Uncovering an invisible network of direct caregivers at the end of life: A population study. *Palliative Medicine, 27*(7), 608–615. https://doi.org/10.1177/0269216313483664

Canada. (2017). *Medical assistance in dying*. https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html

Canadian Association of MAiD Assessore and Providers (CAMAP). (2020). Bringing up Medical Assistance in Dying (MAiD) as a Clinical Care Option. Author. https://camapcanada.ca/wp-content/uploads/2020/02/Bringing-up-MAiD.pdf

Canadian Cancer Society. (2016). *Right to care: Palliative care for all Canadians.* https://cdn.cancer.ca/-/media/files/get-involved/advocacy/what-we-are-doing/palliative-care/palliative-care-report-2016-en.pdf?rev=b6d10617ba524359b1aa7f18ea7fa006&hash=8EB6A3CC6C888441B0CF163066AF7B88

Canadian Council of Registered Nurse Regulators (CCRNR). (2015). *Practice analysis study of nurse practitioners*. http://www.ccrnr.ca/assets/ccrnr-practice-analysis-study-of-nurse-practitioners-report---final.pdf

Canadian Hospice Palliative Care Association (CHPCA). (2014a). *The way forward: Moving towards and integrated palliative approach to care: Survey of GP/FPs and nurses in primary care, final report.* http://www.hpcintegration.ca/media/55755/CHPCA_The%20Way%20Forward%20Survey_Final%20Report_August2014.pdf

Canadian Hospice Palliative Care Association (CHPCA). (2014b). *Attitudes toward palliative and EOL care: A survey of Canadian family physicians.* http://hpcintegration.ca/media/55743/4617_The%20Way%20Forward_11x17_v6_eng_TS%20-2%20(2).pdf

Canadian Hospice Palliative Care Association (CHPCA). (2018). *Palliative care and MAiD: Co-existing in the new environment.*

https://www.virtualhospice.ca/Assets/MAiD_Report_Final_October_15_2018_20181218165246.pdf

Canadian Institute for Health Information (CIHI). (2018). *Access to palliative care in Canada.* https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf

Canadian Institute for Health Information (CIHI). (2021). *Nurse practitioners.* https://www.cihi.ca/en/nurse-practitioners

Canadian Institute for Health Information (CIHI) and the Canadian Nurses Association (CNA). (2006). *The Regulation and Supply of Nurse Practitioners in Canada: 2006. Update*. Ottawa, ON: CIHI. https://international.aanp.org/Content/docs/The_Regulation_and_Supply_of_Nurse_Practitioners_in_Canada_e1.pdf

Canadian Medical Association (CMA). (2016). *A Canadian approach to assisted dying: CMA member dialogue (Summary report).* https://www.cma.ca/Assets/assets-library/document/en/ advocacy/Canadian-Approach-Assisted-Dying-e.pdf

Canadian Nurses Association (CNA). (2010). *Canadian nurse practitioner core competency framework.* http://www.cno.org/globalassets/for/rnec/pdf/competencyframework_en.pdf

Canadian Nurses Association (CNA). (2015). *Joint position statement: The palliative approach to care and the role of the nurse.* https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/the-palliative-approach-to-care-and-the-role-of-the-nurse_e.pdf

Canadian Nurses Association (CNA). (2019). *Advanced practice nursing: A pan Canadian framework.* https://www.cna-aiic.ca/-/media/cna/page-content/pdf-en/apn-a-pan-canadian-framework.pdf

Carlson, E., Rämgård, M., Bolmsjö, I., & Bengtsson, M. (2014). Registered nurses' perceptions of their professional work in nursing homes and home-based care: A focus group study. *International Journal of Nursing Studies*, *51*(5), 761–767. https://doi.org/10.1016/j.ijnurstu.2013.10.002

Cardona-Morrell, K., J., Turner, R. M., Anstey, M., Mitchell, I. A., & Hillman, K. (2016). Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem. *International Journal for Quality in Health Care, 28*(4), 456–469. https://doi.org/10.1093/intqhc/mzw060

Carthon, J. M., Sammarco, T., Pancir, D., Chittams, J., & Nicely, K. W. (2017). Growth in retail-based clinics after nurse practitioner scope of practice reform. *Nursing Outlook*, *65*, 195–201.

Carryer, J., Gardner, G., Dunn, S., & Gardner, A. (2007). The core role of the nurse practitioner: practice, professionalism and clinical leadership. *Journal of Clinical Nursing*, *16*(10), 1818–1825. https://doi.org/10.1111/j.1365-2702.2007.01823.x

Castle, N. (1997). Advance directives in nursing homes: Resident and facility characteristics. *OMEGA Journal of Death and Dying*, *34*(4), 321–232. https://doi.org/10.2190/YKJV-WUXM-EFVF-X1TN

Centeno, C., Lynch, T., Garralda, E., Carrasco, J. M., Guillen-Grima, F., & Clark, D. (2016). Coverage and development of specialist palliative care services across the World Health Organization European Region (2005–2012): Results from a European Association for Palliative Care Task Force survey of 53 countries. *Palliative Medicine*, *30*(4), 351–362. https ://doi.org/10.1177/02692 16315598671

Chambers, E. (2000). Applied ethnography. In N. K. Denzin & Y. S. Lincoln, (Eds.), *Handbook of qualitative research* (2nd ed., pp. 851-869). Sage.

Champlain Hospice Palliative Care. (2017). *What is palliative care?* http://www.champlainpalliative.ca/en/hospice-palliative-care-in-champlain/what-is-palliative-care

Champlain Local Health Integration Network (LHIN). (2020). *Champlain LHIN long-term care home wait times, by home.* http://healthcareathome.ca/champlain/en/care/Documents/LTCHWaitTimes_EN.pdf

Chiseri-Strater, E. (1996). Turning in upon ourselves: Positionality, subjectivity, and reflexivity in case study and ethnographic research. In P. Mortensen & G. E. Kirsh (Eds.), *Ethics and representation in qualitative studies of literacy* (pp. 115–133). National Council of Teachers of English.

Clark, D. (2007). From margins to centre: A review of the history of palliative care in cancer. *Lancet Oncology*, *8*(5), 430–438.

Clark, D., Ingleton, C., Hughes, P., Yap, T., & Noble, B. (2004). Evaluation of a scheme to enhance palliative cancer care in rural Wales. *Supportive Care in Cancer*, *12*(10), 683–691.

Cohen, L., Manion, L., & Morrison, K. (2011). *Research methods in education* (7th ed.). Routledge.

Cole, S. (2017). Case study: Realizing the value of nurse practitioners in long-term care. *Nursing Leadership*, *30*(4), 39–44. https://doi.org/10.12927/cjnl.2017.25450

College of Nurses of Ontario (CNO). (2017). *Practice standard: Nurse practitioner.* https://www.cno.org/globalassets/docs/prac/41038_strdrnec.pdf

College of Nurses of Ontario (CNO). (2018). Entry to practice competencies for nurse practitioners. *College Nurses of Ontario* https://www.cno.org/globalassets/docs/reg/47010-np-etp-competencies.pdf

College of Nurses of Ontario (CNO). (2021). *Guidance on nurses' roles in medical assistance in dying.* https://www.cno.org/globalassets/docs/prac/41056-guidance-on-nurses-roles-in-maid.pdf

Collins, C. M., & Small, S. P. (2019). The nurse practitioner role is ideally suited for palliative care practice: A qualitative descriptive study. *Canadian Oncology Nursing Journal*, *29*(1), 4–9. https://doi.org/10.5737/2368807629149

Commonwealth Fund. (2015). *The Commonwealth Fund 2015 international health policy survey of primary care physicians.* https://www.commonwealthfund.org/publications/surveys/2015/dec/2015-commonwealth-fund-international-survey-primary-care-physicians

Costa V. (2014). The determinants of place of death: an evidence-based analysis. *Ontario Health Technology Assessessment Series, 14*(16), 1–78. http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/ontario-health-technology-assessment-series/eol-determinants-place-of-death

Covenant Health. (2016). *Palliative care matters: How Canada's health system needs to change.* https://static1.squarespace.com/static/5755e91b044262d8f43cf6fa/t/5838878c9f74566f0d65ac72/1480099731622/PCM_+ConsensusStatement__Proof2.pdf

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Sage.

Crotty, M. (2020). *The foundations of social research: Meaning and perspective in the research process*. Sage.

Crumley, Kelly, S., Young, J., Phinney, N., McCarthy, J., & Gubitz, G. (2021). How is the medical assistance in dying (MAID) process carried out in Nova Scotia, Canada? A qualitative process model flowchart study. *BMJ Open, 11*(7), e048698. https://doi.org/10.1136/bmjopen-2021-048698

Cruz, E. V., & Higginbottom, G. (2013). The use of focused ethnography in nursing research. *Nurse Researcher*, *20*(4), 36–43. https://doi.org/10.7748/nr2013.03.20.4.36.e305

Dahlhaus, A., Vanneman, N., Siebenhofer, A., Brosche, M., & Guethlin, C. (2013). Involvement of general practitioners in palliative cancer care: A qualitative study. *Supportive Care in Cancer*, *21*(12), 3293–3300. https://doi.org/10.1007/s00520-013-1904-6

Danielsen, B. V., Sand, A. M., Rosland, J. H., & Førland, O. (2018). Experiences and challenges of home care nurses and general practitioners in homebased palliative care: A qualitative study. *BMC Palliative Care, 17*(1), 95-95. https://doi.org/10.1186/s12904-018-0350-0

Deegan, M. J. (2001). The Chicago school of ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography* (pp. 60–79). Sage. http://methods.sagepub.com/base/download/BookChapter/handbook-of-ethnography/n1.xml

Deitrick, L. M., Rockwell, E. H., Gratz, N., Davidson, C., Lukas, L., Stevens, D., Fitzgerald, G., Naugle, M., Wolf, J., & Sikora, B. (2011). Delivering specialized palliative care in the community: A new role for nurse practitioners. *Advances in Nursing Science*, *34*(4), E23–E36. https://doi.org/10.1097/ANS.0b013e318235834f

deKorte-Verhoef, M., Pasman, H. R., Schweitzer, B. P., Francke, A., Onwuteaka-Philipsen, B., & Deliens, L. (2014). Burden for family carers at the end of life: A mixed-method study of the perspectives of family carers and GPs. *BMC Palliative Care*, *13*(1), 16–16. https://doi.org/10.1186/1472-684X-13-16

DeMiglio, L., & Williams, A. (2011). Shared care: The barriers encountered by community-based palliative care teams in Ontario, Canada. *Health & Social Care in the Community*, *20*(4), 420–429. https://doi.org/10.1111/j.1365-2524.2012.01060.x.

Denier, Y., Gastmans, C., De Bal, N., & Dierckx de Casterlé, B. (2010). Communication in nursing care for patients requesting euthanasia: A qualitative study. *Journal of Clinical Nursing*, *19*(23–24), 3372–3380. https://doi.org/10.1111/j.1365-2702.2010.03367.x

Denzin, N., & Lincoln, Y. S. (2000). *Handbook of qualitative research*. Sage.

Denzin, N., & Lincoln, Y. S. (2005). *The Sage handbook of qualitative research* (3rd ed.). Sage.

Denzin, N. K., & Lincoln, Y. S. (2011). The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (4th ed., pp. 1–20). Sage.

Déry, Paquet, M., Boyer, L., Dubois, S., Lavigne, G., & Lavoie-Tremblay, M. (2022). Optimizing nurses' enacted scope of practice to its full potential as an integrated strategy for the continuous improvement of clinical performance: A multicentre descriptive analysis. Journal of Nursing Management, 30(1), 205–213. https://doi.org/10.1111/jonm.13473

Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *BMJ*, *340*(7751), 47–847. https://doi.org/10.1136/bmj.c1345

DeWalt, K. M., & DeWalt, B. R. (2011). *Participant observation: A guide for fieldworkers* (2nd ed.). Rowman and Littlefield.

Dierckx de Casterlé, B., Denier, Y., De Bal, N., & Gastmans, C. (2010). Nursing care for patients requesting euthanasia in general hospitals in Flanders, Belgium: Nursing care for patients requesting euthanasia. *Journal of Advanced Nursing*, *66*(11), 2410–2420. https://doi.org/10.1111/j.1365-2648.2010.05401.x

Deitrick, L. M., Rockwell, E. H., Gratz, N., Davidson, C., Lukas, L., Stevens, D., Fitzgerald, G., Naugle, M., Wolf, J., & Sikora, B. (2011). Delivering specialized palliative care in the community: A new role for nurse practitioners. *Advances in Nursing Science*, *34*(4), E23–E36. https://doi.org/10.1097/ANS.0b013e318235834f

Doan, G., & Varcoe, C. (2021). *How to nurse: Relational inquiry in action*. Wolters Kluwere Health, Lippincott Williams & Wilkins.

Doane, G. H., & Varcoe, C. (2007). Relational practice and nursing obligations. *Advances in Nursing Science*, *30*(3), 192–205. https://doi.org/10.1097/01.ANS.0000286619.31398.fc

Donner, G., Fooks, C., McReynolds, J., Sinha, S., Smith, K., & Thomson, D. (2015). *Report of the Expert Group on Home and Community Care – Bringing Care Home*. https://health.gov.on.ca/en/public/programs/lhin/docs/hcc_report.pdf

Downie, J. (2018). *Can nurse practitioners mention MAiD to patients?* Impact Ethics. https://impactethics.ca/2018/07/03/can-nurse-practitioners-mention-maid-to-patients/

Dunlay, S. M., & Strand, J. J. (2016). How to discuss goals of care with patients. *Trends in Cardiovascular Medicine*, *26*(1), 36–43. https://doi.org/10.1016/j.tcm.2015.03.018

Dusseldorp, Groot, M., Aiaansen, M. J., Vught, A. J. A. H. van, Vissers, K., & Peters, J. (2018). What does the nurse practitioner mean to you? A patient-oriented qualitative study in

oncological/palliative care. *Journal of Clinical Nursing*, 28(3-4), 589–602. https://doi.org/10.1111/jocn.14653

Edwards, J., Hooper, D., Rothwell, G., Kneen, K., Watson, J., & Saurman, E. (2019). A nurse practitioner-led community palliative care service in Australia. *International Journal of Palliative Nursing*, *25*(5), 245–253. https://doi.org/10.12968/ijpn.2019.25.5.245

El Nawawi, N. M., Balboni, M. J., & Balboni, T. A. (2012). Palliative care and spiritual care: The crucial role of spiritual care in the care of patients with advanced illness. *Current Opinions in Supportive Palliative Care*, *6*, 269–274.

Elliott, L., Persaud, M., Seto Nielsen, L., & Boscart, V. (2018). A focused ethnography of nursing team culture and leadership on a transitional care unit. *Perspectives the Journal of the Gerontological Nursing Association*, *40*(2), 6–14.

Friedrichsen, Lindholm, A., & Milberg, A. (2011). Experiences of truth disclosure in terminally ill cancer patients in palliative home care. *Palliative & Supportive Care, 9*(2), 173–180. https://doi.org/10.1017/S1478951511000046

Field, P. A. (1983). An ethnography: Four public health nurses' perspectives of nursing. *Journal of Advanced Nursing*, *8*(1), 3–12. https://doi.org/10.1111/j.1365-2648.1983.tb00284.x

Foote, M. Q, & Gau Bartell, T. (2011). Pathways to equity in mathematics education: how life experiences impact researcher positionality. *Educational Studies in Mathematics, 78*(1), 45–68. https://doi.org/10.1007/s10649-011-9309-2

Fowler, L. H., Landry, J., & Nunn, M. F. (2019). Nurse practitioners improving emergency department quality and patient outcomes. *Critical Care Nursing Clinics of North America*, *31*, 237–247.

Franks, P. J., Bosanquet, N. K., Kite, S., Naysmith, A., Higginson, I., Salisbury, C., & Wilkinson, E. (2000). The level of need for palliative care: A systematic review of the literature. *Palliative Medicine*, *14*(2), 93–104.

Funk, L., Stajduhar, K., Outcalt, L., & Funk, L. (2015). What family caregivers learn when providing care at the end of life: A qualitative secondary analysis of multiple datasets. *Palliative & Supportive Care*, *13*(3), 425–433. https://doi.org/10.1017/S1478951513001168

Funk, L., Stajduhar, K., Toye, C., Aoun, S., Grande, G., & Todd, C. (2010). Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research. *Palliative Medicine*, *24*(6), 594–607. https://doi.org/10.1177/0269216310371411

García-Pérez, L., Linertová, R., Martín-Olivera, R., Serrano-Aguilar, P., & Benítez-Rosario, M. (2009). A systematic review of specialised palliative care for terminal patients: Which model is better? *Palliative Medicine*, *23*(1), 17–22. https://doi.org/10.1177/0269216308099957

Gardiner, C., Brereton, L., Frey, R., Wilkinson-Meyers, L., & Gott, M. (2014). Exploring the financial impact of caring for family members receiving palliative and end-of-life care: a systematic review of the literature. *Palliative medicine*, *28*(5), 375–390. https://doi.org/10.1177/0269216313510588

Geertz, C. (1973). *The interpretation of cultures selected essays*. Basic Books.

Gemmill, A. (2018). Nurse practitioners not always compensated for providing medical assistance in dying. *CBC News.* https://www.cbc.ca/news/canada/sudbury/nurse-practitioners-maid-ontario-1.4588706

Gerson, S. M., Koksvik, G. H., Richards, N., Materstvedt, L. J., & Clark, D. (2020). The relationship of palliative care with assisted dying where assisted dying is lawful: A systematic scoping review of the literature. *Journal of Pain and Symptom Management*, *59*(6), 1287–1303. https://doi.org/10.1016/j.jpainsymman.2019.12.361

Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar, M. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*, *31*(6), 1105–1117. https://doi.org/10.1188/04.ONF.1105-1117

Given, L. M. (2008). Relational ethics. In *The SAGE encyclopedia of qualitative research methods* (Vol. 1, pp. 749-749). SAGE Publications, Inc., https://dx.doi.org/10.4135/9781412963909.n378

Goetz, J. P., & LeCompte, M. D. (1984). *Ethnography and qualitative design in educational research*. New York. Academic Press.

Gold, R. L. (1958). Roles in Sociological Field Observations. *Social Forces, 36*(3), 217–223. https://doi.org/10.2307/2573808

Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. (2013). Heterogeneity and changes in preferences for dying at home: A systematic review. *BMC Palliative Care*, *12*(1), 7. https://doi.org/10.1186/1472-684X-12-7

Gomes, B., & Higginson, I. (2006). Factors influencing death at home in terminally ill patients with cancer: Systematic review. *BMJ*, *332*(7540), 515–518. https://doi.org/10.1136/bmj.38740.614954.55

Gott, M., Frey, R., Robinson, J., Boyd, M., O'Callaghan, A., Richards, N., & Snow, B. (2013). The nature of, and reasons for, "inappropriate" hospitalisations among patients with palliative care needs: A qualitative exploration of the views of generalist palliative care

providers. *Palliative Medicine*, *27*(8), 747–756. https://doi.org/10.1177/0269216312469263

Government of Canada. (2017). *A common statement of principles on shared health priorities.* https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/principles-shared-health-priorities.html

Government of Canada. (2019). *Fourth interim report on medical assistance in dying in Canada.* https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-april-2019.html/ https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/medical-assistance-dying-interim-report-april-2019/medical-assistance-dying-interim-report-april-2019-eng.pdf

Grant, M. S., Wiegand, D. L., & Dy, S. M. (2015). Asking questions of a palliative care nurse practitioner on a pancreatic cancer website. *Palliative & Supportive Care*, *13*(3), 787–793. https://doi.org/10.1017/S1478951514000637

Graydon, J., & Hendry, J. (1977). Outpost nursing in Northern Newfoundland. *Canadian Nurse*, *73*(8), 34–37.

Green, E., Gott, M., & Wong, J. (2016). Why do adults with palliative care needs present to the emergency department? A narrative review of the literature. *Progress in Palliative Care*, *24*(4), 195–203. https://doi.org/10.1080/09699260.2015.1115805

Griffiths, P. (2011). A community of practice: The nurses' role on a medical assessment unit. *Journal of Clinical Nursing*, *20*(1–2), 247–254. https://doi.org/10.1111/j.1365-2702.2009.03135.x

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 191-215). Sage.

Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions and emerging confluences. N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 191–216). Sage.

Håkansson, E., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., Sundler, A. J., Condén, E., & Summer Meranius, M. (2019). "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Education and Counseling, 102*(1), 3–11. https://doi.org/10.1016/j.pec.2018.08.029

Hammersley, M., & Atkinson, P. (2019). *Ethnography: Principles in practice.* Routledge.

Haron, Y., Romem, A., & Greenberger, C. (2019). The role and function of the palliative care nurse practitioner in Israel. *International Journal of Palliative Nursing*, *25*(4), 186–192. https://doi.org/10.12968/ijpn.2019.25.4.186

Hart, Harhay, M. O., Gabler, N. B., Ratcliffe, S. J., Quill, C. M., & Halpern, S. D. (2015). Variability Among US Intensive Care Units in Managing the Care of Patients Admitted With Preexisting Limits on Life-Sustaining Therapies. *JAMA Internal Medicine, 175*(6), 1019–1026. https://doi.org/10.1001/jamainternmed.2015.0372

Heale, R., & Pilon, R. (2012). An exploration of patient satisfaction in a nurse practitioner-led clinic. *Nursing Leadership*, *25*(3), 43–55.

Health Canada. (2019). *Action plan on palliative care: Building on the framework on palliative care in Canada.* https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/action-plan-palliative-care/action-plan-palliative-care-eng.pdf

Health Canada (2018). *Framework on Pallietive Care in Canada*. https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada/framework-palliative-care-canada.pdf

Health Professions Regulatory Advisory Council. (2008). *A report to the Minister of Health and Long-Term Care on the review of the scope of practice for registered nurses in the extended class (nurse practitioners)*. http://www.hprac.org/en/reports/resources/hpracextendedclassnursereportengmar08.pdf

Health Quality Ontario. (2016a). *Palliative care at the end of life*. Queen's Printer for Ontario. http://www.hqontario.ca/Portals/0/documents/system-performance/palliative-care-report-en.pdf

Health Quality Ontario. (2016b). *The reality of caring.* Queen's Printer for Ontario. http://www.hqontario.ca/Portals/0/documents/system-performance/reality-caring-report-en.pdf

Health Quality Ontario. (2019). Palliative Care at the End of Life: Report Update, 2019. https://www.hqontario.ca/Portals/0/documents/system-performance/palliative-care-report-2019-en.pdf

Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., Shortt, S., Tranmer, J., Lazar, N., Kutsogiannis, J., & Lam, M. (2006). What matters most in EOL care: Perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal*, *174*(5), 627–633. https://doi.org/10.1503/cmaj.050626

Higginbottom, G. M., Pillay, J. J., & Boadu, N. Y. (2013). Guidance on performing focused ethnographies with an emphasis on healthcare research. *Qualitative Report, 18*(9), 1.

https://link.gale.com/apps/doc/A350337131/AONE?u=otta77973&sid=bookmark-AONE&xid=0ff3a021

Hoare, S., Kelly, M. P., & Barclay, S. (2019). Home care and EOL hospital admissions: A retrospective interview study in English primary and secondary care. *British Journal of General Practice*, *69*(685), e561–e569. https://doi.org/10.3399/bjgp19X704561

Holland, C. K. (1993). An ethnographic study of nursing culture as an exploration for determining the existence of a system of ritual. *Journal of Advanced Nursing, 18*(9), 1461–1470. https://doi.org/10.1046/j.1365-2648.1993.18091461.x

Holmes, A. G. D. (2020). Researcher positionality: A consideration of its influence and place in qualitative research. A new researcher guide. *International Journal of Education, 8*(4), 1-10. https://doi.org/10.34293/ education.v8i4.3232

Home Care Ontario. (2018). *More home care for me and you.* https://www.homecareontario.ca/docs/default-source/position-papers/home-care-ontario-more-home-care-for-me-and-you-february-28-2018.pdf?sfvrsn=16

Htay, M., & Whitehead, D. (2021). The effectiveness of the role of advanced nurse practitioners compared to physician-led or usual care: A systematic review. *International Journal of Nursing Studies Advances*, *3*, 100034–. https://doi.org/10.1016/j.ijnsa.2021.100034

Hummel, D. L., Hill, C., Shaw, J. G., Slightam, C., Asch, S. M., & Zulman, D. M. (2017). Nurse practitioner-led intensive outpatient team: Effects on EOL care. *Journal for Nurse Practitioners*, *13*(5), e245–e248. https://doi.org/10.1016/j.nurpra.2017.01.007

Hunstad, I., & Foelsvik Svindseth, M. (2011). Challenges in home-based palliative care in Norway: A qualitative study of spouses' experiences. *International Journal of Palliative Nursing*, *17*(8):398-404. https://doi.org/10.12968/ijpn.2011.17.8.398. PMID: 22067680.

Insight West. (2015). *Four-in-five Canadians favor allowing physician assisted suicide in Canada.* https://thinkpol.ca/2015/12/03/four-infive-canadians-favour-allowing-physician-assisted-suicide-in-canada/

International Council of Nurses (ICN). (2008). *The scope of practice, standards and competencies of the advanced practice nurse.* Author.

International Council of Nurses (ICN). (2020). *Guidelines on advanced practice nursing 2020.* https://www.icn.ch/system/files/documents/2020-04/ICN_APN%20Report_EN_WEB.pdf

Irvine, D., Sidani, S., & Hall, L. M. (1998). Linking outcomes to nurses' roles in health care. Nursing Economic, 16(2), 58–87.

Jack, B., & O'Brien, M. (2010). Dying at home: Community nurses' views on the impact of informal carers on cancer patients' place of death. *European Journal of Cancer Care*, *19*(5), 636–642. https://doi.org/10.1111/j.1365-2354.2009.01103.x

Jangland, E., Teodorsson, T., Molander, K., & Muntlin Athlin, Å. (2018). Inadequate environment, resources and values lead to missed nursing care: A focused ethnographic study on the surgical ward using the fundamentals of care framework. *Journal of Clinical Nursing*, *27*(11–12), 2311–2321. https://doi.org/10.1111/jocn.14095

Janssens, R. M., Zylicz, Z., & Ten Have, H. A. (1999). Articulating the concept of palliative care: Philosophical and theological perspectives. *Journal of Palliative Care*, *15*(2), 38–44. https://doi.org/10.1177/082585979901500207

Jennings, N., Clifford, S., Fox, A. R., O'Connell, J., & Gardner, G. (2015). The impact of nurse practitioner services on cost, quality of care, satisfaction and waiting times in the

emergency department: A systematic review. *International Journal of Nursing Studies*, *52,* 421–435.

Jeong, S., Higgins, I., & McMillan, M. (2011). Experiences with advance care planning: nurses' perspective: Experiences with advance care planning (ACP). *International Journal of Older People Nursing, 6*(3), 165–175. https://doi.org/10.1111/j.1748-3743.2009.00200.x

Jocham, H., Dassen, T., Widdershoven, G., & Halfens, R. (2006). Quality of life in palliative care cancer patients: A literature review. *Journal of Clinical Nursing*, *15*(9), 1188–1195.

Johnston, B., & Smith, L. N. (2006). Nurses' and patients' perceptions of expert palliative nursing care. *Journal of Advanced Nursing*, *54*(6), 700–709. https://doi.org/10.1111/j.1365-2648.2006.03857.x

Kaasalainen, S., Brazil, K., Williams, A., Wilson, D., Willison, K., Marshall, D., Taniguchi, A., & Phillips, C. (2014). Nurses' experiences providing palliative care to individuals living in rural communities: Aspects of the physical residential setting. *Rural and Remote Health*, *14*(2), 2728–2728.

Kaasalainen, S., Brazil, K., Wilson, D., Willison, K., Marshall, D., Taniguchi, A., & Williams, A. (2011). Palliative care nursing in rural and urban community settings: A comparative analysis. *International Journal of Palliative Nursing*, *17*(7), 344–352.

Kaasalainen, S., Brazil, K., Williams, A., Wilson, D., Willison, K., Marshall, D., & Taniguchi, A. (2012). Barriers and enablers to providing palliative care in rural communities: A nursing perspective. *The Journal of Rural and Community Development*, *7*(4), 4-19.

Kaasalainen, S., Martin-Misener, R., Kilpatrick, K., Harbman, P., Bryant-Lukosius, D., Donald, F., Carter, N., & DiCenso, A. (2010). A historical overview of the development of

advanced practice nursing roles in Canada. *Nursing Leadership*, *23*(SP2), 35–60. https://doi.org/10.12927/cjnl.2010.22268

Kaasalainen, S., Ploeg, J., McAiney, C., Martin, L. S., Donald, F., Martin-Misener, R., Brazil, K., Taniguchi, A., Wickson-Griffiths, A., Carter, N., & Sangster-Gormley, E. (2013). Role of the nurse practitioner in providing palliative care in long-term care homes. *International Journal of Palliative Nursing, 19*(10), 477–485. https://doi.org/10.12968/ijpn.2013.19.10.477

Kaasalainen, S., Sussman, T., Bui, M., Akhtar-Danesh, N., Laporte, R. D., McCleary, L., Wickson Griffiths, A., Brazil, K., Parker, D., Dal Bello-Haas, V., Papaioannou, A., & O'Leary, J. (2017). What are the differences among occupational groups related to their palliative care-specific educational needs and intensity of interprofessional collaboration in long-term care homes? *BMC Palliative Care, 16*(1), 33–33. https://doi.org/10.1186/s12904-017-0207-y

Kaasalainen, S., Sussman, T., McCleary, L., Thompson, G., Hunter, P. V., Wickson-Griffiths, A, Cook, R., Bello-Haas, V. D., Venturato, L., Papaioannou, A., You, J., & Parker, D. (2019). Palliative care models in long-term care: A scoping review. *Nursing Leadership*, *32*(3), 8–26. https://doi.org/10.12927/cjnl.2019.25975.

Kaldjian, L. C. (2020). Clarifying core content of goals of care discussions. *Journal of General Internal Medicine*, *35*(3), 913–915. https://doi.org/10.1007/s11606-019-05522-5

Kane, R. L., Flood S., Keckhafer, G., Bershadsky, B., & Lum, Y. (2002). Nursing home residents covered by Medicare risk contracts: Early findings from the EverCare evaluation project. *Journal of the American Geriatrics Society*, *50,* 719–727.

Kane R. L., Keckhafer G., & Robst J. (2002). *Evaluation of the EverCare demonstration program: Final report.* http://www. cms.gov/Medicare/Demonstration-Projects/DemoProjectsEvalRpts/Downloads/Evercare_Final_Report.pdf on 6 June 2012

Karlsson, M., Karlsson, C., Barbosa da Silva, A., Berggren, I., & Söderlund, M. (2013). Community nurses' experiences of ethical problems in EOL care in the patient's own home. *Scandinavian Journal of Caring Sciences*, *27*(4), 831–838. https://doi.org/10.1111/j.1471-6712.2012.01087.x

Kelley, A. S., & Morrison, S. (2015). Palliative care for the seriously ill. *The New England Journal of Medicine*, *373*(8), 747–755. https://doi.org/10.1056/NEJMra1404684

Kennedy, C. M. (2002). The work of district nurses: First assessment visits. *Journal of Advanced Nursing, 40*(6), 710–720. https://doi.org/10.1046/j.1365-2648.2002.02430.x

Kilpatrick, K., Tchouaket, É., Jabbour, M., & Hains, S. (2020). A mixed methods quality improvement study to implement nurse practitioner roles and improve care for residents in long-term care facilities. *BMC Nursing*, *19*(1), 6–6. https://doi.org/10.1186/s12912-019-0395-2

Knoblauch, H. (2005). Focused Ethnography. *orum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *6*(3), Art. 44, http://nbn-resolving.de/urn:nbn:de:0114-fqs0503440.

Krishna, Tan, L. H. E., Ong, Y. T., Tay, K. T., Hee, J. M., Chiam, M., Chia, E. W. Y., Sheri, K., Tan, X. H., Teo, Y. H., Kow, C. S., Mason, S., & Toh, Y. P. (2020). Enhancing Mentoring in Palliative Care: An Evidence Based Mentoring Framework. Journal of Medical Education and Curricular Development, 7, 2382120520957649–2382120520957649. https://doi.org/10.1177/2382120520957649

Kristjanson, L. J., & Aoun, S. (2004). Palliative care for families: remembering the hidden patients. *The Canadian Journal of Psychiatry*, *49*(6), 359–365. https://doi.org/10.1177/070674370404900604

Kuhn, T. S. (1970). *The structure of scientific revolutions* (2nd ed.). University of Chicago Press.

Lang, A., Macdonald, M., Storch, J., Elliott, K., Stevenson, L., Lacroix, H., Donaldson, S., Corsini-Munt, S., Francis, F., & Curry, C. (2009). Home care safety perspectives from clients, family members, caregivers and paid providers. *Healthcare Quarterly*, *12*, 97–101. https ://doi.org/10.12927/ hcq.2009.20720

Lang, A., Macdonald, M. T., Storch, J., Stevenson, L., Mitchell, L., Barber, T., Roach, S., Toon, L., Griffin, M., Easty, A., Curry, C. G., LaCroix, H., Donaldson, S., Doran, D., & Blais, R. (2014). Researching triads in home care: Perceptions of safety from home care clients, their caregivers, and providers. *Home Health Care Management & Practice*, *26*(2), 59–71. https://doi.org/10.1177/1084822313501077

Lau, D., Berman, R., Halpern, L., Pickard, A., Schrauf, R., Witt, W., & Lau, D. (2010). Exploring factors that influence informal caregiving in medication management for home hospice patients. *Journal of Palliative Medicine*, *13*(9), 1085–1090. https://doi.org/10.1089/jpm.2010.0082

Lau, D., Masin-Peters, J., Berdes, C., Ong, M., & Lau, D. (2010). Perceived barriers that impede provider relations and medication delivery: Hospice providers' experiences in nursing homes and private homes. *Journal of Palliative Medicine*, *13*(3), 305–310. https://doi.org/10.1089/jpm.2009.0283

LeCompte, M. D., & Goetz, J. P. (1982). Problems of reliability and validity in ethnographic research. *Review of Educational Research*, *52*, 31–60. https://doi.org/10.3102/00346543052001031

LeCompte, M. D., & Schensul, J. J. (2010). *Designing and conducting ethnographic research*. Alta Mira Press.

Leipert, B. D., Delaney, J. W., Forbes, D., & Forchuk, C. (2011). Canadian rural women's experiences with rural primary health care nurse practitioners. *Online Journal of Rural Nursing & Health Care*, *11*(1), 37.

Lentz, E. R., Mundinger, M. O., Kane, R. L., Hopkins, S., C., & Lin, S. X. (2004). Primary care outcomes by nurse practitioners in patients treated by nurse practitioners or physicians: Two year follow-up. *Medical Care Research and Review*, *61*(3), 332–351.

Lesemann, F., & Martin, C. (1993). *Home based care, the elderly, the family and the welfare state: An international comparison.* University of Ottawa Press.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Sage.

Liu, L. M., Guarino, A. J., & Lopez, R. P. (2012). Family satisfaction with care provided by nurse practitioners to nursing home residents with dementia at the end of life. *Clinical Nursing Research*, *21*(3), 350–367. https://doi.org/10.1177/1054773811431883

Lukas, L., Foltz, C., & Paxton, H. (2013). Hospital outcomes for a home-based palliative medicine consulting service. *Journal of Palliative Medicine*, *16*(2), 179–184. https://doi.org/10.1089/jpm.2012.0414

MacDonald, N., Findlay, H. P., Bruera, E., Dudgeon, D. & Kramer, J. (1997). A Canadian survey of issues in cancer pain management. *Journal of Pain and Symptom Management, 14*(6), 332–42. https://doi.org/10.1016/S0885-3924(97)00259-5

Macdonald, S. (2001). British social anthropology. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography.* Sage.

Mackenzie, N., & Knipe, S. (2006). Research dilemmas: Paradigms, methods and methodology. *Issues in Educational Research*, *16*(2), 193–205.

Marchildon, G. P. (2006). *Health systems in transition: Canada*. University of Toronto: The European Observatory on Health Systems and Policies. http://gregmarchildon.ca/health-systems-in-transition-canada/

Marshall, D., Howell, D., Brazil, K., Howard, M., & Taniguchi, A. (2008). Enhancing family physician capacity to deliver quality palliative home care: An EOL, shared-care model. *Canadian Family Physician*, *54*, 1703.

Maier, C., Aiken, L., & Busse, R. (2017). *Nurses in advanced roles in primary care: Policy levers for implementation* (OECD Health Working Paper No. 98). OECD Publishing. http://dx.doi.org/10.1787/a8756593-en

Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. *The Lancet (British Edition)*, *358*(9280), 483–488. https://doi.org/10.1016/S0140-6736(01)05627-6

Markkanen, P., Quinn, M., Galligan, C., Chalupka, S., Davis, L., & Laramie, A. (2007). There's no place like home: A qualitative study of the working conditions of home health care providers. *Journal of Occupational and Environmental Medicine*, *49*(3), 327–337. https://doi.org/10.1097/JOM.0b013e3180326552

Martin-Misener, R. (2015). A mixed methods study of the work patterns of full-time nurse practitioners in nursing homes. *Journal of Clinical Nursing*, *24*(9-10), 1327–1337. https://doi.org/10.1111/jocn.12741

Mason, N., & Hodgkin, S. (2019). Preparedness for caregiving: A phenomenological study of the experiences of rural Australian family palliative carers. *Health & Social Care in the Community*, *27*(4), 926–935. https://doi.org/10.1111/hsc.12710

McAiney, C., Haughton, D., Jennings, J., Farr, D., Hillier, L., & Morden, P. (2008). A unique practice model for nurse practitioners in long-term care homes. *Journal of Advanced Nursing*, *62*(5), 562–571.

McSkimming, S., Hodges, M., Super, A., Driever, M, Schoessler, M., Franey, S. G., & Lee, M. (1999). The experience of life-threatening illness: Patients' and their loved ones' perspectives. *Journal of Palliative Medicine*, *2*(2), 173–184.

Menec, V. H., Nowicki, S., Blandford, A., & Veselyuk, D. (2009). Hospitalizations at the end of life among long-term care residents. *The Journal of Gerontology*, *64A*(3), 395–402. https://doi.org/10.1093/gerona/gln034

Mercer, J. (2007). The challenges of insider research in educational institutions: Wielding a double-edged sword and resolving delicate dilemmas. *Oxford Review of Education*, *33*(1), 1–17. https://doi.org/10.1080/03054980601094651

Mertens, D. (2014). *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative, and mixed methods* (4th ed.). Sage.

Mertens, F., De Gendt, A., Deveugele, M., Van Hecke, A., & Pype, P. (2019). Interprofessional collaboration within fluid teams: Community nurses' experiences with palliative home care. *Journal of Clinical Nursing*, *28*(19–20), 3680–3690. https://doi.org/10.1111/jocn.14969

Mertens, F., Pype, P., & Deveugele, M. (2018). Healthcare professionals' experiences of interprofessional collaboration during palliative patients' transfer of care setting: A focus

group study. *International Journal of Integrated Care*, *18*(s2), 262. https://doi.org/10.5334/ijic.s2262

Milberg, A., & Strang, P. (2007). What to do when "there is nothing more to do"? A study within a salutogenic framework of family members' experience of palliative home care staff. *Psycho-Oncology*, *16*(8), 741–751. https://doi.org/10.1002/pon.1124

Miller, S., Gozalo, P., & Mor, V. (2001). Hospice enrollment and hospitalization of dying nursing home patients. *American Journal of Medicine*, *111*(1), 38–44. https://doi.org/10.1016/S0002- 9343(01)00747-1.

Ministry of Health and Long-Term Care (MoHLTC). (2017). *Attending Nurse Practitioners in Long-Term Care Homes. Recruitment and Integration Toolkit*. https://www.health.gov.on.ca/en/pro/programs/hhrsd/nursing/docs/2017_NP_LTCH_Rec_int_toolkit.pdf

Ministry of Long-Term Care (MoLTC). (2020). *Long-term care staffing study.* https://files.ontario.ca/mltc-long-term-care-staffing-study-en-2020-07-31.pdf

Mitchell, G. K. (2002). How well do general practitioners deliver palliative care? A systematic review. *Palliative Medicine*, *16*(6), 457–464. https://doi.org/10.1191/0269216302pm573oa

Mitchell, G., & Price, J. (2001). Developing palliative care services in regional areas. The Ipswich Palliative Care Network Model. *Aust Fam Physician*, *30*, 59–62.

Mitchell, G. K., Reymond, E. J., & McGrath, B. P. (2004). Palliative care: Promoting general practice participation. *Medical Journal of Australia, 180*(5), 207–208. doi:10.5694/j.1326-5377.2004.tb05885.x

Mitchell, G. K., Senior, H. E., Bibo, M. P., Makoni, B., Young, S. N., Rosenberg, J. P., & Yates, P. (2016). Evaluation of a pilot of nurse practitioner led, GP supported rural palliative care provision. *BMC Palliative Care*, *15*(1), 93–93. https://doi.org/10.1186/s12904-016-0163-y

Monahan, T., & Fisher, J. A. (2010). Benefits of "observer effects": lessons from the field. *Qualitative Research, 10*(3), 357–376. https://doi.org/10.1177/1468794110362874

Morasso, G., Costantini, M., Di Leo, S., Roma, S., Miccinesi, G., Merlo, D. F., & Beccaro, M. (2008). EOL care in Italy: Personal experience of family caregivers. A content analysis of open questions from the Italian Survey of the Dying of Cancer (ISDOC). *Psycho-Oncology (Chichester, England), 17*(11), 1073–1080. https://doi.org/10.1002/pon.1332

Morilla-Herrera, J. C., Garcia-Mayor, S., Martín-Santos, F. J., Kaknani Uttumchandani, S., Leon Campos, Á., Caro Bautista, J., & Morales-Asencio, J. M. (2016). A systematic review of the effectiveness and roles of advanced practice nursing in older people. *International Journal of Nursing Studies*, *5*3, 290–307. https://doi.org/10.1016/j.ijnurstu.2015.10.010

Morrison, R. S. (2018). A national palliative care strategy for Canada. *Journal of Palliative Medicine*, *21*(S1), S63–S75. https://doi.org/10.1089/jpm.2017.0431

Mueke, M. (1993). On the evaluation of ethnographies. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 187–209). Sage.

Munday, D., Petrova, M., & Dale, J. (2009). Exploring preferences for place of death with terminally ill patients: Qualitative study of experiences of general practitioners and community nurses in England. *BMJ*, *338*, 1–9. http://dx.doi.org/10.1136/bmj.b2391

Mundinger, M. O., Kane, R. L., & Lenz, E. R. (2000). Primary care outcomes in patients treated by nurse practitioners or physicians. *JAMA*, *283*(1), 59–68. https://doi.org/10.1001/jama.283.1.59

Munro, D. (2011). *Elements of an effective innovation strategy for long term care in Ontario.* Conference Board of Canada. https://neltoolkit.rnao.ca/sites/default/files/Elements%20of%20an%20Effective%20Innovation%20Strategy%20for%20Long%20Term%20Care%20in%20Ontario%202011.pdf

Murchison, J. M. (2010). *Ethnography essentials: Designing, conducting and presenting your research.* Jossey-Bass.

Murphy, A., Siebert, K., Owens, D., & Doorenbos, A. (2013). Healthcare utilization by patients whose care is managed by a primary palliative care clinic. *Journal of Hospice and Palliative Nursing*, *15*(7), 1-12. https://doi.org/10.1097/NJH.0b013e3182a02b9d

Murray, S. A., Kendall, M., Boyd, K., Worth, A., & Benton, T. F. (2004). Exploring the spiritual needs of people dying of lung cancer or heart failure: A prospective qualitative interview study of patients and their carers. *Palliative Medicine*, *18*(1), 39–45. https://doi.org/10.1191/0269216304pm837oa

National Academies of Sciences, Engineering, and Medicine (NASEM). (2016). *Families caring for an aging America.* The National Academies Press. https://www.ncbi.nlm.nih.gov/books/NBK396401/pdf/Bookshelf_NBK396401.pdf

Neimeyer, R., Currier, J., Coleman, R., Tomer, A., & Samuel, E. (2011). Confronting suffering and death at the end of life: The impact of religiosity, psychosocial factors, and life regret among hospice patients. *Death Studies*, *35*(9), 777–800.

O'Connor, M., Palfreyman, S., & Borghmans, F. (2018). Reflections on establishing a nurse practitioner role across acute hospital and home-based palliative care settings in Australia. *International Journal of Palliative Nursing*, *24*(9), 436–442. https://doi.org/10.12968/ijpn.2018.24.9.436

Oczkowski, S. J. W., Crawshaw, D. E., Austin, P., Versluis, D., Kalles-Chan, G., Kekewich, M., Curran, D., Miller, P., Kelly, M., Wiebe, E., & Frolic, A. (2021). How can we improve the experiences of patients and families who request medical assistance in dying? A multi-centre qualitative study. *BMC Palliative Care, 20*(1), 185–185. https://doi.org/10.1186/s12904-021-00882-4

Oczkowski, S. J. W., Crawshaw, D., Austin, P., Versluis, D., Kalles-Chan, G., Kekewich, M., Curran, D., Miller, P. Q., Kelly, M., Wiebe, E., Dees, M., & Frolic, A. (2021). How We Can Improve the Quality of Care for Patients Requesting Medical Assistance in Dying: A Qualitative Study of Health Care Providers. *Journal of Pain and Symptom Management, 61*(3), 513–521.e8. https://doi.org/10.1016/j.jpainsymman.2020.08.018

Office of the Auditor General of Ontario. (2014). *Annual report.* http://www.auditor.on.ca/en/reports_en/en14/308en14.pdf

Office of the Auditor General of Ontario. (2016). *Annual report.* https://www.auditor.on.ca/en/content/annualreports/arreports/en16/v2_108en16.pdf

Oneschuk, D., & Bruera, E. (1998). Access to palliative medicine training for Canadian family medicine residents. *Palliative Medicine*, *12*(1), 23–27. https://doi.org/10.1191/026921698669739412

Ontario Ministry of Health and Long-Term Care. (2015). *Patients first: Action plan for health care.* http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_

patientsfirst.pdf

O'Reilly, K. (2009). *Key concepts in ethnography*. Sage.

Osborn, C. L., & Townsend, C. H. (1997). Analysis of telephone communication between hospice nurses and a nurse practitioner group. *Home Health Care Management & Practice*, *9*(5), 52–58. https://doi.org/10.1177/108482239700900513

Owens, D., Eby, K., Burson, S., Green, M., McGoodwin, W., & Isaac, M. (2012). Primary palliative care clinic pilot project demonstrates benefits of a nurse practitioner-directed clinic providing primary and palliative care. *Journal of the American Academy of Nurse Practitioners*, *24*(1), 52–58. https://doi.org/10.1111/j.1745-7599.2011.00664.x

Oyebode, J. R., Smith, H.-J., & Morrison, K. (2013). The personal experience of partners of individuals with motor neuron disease. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, *14*(1), 39–43. https://doi.org/10.3109/17482968.2012.719236

Parker, S. M., Clayton, J. M., Hancock, K., Walder, S., Butow, P. N., Carrick, S., Currow, D., Ghersi, D., Glare, P., Hagerty, R., & Tattersall, M. H. N. (2007). A Systematic Review of Prognostic/End-of-Life Communication with Adults in the Advanced Stages of a Life-Limiting Illness: Patient/Caregiver Preferences for the Content, Style, and Timing of Information. *Journal of Pain and Symptom Management, 34*(1), 81–93. https://doi.org/10.1016/j.jpainsymman.2006.09.035

Parker, S.-M., Remington, R., Nannini, A., & Cifuentes, M. (2013). Patient outcomes and satisfaction with care following palliative care consultation. *Journal of Hospice and Palliative Nursing*, *15*(4), 225–232. https://doi.org/10.1097/NJH.0b013e318279f4ce

Pastrana, T., Jünger, S., Ostgathe, C., Elsner, F., & Radbruch, L. (2008). A matter of definition: Key elements identified in a discourse analysis of definitions of palliative care. *Palliative Medicine*, *22*(3), 222–232.

Payne, S., Turner, M., Seamark, D., Thomas, C., Brearley, S., Wang, X., Blake, S., & Milligan, C. (2015). Managing end of life medications at home—accounts of bereaved family carers: a qualitative interview study. *BMJ Supportive & Palliative Care, 5(2), 181–188. https://doi.org/10.1136/bmjspcare-2014-000658*

Pellatt, G. (2003). Ethnography and reflexivity: Emotions and feelings in fieldwork. *Nurse Researcher*, *10*(3), 28–37. https://doi.org/10.7748/nr2003.04.10.3.28.c5894

Penz, K., & Duggleby, W. (2012). "It's different in the home …" The contextual challenges and rewards of providing palliative nursing care in community settings. *Journal of Hospice and Palliative Nursing*, *14*(5), 365–373. https://doi.org/10.1097/NJH.0b013e3182553acb

Pereira, G. J. (2005). Palliative care in the hinterlands: A description of existing services and doctors' attitudes. *Australian Journal of Rural Health*, *13*, 343–347. https://doi.org/10.1111/j.1440-1584.2005.00735.x

Pesut, B., Robinson, C. A., & Bottorff, J. L. (2014). Among neighbors: An ethnographic account of responsibilities in rural palliative care. *Palliative & Supportive Care*, *12*(2), 127–138. https://doi.org/10.1017/S1478951512001046

Pesut, B., Thorne, S., & Greig, M. (2020). Shades of gray: Conscientious objection in medical assistance in dying. *Nursing Inquiry*, *27*(1), e12308. https://doi.org/10.1111/nin.12308

Pesut, B., Thorne, S., Schiller, C. J., Greig, M., & Roussel, J. (2020). The rocks and hard places of MAiD: A qualitative study of nursing practice in the context of legislated assisted death. *BMC Nursing*, *19*(1), 12–12. https://doi.org/10.1186/s12912-020-0404-5

Pesut, B., Thorne, S., Schiller, C., Greig, M., Roussel, J., & Tishelman, C. (2020). Constructing good nursing practice for medical assistance in dying in Canada: An interpretive descriptive study. *Global Qualitative Nursing Research*, 7. https://doi.org/10.1177/2333393620938686

Pesut, B., Thorne, S., Stager, M. L., Schiller, C. J., Penney, C., Hoffman, C., Greig, M., & Roussel, J. (2019). Medical assistance in dying: A review of Canadian nursing regulatory documents. *Policy, Politics & Nursing Practice*, *20*(3), 113–130. https://doi.org/10.1177/1527154419845407

Picot, S. A., Glaetzer, K. M., & Myhill, K. J. (2015). Coordinating end of life care for individuals with a mental illness: A nurse practitioner collaboration. *Collegian*, *22*(1), 143–149. https://doi.org/10.1016/j.colegn.2013.12.007

Pope, C. (2005). Conducting ethnography in medical settings. *Medical Education*, *39*(12), 1180–1187. https://doi.org/10.1111/j.1365-2929.2005.02330.x

Proot, I. M., Abu-Saad, H. H., Crebolder, H. F. J., Goldsteen, M., Luker, K. A., & Widdershoven, G. A. (2003). Vulnerability of family caregivers in terminal palliative care at home: Balancing between burden and capacity. *Scandinavian Journal of Caring Sciences*, *17*(2), 113–121. https://doi.org/10.1046/j.1471-6712.2003.00220.x

Pype, P., Symons, L., Wens, J., Van den Eynden, B., Stess, A., Cherry, G., & Deveugele, M. (2013). Healthcare professionals' perceptions toward interprofessional collaboration in palliative home care: A view from Belgium. *Journal of Interprofessional Care*, *27*(4), 313–319. https://doi.org/10.3109/13561820.2012.745488

Quaglietti, S., Blum, L., & Ellis, V. (2004). The role of the adult nurse practitioner in palliative care. *Journal of Hospice and Palliative Nursing*, *6*(4), 209–214. https://doi.org/10.1097/00129191-200410000-00009

Quill, T. E., & Abernethy, A. P. (2013). Generalist plus specialist palliative care—Creating a more sustainable model. *The New England Journal of Medicine*, *368*(13), 1173–1175. https://doi.org/10.1056/NEJMp1215620

Rabbetts, L., Harrington, A., & Breaden, K. (2020). Nurses' experience of providing home-based palliative care in the country setting: An integrated literature review. *International Journal of Nursing Practice*, *26*(1), e12773. https://doi.org/10.1111/ijn.12773

Randall, G., & Williams, A. P. (2006). Exploring limits to market-based reform: Managed competition and rehabilitation home care services in Ontario. *Social Science and Medicine*, *62*(7), 1594–1604.

Ray, R. A., & Street, A. F. (2007). Non-finite loss and emotional labour: Family caregivers' experiences of living with motor neuron disease. *Journal of Clinical Nursing*, *16*(3a), 35–43. https://doi.org/10.1111/j.1365-2702.2006.01722.x

Reay, T. M., Patterson, E. B., Halma, L., & Steed, W. (2006). Introducing a nurse practitioner: Experiences in a rural Alberta family practice clinic. *Canadian Journal of Rural Medicine*, *11*(2), 101–107.

Reblora, J. M., Dong, L., Lopez, V., & Goh, Y.-S. (2021). "The same but different:" Triaging in primary healthcare settings. A focused ethnography study. *Collegian*, *28*(1), 35–41. https://doi.org/10.1016/j.colegn.2020.02.003

Reed, P., & Shearer, N. (2012). *Perspectives on nursing theo*ry (6th ed.). Lippincott Williams & Wilkins.

Rees, C., & Bath, P. (2000). The information needs and source preferences of women with breast cancer and their family members: A review of the literature published between 1988 and 1998. *Journal of Advanced Nursing*, *31*(4), 833–841. https://doi.org/10.1046/j.1365-2648.2000.01341.x

Reimer-Kirkham, S., Sawatzky, R., Roberts, D., Cochrane, M., & Stajduhar, K. (2016). "Close to" a palliative approach: nurses' and care aides' descriptions of caring for people with advancing chronic life-limiting conditions. *Journal of Clinical Nursing*, *25*(15-16), 2189–2199. https://doi.org/10.1111/jocn.13256

Reyniers, T., Houttekieri, D., Cohen, J., Pasman, H., & Deliens, L. (2014). What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses. *Palliative Medicine*, *28*(7), 941–948. https://doi.org/10.1177/0269216314522317

Richards, L., & Morse, J. M. (2012). *Readme first for a user's guide to qualitative methods* (3rd ed.). Sage.

Richardson, J. (2002). Health promotion in palliative care: The patients' perception of therapeutic interaction with the palliative nurse in the primary care setting. *Journal of Advanced Nursing*, *40*(4), 432–440. https://doi.org/10.1046/j.1365-2648.2002.02391.x

Richardson, L. (2000). Writing: A method of inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 923–948). Sage.

Ritchie, J., & Lewis, J. (2003). *Qualitative research practice. A guide for social science students and researchers*. Sage.

Roberts, N. K., Williams, R. G., Schwind, C. J., Sutyak, J. A., McDowell, C., Griffen, D., Wall, J., Sanfey, H., Chestnut, A., Meier, A. H., Wohltmann, C., Clark, T. R., & Wetter, N.

(2014). The impact of brief team communication, leadership and team behavior training on ad hoc team performance in trauma care settings. *The American Journal of Surgery*, *207*(2), 170–178. https://doi.org/10.1016/j.amjsurg.2013.06.016

Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2015). A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. *Palliative Medicine*, *29*(8), 703–710. https://doi.org/10.1177/0269216315575841

Rocker, G., Downar, J., & Morrison, R. S. (2016). Palliative care for chronic illness: Driving change. *Canadian Medical Association Journal*, *188*(17–18), E493–E498. https://doi.org/10.1503/cmaj.151454

Rollison, B., & Carlsson, M. (2002). Evaluation of advanced home care (AHC). The next-of-kin's experiences. *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society*, *6*(2), 100–106. https://doi.org/10.1054/ejon.2001.0172

Roots, A., & Macdonald, M. (2014). Outcomes associated with nurse practitioners in collaborative practice with general practitioners in rural settings in Canada: A mixed methods study. *Human Resources for Health*, *12*(1), 69-69. https://doi.org/10.1186/1478-4491-12-69.

Roper, J. M., & Shapira, J. (2000). *Ethnography in nursing research*. Sage.

Rose, J., & Glass, N. (2006). Nurses and palliation in the community: The current discourse. *International Journal of Palliative Nursing*, *12*(12), 588–594. https://doi.org/10.12968/ijpn.2006.12.12.22545

Rosenberg, J. P., Bullen, T., & Maher, K. (2015). Supporting family caregivers with palliative symptom management: A qualitative analysis of the provision of an emergency

medication kit in the home setting. *American Journal of Hospice & Palliative Medicine*, *32*(5), 484–489. https://doi.org/10.1177/1049909114531326

Rosser, W. W., Colwill, J. M., Kasperski, J., & Wilson, L. (2011). Progress of Ontario's Family Health Team model: a patient-centered medical home. *Annals of family medicine*, *9*(2), 165–171. https://doi.org/10.1370/afm.1228

Rowe, W. E. (2014). Positionality. In D. Coghlan & M. Brydon-Miller (Eds.), *The Sage encyclopedia of action research* (628-628). Sage.

Safriet, B. J. (2002). Closing the gap between can and may in health-care providers' scopes of practice: A primer for policymakers. *Yale Journal on Regulation*, *19*(2), 301–334.

Samia, L. W., Ellenbecker, C. H., Friedman, D. H., & Dick, K. (2012). Home care nurses' experience of job stress and considerations for the work environment. *Home Health Care Services Quarterly*, *31*(3), 243–265. https://doi.org/10.1080/01621424.2012.703903Alvariza

Sangster-Gormley, E., Carter, N., Donald, F., Misener, R., Ploeg, J., Kaasalainen, S., & Wickson-Griffiths, A. (2013). A value-added benefit of nurse practitioners in long-term care settings: Increased nursing staff's ability to care for residents. *Nursing Leadership*, *26*(3), 24–37.

Sarmento, V. P., Gysels, M., Higginson, I. J., & Gomes, B. (2017). Home palliative care works: but how? A meta-ethnography of the experiences of patients and family caregivers. *BMJ supportive & palliative care*, *7*(4), 0. https://doi.org/10.1136/bmjspcare-2016-001141

Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., Roberts, D., Tayler, C., Voth, J., & Stajduhar, K. (2016). Conceptual foundations of a palliative approach: A

knowledge synthesis. *BMC Palliative Care*, *15*(1), 5–5. https://doi.org/10.1186/s12904-016-0076-9

Sawatzky, R., Porterfield, P., Roberts, D., Lee, J., Liang, L., Reimer-Kirkham, S., Pesut, B., Schalkwyk, T., Stajduhar, K., Tayler, C., Baumbusch, J., & Thorne, S. (2017). embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis. *Advances in Nursing Science*, *40*(3), 261–277. https://doi.org/10.1097/ANS.0000000000000163

Schein, E. H. (2010). *Organizational culture and leadership* (4th ed.). Jossey-Bass.

Schensul, J. J., & LeCompte, M. D. (2013). *Essential ethnographic methods: A mixed methods approach*. AltaMira Press.

Schensul, S. L., Schensul, J. J., & LeCompte, M. D. (2013). *Initiating ethnographic research: A mixed methods approach.* AltaMira Press.

Schultz, P. R., & McGlone, F. B. (1977). Primary health care provided to the elderly by a nurse practitioner/physician team: Analysis of cost effectiveness. *Journal of the American Geriatrics Society*, *25*, 443–446.

Schwandt, T. (2007). *The Sage dictionary of qualitative inquiry*. Sage.

Scott, S. D., & Pollock, C. (2008). The role of nursing unit culture in shaping research utilization behaviors. *Research in Nursing & Health*, *31*(4), 298–309. https://doi.org/10.1002/nur.20264

Selman, L. E., Brighton, L. J., Robinson, V., George, R., Khan, S. A., Burman, R., & Koffman, J. (2017). Primary care physicians' educational needs and learning preferences in end of life care: A focus group study in the UK. *BMC Palliative Care*, *16*(1), 17–17. https://doi.org/10.1186/s12904-017-0191-2

Seow, H., Bainbridge, D., Brouwers, M., Bryant, D., Tan Toyofuku, S., & Kelley, M. L. (2020). Common care practices among effective community-based specialist palliative care teams: A qualitative study. *BMJ Supportive & Palliative Care*, *10*(1), 1-8. https://doi.org/10.1136/bmjspcare-2016-001221

Seow, H. M., Barbera, L., Howell, D., & Dy, S. (2010). Using more EOL homecare services is associated with using fewer acute care services: A population-based cohort Study. *Medical Care*, *48*(2), 118–124.

Seow, H., Brazil, K., Sussman, J., Pereira, J., Marshall, D., Austin, P., & Barbera, L. (2014). Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: A pooled analysis. *British Medical Journal*, *348*(2), g3496–g3496, https://doi.org/10.1136/bmj.g3496.

Seymour, J. (2012). Looking back, looking forward: The evolution of palliative and EOL care in England. *Mortality*, *17*(1), 1–17.

Smigorowsky, M. J., Sebastianski, M., Sean McMurtry, M., Tsuyuki, R. T., & Norris, C. M. (2020). Outcomes of nurse practitioner-led care in patients with cardiovascular disease: A systematic review and meta-analysis. *Journal of Advanced Nursing*, *76*, 81–95.

Spence, L., Agnew, T., & Fahey-Walsh, J. (2015). *A pan-Canadian environmental scan of the scope of practice of nurse practitioners.* Ontario Nurse Practitioners' Association.

Spradley, J. P. (1980). *Participant observation.* Holt, Rhinehart & Winston.

Staats, K., Tranvåg, O., & Grov, E. K. (2018). Home-care nurses' experience with medication kit in palliative care. *Journal of Hospice and Palliative Nursing*, *20*(6), E1–E9. https://doi.org/10.1097/NJH.0000000000000518

Stajduhar, K. I. (2011). Chronic illness, palliative care, and the problematic nature of dying. *Canadian Journal of Nursing Research*, *43*(3), 7–15.

Stajduhar, K. I., & Davies, B. (2005). Variations in and factors influencing family members' decisions for palliative home care. *Palliative Medicine*, *19*(1), 21–32. https://doi.org/10.1191/0269216305pm963oa

Stajduhar, K. I., Funk, L., Roberts, D., McLeod, B., Cloutier-Fisher, D., Wilkinson, C., & Purkis, M. E. (2011). Home care nurses' decisions about the need for and amount of service at the end of life. *Journal of Advanced Nursing*, *67*(2), 276–286. https://doi.org/10.1111/j.1365-2648.2010.05491.x

Stajduhar, K., Funk, L., Toye, C., Grande, G. E., Aoun, S., & Todd, C. J. (2010). Home-based family caregiving at the end of life, part 1: A comprehensive review of published quantitative research. *Palliative Medicine*, *24*(6), 573–593.

Stanek, S. (2017). Goals of care: A concept clarification. *Journal of Advanced Nursing*, *73*(6), 1302–1314. https://doi.org/10.1111/jan.13243

Staples, E., Hannon, R., & Ray, S. L. (2016). *Canadian perspectives on advanced practice nursing.* Canadian Scholar's Press Inc.

Stolee, P., Hillier, L., Esbaugh, J., Griffiths, N., & Borrie, M. (2006). Examining the nurse practitioner role in long-term care: Evaluation of a pilot project in Canada. *Journal of Gerontological Nursing*, *32*(10), 28–36.

Strandås, M., Wackerhausen, S., & Bondas, T. (2019). Gaming the system to care for patients: A focused ethnography in Norwegian public home care. *BMC Health Services Research*, *19*(1), 121–121. https://doi.org/10.1186/s12913-019-3950-3

Sun, W., Doran, D. M., Wodchis, W. P., & Peter, E. (2017). Examining the relationship between therapeutic self-care and adverse events for home care clients in Ontario, Canada: A retrospective cohort study. *BMC Health Services Research*, *17*(1), 1-13. https://doi.org/10.1186/s12913-017-2103-9

Sussman, J., Barbera, L., Bainbridge, D., Howell, D., Yang, J., Husain, A., Librach, L., Viola, R., & Walker, H. (2012). Health system characteristics of quality care delivery: A comparative case study examination of palliative care for cancer patients in four regions in Ontario, Canada. *Palliative Medicine*, *26*(4), 322–335.

Swan, M., Ferguson, S., Chang, A., Larson, E., & Smaldone, A. (2015). Quality of primary care by advanced practice nurses: A systematic review. *Int J Qual Health Care*, *27*(5), 396–404. https://doi.org/10.1093/intqhc/mzv054

Tavares, P., Rodrigues, C., & Neto, I. G. (2021). The Impact of COVID-19 on Palliative Care: Perspective of Healthcare Professionals. *Cureus*, *13*(11), e19522. https://doi.org/10.7759/cureus.19522

Tedlock, B. (2000). Ethnography and ethnographic representation. In N. Denzin & Y. S. Lincoln (Eds.). *Handbook of qualitative research* (2nd ed.) (455-486). Sage.

Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end of life care at the last place of care. *Journal of the American Medical Association*, *291*(1), 88–93. https://doi.org/10.1001/jama.291.1.88

Thielemann, P. (2000). Educational needs of home caregivers of terminally ill patients: Literature review. *American Journal of Hospice and Palliative Medicine*, *17*(4), 253–257. https://doi.org/10.1177/104990910001700411

Tilden, V., Tolle, S., Drach, L., & Perrin, N. (2004). Out-of-hospital death: Advance care planning, decedent symptoms, and caregiver burden. *Journal of the American Geriatrics Society*, *52*(4), 532–539. https://doi.org/10.1111/j.1532-5415.2004.52158.x

Topf, L., Robinson, C. A., & Bottorff, J. L. (2013). When a desired home death does not occur: The consequences of broken promises. *Journal of Palliative Medicine*, *16*(8), 875–880. https://doi.org/10.1089/jpm.2012.0541

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837–851. https://doi.org/10.1177/1077800410383121

Van Dusseldorp, L., Groot, M., Aiaansen, M. J., van Vught, A. J., Vissers, K., & Peters, J. W. (2019). What does the nurse practitioner mean to you? A patient-oriented qualitative study in oncological/palliative care. *Journal of Clinical Nursing*, *28*(3–4), 589–602. https://doi.org/10.1111/jocn.14653

van Gijn, F., D., van de Glind, E. M. M., C van Munster, B., & Hamaker, M. E. (2014). The chance of survival and the functional outcome after in-hospital cardiopulmonary resuscitation in older people: a systematic review. Age and Ageing, 43(4), 456–463. https://doi.org/10.1093/ageing/afu035Van Maanen, J. (1988). *Tales of the field.* University of Chicago Press.

Van Maanen, J. (1988). *Tales of the field.* University of Chicago Press.

Vellani, S., Boscart, V., Escrig-Pinol, A., Cumal, A., Krassikova, A., Sidani, S., Zheng, N., Yeung, L., & McGilton, K. S. (2021). Complexity of Nurse Practitioners' Role in Facilitating a Dignified Death for Long-Term Care Home Residents during the COVID-

19 Pandemic. *Journal of Personalized Medicine, 11*(5), 433–. https://doi.org/10.3390/jpm11050433

Villaseñor, S., & Krouse, H. J. (2016). Can the use of urgent care clinics improve access to care without undermining continuity in primary care? *Journal of the American Association of Nurse Practitioners*, *28*(6), 335–341. https://doi.org/10.1002/2327-6924.12314

Visser, G., Klinkenberg, M., Broese van Groenou, M. I., Willems, D. L., Knipscheer, C. P. M., & Deeg, D. J. H. (2004). The end of life: Informal care for dying older people and its relationship to place of death. *Palliative Medicine*, *18*(5), 468–477. https://doi.org/10.1191/0269216304pm888oa

Wahid, A., Sayma, M., Jamshaid, S., Kerwat, D., Oyewole, F., Saleh, D., Ahmed, A., Cox, B., Perry, C., & Payne, S. (2018). Review of barriers and facilitators influencing death at home: A meta-ethnography. *Palliative Medicine*, *32*(2), 314–328. https://doi.org/10.1177/0269216317713427

Wakefield, M. A., Beilby, J., & Ashby, M. A. (1993). General practitioners and palliative care. *Palliative Medicine, 7*(2), 117–126. https://doi.org/10.1177/026921639300700205

Waldrop, D. P. (2007). Caregiver grief in terminal illness and bereavement: A mixed-methods study. *Health & Social Work*, *32*(3), 197–206. https://doi.org/10.1093/hsw/32.3.197

Waldrop, D. P., Kramer, B. J., Skretny, J. A., Milch, R. A., & Finn, W. (2005). Final transitions: Family caregiving at the end of life. *Journal of Palliative Medicine*, *8*(3), 623–638.

Wall, S. (2015). Focused ethnography: A methodological adaptation for social research in emerging contexts. *Forum, Qualitative Social Research*, *16*(1), 1. https://doi.org/10.17169/fqs-16.1.2182

Walling, A. M., D'Ambruoso, S. F., Malin, J. L., Hurvitz, S., Zisser, A., Coscarelli, A., Clarke, R., Hackbarth, A., Pietras, C., Watts, F., Ferrell, B., Skootsky, S., & Wenger, N. S. (2017). Effect and efficiency of an embedded palliative care nurse practitioner in an oncology clinic. *Journal of Oncology Practice*, *13*(9), e792–e799. https://doi.org/10.1200/JOP.2017.020990

Walshe, C., Todd, C., Caress, A. L., & Chew-Graham, C. (2008). Judgements about fellow professionals and the management of patients receiving palliative care in primary care: A qualitative study. *British Journal of General Practice*, *58*(549), 264–272. https://doi.org/10.3399/bjgp08X279652

Wasylenko, E. (2017). Becoming dead: Two solitudes? *Healthcare Management Forum*, *30*(5), 262–265. https://doi.org/10.1177/0840470417714886

Weaver, K., & Olson, J. K. (2005). Understanding paradigms used for nursing research. *Journal of Advanced Nursing*, *53*(4), 459–469.

Webber, C., Hsu, A., Tanuseputro, P., Fitzgibbon, E., & Li, C. (2020). Acute care utilization and place of death among patients discharged from an inpatient palliative care unit. *Journal of Palliative Medicine*, *23*(1), 54–59. https://doi.org/10.1089/jpm.2019.0162

Whitehead, T. L. (2004). *What is ethnography? Methodological, ontological and epistemological attributes.* Cultural Ecology of Health and Change. http://www.cusag.umd.edu/documents/workingpapers/epiontattrib.pdf

Whitehead, T. L. (2005). Basic classical ethnographic research methods. *Cultural Ecology of Health and Change*. http://www.dphu.org/uploads/attachements/books/books_5014_0.pdf

Willard, C. (1999). Caring for patients and relatives: An appraisal of palliative care philosophy. *European Journal of Oncology Nursing*, *3*(1), 38–43.

Williams, A. M., Crooks, V. A., Whitfield, K., Kelley, M.-L., Richards, J.-L., DeMiglio, L., & Dykeman, S. (2010). Tracking the evolution of hospice palliative care in Canada: A comparative case study analysis of seven provinces. *BMC Health Services Research*, *10*(1), 147. https://doi.org/10.1186/1472-6963-10-147

Williams, A. P., Lum, J., & Morton-Chang, F. (2016). *Integrating long-term care into a community-based continuum: Shifting from "beds" to "places."* Institute for Research on Public Policy. https://irpp.org/research-studies/integrating-long-term-care-into-a-community-based-continuum/

Williams, D., & Sidani, S. (2001). An analysis of the nurse practitioner role in palliative care. *Canadian Journal of Nursing Leadership*, *14*(4), 13–19.

Williamson, K. (2013). *Research methods: Information, systems and contexts.* Tilde Publishing.

Williamson, S., Twelvetree, T., Thompson, J., & Beaver, K. (2012). An ethnographic study exploring the role of ward-based advanced nurse practitioners in an acute medical setting. *Journal of Advanced Nursing*, *68*(7), 1579–1588. https://doi.org/10.1111/j.1365-2648.2012.05970.x

Wilson, E., Caswell, G., Turner, N., & Pollock, K. (2018). Managing medicines for patients dying at home: A review of family caregivers' experiences. *Journal of Pain and Symptom Management*, *56*(6), 962–974. https://doi.org/10.1016/j.jpainsymman.2018.08.019

Wilson, E., Morbey, H., Brown, J., Payne, S., Seale, C., & Seymour, J. (2015). Administering anticipatory medications in EOL care: A qualitative study of nursing practice in the

community and in nursing homes. *Palliative Medicine*, *29*(1), 60–70. https://doi.org/10.1177/0269216314543042

Win, M., Fischer, A., & Good, P. (2019). The pattern and timing of changes in preferred place of death for patients admitted to a community specialist palliative care service. *Progress in Palliative Care*, *27*(1), 4–9. https://doi.org/10.1080/09699260.2019.1592947

Winkelman, W. D., Lauderdale, K., Balboni, M. J., Phelps, A. C., Peteet, J. R., Blosck, S. D., Kachnic, L. A., VanderWeele, T. J., & Balboni, T. A. (2011). The relationship of spiritual concerns to the quality of life of advanced cancer patients: Preliminary findings. *Journal of Palliative Medicine*, *14*, 1022–1028.

Wolcott, H. F. (2008). *Ethnography: A way of seeing*. AltaMira.

Woo, B. F. Y., Lee, J. X. Y., & Tam, W. W. S. (2017). The impact of the advanced practice nursing role on quality of care, clinical outcomes, patient satisfaction, and cost in the emergency and critical care settings: A systematic review. *Human Resources for Health*, *15*(1), 63–63. https://doi.org/10.1186/s12960-017-0237-9

Woodman, C., Baillie, J., & Sivell, S. (2016). The preferences and perspectives of family caregivers towards place of care for their relatives at the EOL. A systematic review and thematic synthesis of the qualitative evidence. *BMJ Supportive & Palliative Care*, *6*(4), 418–429. https://doi.org/10.1136/bmjspcare-2014-000794

Woodward, C. A., Abelson, J., Tedford, S., & Hutchison, B. (2004). What is important to continuity in home care? Perspectives of key stakeholders. *Social Science & Medicine*, *58*(1), 177–192. https://doi.org/10.1016/S0277-9536(03)00161

World Health Organization (WHO). (2014). Strengthening of palliative care as a component of integrated treatment throughout the life course. *Journal of Pain & Palliative Care Pharmacotherapy*, *28*(2), 130–134. https://doi.org/10.3109/15360288.2014.911801

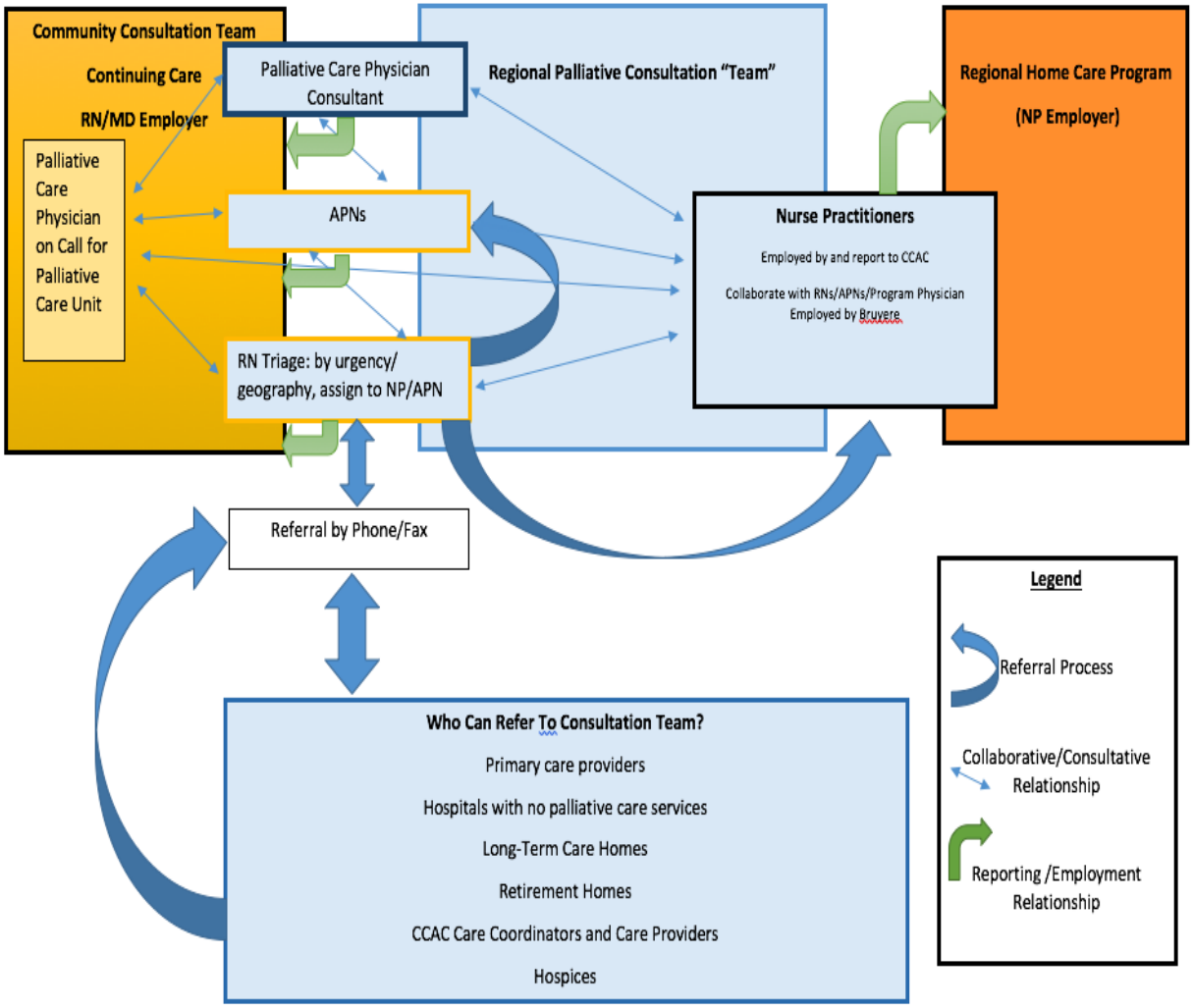
World Health Organization (WHO). (2020). *Palliative care: Key facts.* https://www.who.int/news-room/fact-sheets/detail/palliative-car

Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., Mitcheel, S. L., Jackson V. A., Block, S. D., Maciejewski, P. K., & Prigerson, H. G. (2008). Associations between EOL discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*, *300,* 1665–1673.

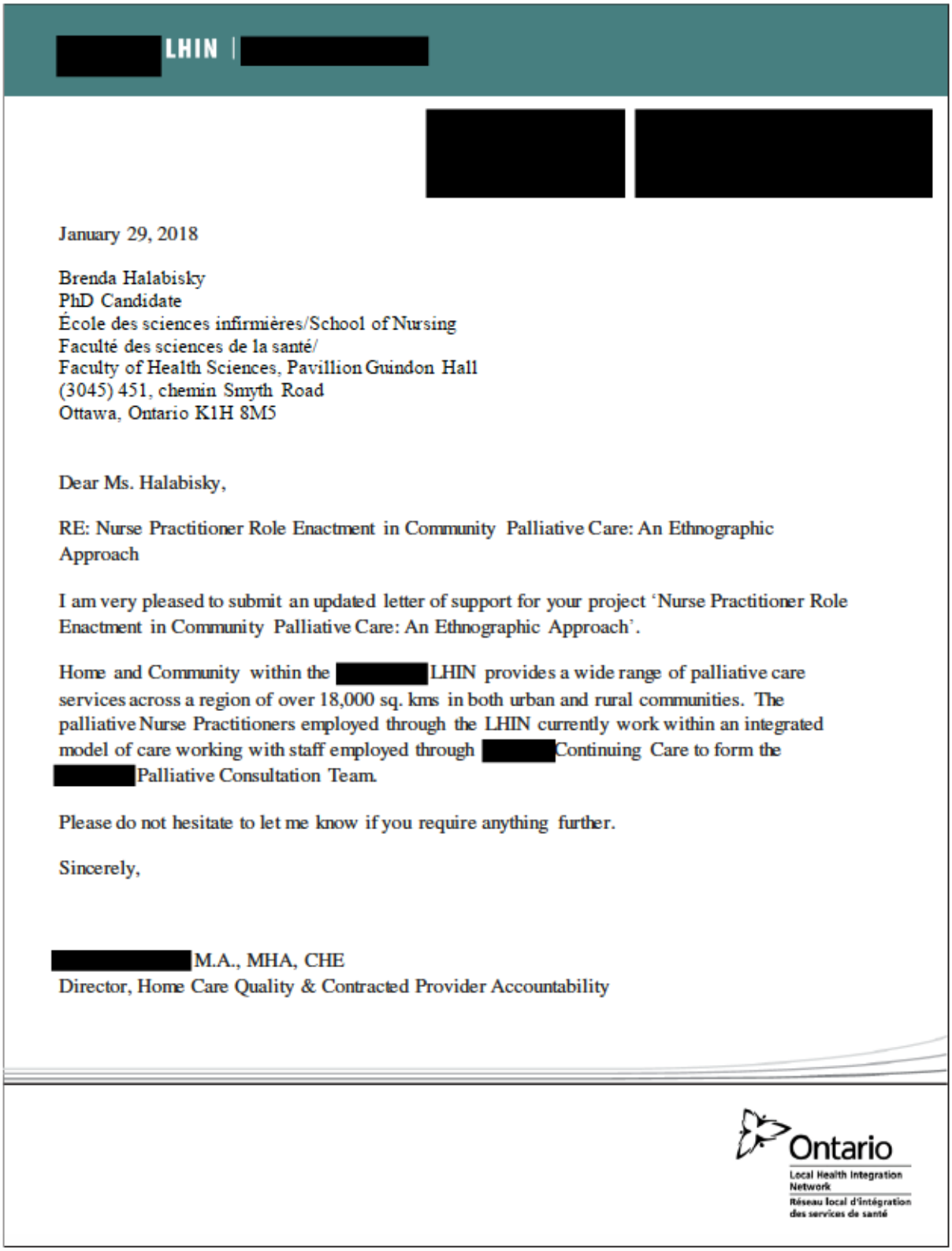
Xyrichis, A., & Ream, E. (2008). Teamwork: A concept analysis. *Journal of Advanced Nursing*, *61*(2), 232–241. https://doi.org/10.1111/j.1365-2648.2007.04496.x

Yu, M., Guerriere, D. N., & Coyte, P. C. (2015). Societal costs of home and hospital end-of-life care for palliative care patients in Ontario, Canada. *Health & Social Care in the Community, 23*(6), 605–618. https://doi.org/10.1111/hsc.12170

Appendix I: Organizational, Reporting and Collaborative Relationship of Specialized Palliative Care Consultation Team



Appendix II: Regional Home Care Program Letter of Support



[redacted] LHIN | [redacted]

[redacted]

January 29, 2018

Brenda Halabisky
PhD Candidate
École des sciences infirmières/School of Nursing
Faculté des sciences de la santé/
Faculty of Health Sciences, Pavillion Guindon Hall
(3045) 451, chemin Smyth Road
Ottawa, Ontario K1H 8M5

Dear Ms. Halabisky,

RE: Nurse Practitioner Role Enactment in Community Palliative Care: An Ethnographic Approach

I am very pleased to submit an updated letter of support for your project 'Nurse Practitioner Role Enactment in Community Palliative Care: An Ethnographic Approach'.

Home and Community within the [redacted] LHIN provides a wide range of palliative care services across a region of over 18,000 sq. kms in both urban and rural communities. The palliative Nurse Practitioners employed through the LHIN currently work within an integrated model of care working with staff employed through [redacted] Continuing Care to form the [redacted] Palliative Consultation Team.

Please do not hesitate to let me know if you require anything further.

Sincerely,

[redacted] M.A., MHA, CHE
Director, Home Care Quality & Contracted Provider Accountability

Ontario
Local Health Integration Network
Réseau local d'intégration des services de santé

Appendix III: Ethics Certificate

16/06/2021

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-04-18-525
Titre du projet / Project Title	Nurse Practitioner Role Enactment in Community Palliative Care
Type de projet / Project Type	Thèse de doctorat / Doctoral thesis
Statut du projet / Project Status	Renouvelé / Renewed
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	09/06/2018
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	28/02/2022

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Brenda HALABISKY	École des sciences infirmières / School of Nursing	Chercheur Principal / Principal Investigator
David WRIGHT	École des sciences infirmières / School of Nursing	Superviseur / Supervisor
Christine MCPHERSON	École des sciences infirmières / School of Nursing	Co-superviseur / Co-supervisor

Conditions spéciales ou commentaires / Special conditions or comments

Appendix IV: Voluntary Participation Script from Employer

Attention Nurse Practitioners,

Please find attached an invitation to participate in a research study about NP work in Community Palliative Care.

While the [redacted] supports this study, as an employee, you are not under any obligation to participate. Your participation in this study is voluntary and any decision to not participate in this study will not result in any penalties related to your employment.

[redacted] Director, Home Care Quality & Contracted Provider Accountability

Appendix V: NP Recruitment Email

Recruitment e-mail for NPs (to be forwarded to all [redacted]

NPs)

Subject line: NP Role Enactment in Community Palliative Care

Attachment: Letter from employer

Dear Nurse Practitioner,

I would like to invite you to participate in a study that I am conducting entitled: Nurse Practitioner Role Enactment in Community Palliative Care: An Ethnographic Inquiry

I am a PhD student working on this study, which is being supervised by Christine McPherson PhD and David Wright PhD. This study, which is taking place in [redacted], involves participant observation and in-depth interviews. I am contacting you to see if you are interested in participating in this study.

Your participation is voluntary and you may withdraw from this study without penalty at any time.

If you are interested in participating or would like more information regarding this study, please email me at: [redacted] or contact me by phone at [redacted].

Thank you,

Brenda Halabisky, RN, MSc, NP-PHC, PhD Student,

University of Ottawa School of Nursing

Appendix VI: NP Written Consent Form

Title of the study: Nurse Practitioner Role Enactment in Community Palliative Care: An Ethnographic Approach

Name of researcher: Brenda Halabisky RN, MSc,

School of Nursing, Faculty of Health Sciences, University of Ottawa.

[redacted]

Research Supervisors:

Christine McPherson, RN, PhD, School of Nursing, Faculty of Health Sciences,

University of Ottawa, Faculty of Health Sciences, School of Nursing

Roger-Guindon Hall #3045, 451 Smyth Road Ottawa, Ontario, Canada K1H 8M5

[redacted]

David Wright, RN, PhD, School of Nursing, Faculty of Health Sciences,

University of Ottawa, Faculty of Health Sciences, School of Nursing

Roger-Guindon Hall #3045, 451 Smyth Road Ottawa, Ontario, Canada K1H 8M5

[redacted]

Invitation to Participate:

I am invited to participate in the abovementioned research study which is a doctoral thesis project conducted by Brenda Halabisky and her supervisors Christine McPherson and David Wright.

Purpose of the Study:

The purpose of the study is to understand how nurse practitioners enact their role in community palliative care and to identify contextual influences on their work.

Participation:

My participation will include completion of a short demographic survey, observations and interviews. Observations will focus on interactions that occur in my natural role activities as a nurse practitioner working as a member of the [redacted]. Approximately 40-80 hours of observation will be scheduled with me over the course of the study period. Observations will take place in the various locations in which I conduct my work. During or after observations, the student researcher will engage in conversation with me and ask me questions related to the activities observed in order to facilitate further understanding of my role. The student researcher will also make notes during or after observations and conversations. For observations in patient homes, I will be asked to obtain the patient's consent for the student researcher to be present. At the end of each day, the researcher and I will spend five to ten minutes debriefing about the day's activities. The observations will not interfere with my provision of care. I am free to choose not to speak with the student researcher and may tell her that I do not wish to speak with her at any time during the study. If at any time I feel that the student researcher is bothersome to me, or to the patient, I may ask her to leave the situation. In addition to the observations, I will be asked to participate in a minimum of two semi-structured interviews, each lasting approximately 45-60 minutes. The interviews will occur approximately midway through the observation period and near the end of the observation period. Interviews will occur either during work hours or after work hours as per my preference. During these interviews, I will be asked questions about my role within the regional palliative consultation team. Each interview will be conducted in a private

space of my choice. With my permission, the interview will be audio recorded. During interviews, I am free to stop or end the interview at any time. If I choose to stop the interview, I understand that I may request that the data collected during the interview be destroyed or returned to me.

Risks:

I understand that my participation in this study involves minimal risk as in similar studies involving observations and interviews. Participation will entail that I volunteer my personal insights, feelings and opinions that may cause me to feel uncomfortable. If this occurs, I understand that I can refuse to answer a specific question, end the discussion with the student researcher or withdraw from the study. There might be some possibility that discussion topics and recall of previous experience may bring forward feelings or emotions that may be distressing if these were stressful experiences. If this occurs, the researcher will ensure that I receive counseling and support from my employee assistance program or an external counselor of my choice.

Benefits:

My participation in this study will not benefit me directly aside from feelings of contributing to a larger body of knowledge by facilitating a broader understanding related to the nurse practitioner role in community palliative care. I may also benefit from engaging in a meaningful discussion related to my professional experiences and achieve personal insights related professional practices. Beyond this, benefits are indirect and related to a broader understanding of the nurse practitioner role in this setting as well as potential identification of modification of educational programs, organizational processes and policies, all which can ultimately lead to improvements to patient access to timely and appropriate care.

Confidentiality and Anonymity:

I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for study purposes. I understand that any information I share with the student researcher will not be disclosed to other participants without my express permission. All information linked to me will be made anonymous by the student researcher through the use of pseudonyms. My name will not appear in any research data. The only individuals who will have access to any of the aforementioned data related to this study are the student researcher and her research supervisors (Dr. Christine McPherson and Dr. David Wright).

I am aware that my anonymity within the [redacted] as a participant in this research study is not guaranteed as other members of the team may see me interacting with the researcher. All information I provide to the student researcher will be kept confidential. Results from this study will be published, and quotations may be used in publications and presentations. My anonymity will be protected by not using any personal identifiers or my name in these publications and presentations. Withholding identifiers related to the specific location of this study will further protect anonymity.

Conservation of Data: The data collected, including written field notes, audio recordings and electronic transcripts will be kept in a secure manner in a locked filing cabinet and/or a password protected device (computer or voice recorder), using password protected files, in the office of Brenda Halabisky. Once the study is completed, all data will be kept in a locked filing cabinet and/or password protected computer, using password protected files, in the office of Christine McPherson for a minimal period of five years and when no longer required, be destroyed by secure deletion.

Voluntary Participation:

I understand that this is an independent study not linked to my employment and I am under no obligation to participate in this study. If I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. My participation in this study will in no way affect my status as an employee or professional. If I choose to withdraw, I may choose to allow my data collected to date to be used, or I may request that all data gathered until the time of withdrawal to be removed from the study, destroyed or returned to me.

Acceptance:

I, _____ agree to participate in the above research study conducted by Brenda Halabisky, of the School of Nursing, Faculty of Health Sciences, University of Ottawa, under the supervision of Christine McPherson and David Wright.

I consent to completing the demographic questionnaire _____Yes _____No

I consent to participate in the observation component of the study: _____Yes _____No

I consent to the interview component of the study: _____Yes _____No

I consent to audio-recording of the interview component of the study: _____Yes _____No

If I have any questions about the study, I may contact the researcher or her supervisor at the contact information listed above.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5

Tel.: (613) 562-5387

Email: ethics@uottawa.ca

There are two copies of the consent form, one of which is mine to keep.

Participant's signature: _____ Date: _____

Researcher's signature: _____ Date: _____

Appendix VII: Demographic Survey

1. Name: _____
2. Education. Please identify you highest level of NP education:

   _____

   _____
3. Number of years registered as a nurse practitioner: _____
4. Number of years as a registered nurse prior to nurse practitioner registration: _____
5. Number of years in this position: _____
6. List your experience related to palliative care prior to this role:

   _____

   _____
7. Did your nurse practitioner education provide the education required for you to feel competent in your current role? Please explain your view.

   _____
8. Education. Please identify education beyond your NP certification that you have been provided with or undertaken to address your learning needs in this role:

1. _____
2. _____
3. _____
4. _____

Appendix VIII: Interview Topics Areas

1. Organization of community palliative care
2. Domains and scope of NP work/responsibility
3. NP role in facilitating patient access to care
4. NP Collaborators/processes/challenges
5. MAiD processes, views and experiences
6. Influences on NP practice: employer, geographic, legislative, education.

Sample Questions:

1. What is your role in the provision of community palliative care?
2. How do NPs contribute to patient access to care?
3. What are the geographical, clinical, educational, political and legislative influences on NP work in relation to facilitators and constraints.
4. How do the previously mentioned facilitators and constraints impact NP work and patient access to care?
5. Are there gaps to care that you think you could address with additional facilitators or removal of particular constraints to practice?
6. Who do NPs collaborate with, under which circumstances and how does collaboration occur?
7. What is the outcome of successful or unsuccessful collaboration?
8. What are examples of successful/unsuccessful collaboration?

Appendix IX: NP Script for Patient Consent for Student Researcher to Accompany NP on Home Visit

Mr./Mrs. XXXX.

I will be doing a home visit today.

Brenda Halabisky is a nurse practitioner who is a Ph. D. student conducting research on nurse practitioners in community palliative care who is observing my role. She would like your permission to come with me when I visit you in your home.

You are free to decline this request and this will not affect my visit with you today or in the future.

The researcher will also ask for your permission to attend the visit once in your home.
If you change your mind when we arrive, you may indicate that you do not want the researcher present and this will not affect my visit with you.

Do you consent at this time to allow the student researcher to attend the visit with me?
Yes……Thank you we will see you soon.
No……Thank you, I will see you soon.

Appendix X: Study Information for Caregivers (Handout)

Dear Caregivers: Family, Nurses, Personal Support Workers, Social Workers, Counsellors, Volunteers, Physicians

Hello, my name is Brenda Halabisky, I am a PhD student working on this study.

I am conducting a study entitled: Nurse Practitioner Role Enactment in Community Palliative Care.

This study, which is taking place in the [redacted] Region, involves observation of Nurse Practitioners of the [redacted] Palliative Consultation Team and focuses on their work in providing community palliative care.

If you have any questions about the study, you may contact the student researcher (Brenda Halabisky) or her supervisors at the contact information listed below.

Christine McPherson, RN, PhD, School of Nursing, Faculty of Health Sciences, University of Ottawa, [redacted]
David Wright, RN, MSc (A), PhD, School of Nursing, Faculty of Health Sciences, University of Ottawa, [redacted]

If you have any questions regarding the ethical conduct of this study, you may contact the protocol officer for ethics in research at the University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

Thank you,

Brenda Halabisky, RN, MSc, NP-PHC, PhD Student
University of Ottawa
School of Nursing
[redacted]