Medical Assistance in Dying (MAiD) from the Perspective of the Registered Nurse Working in Palliative Care

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List of Abbreviations and Definitions

The following abbreviations and definitions are used throughout this thesis.

HCP	Health Care Provider
IPCP	Integrated Palliative Care Program
MAiD	Medical Assistance in Dying
NP	Nurse Practitioner
PEI	Prince Edward Island
PCC	Palliative Care Coordinator
PCP	Palliative Care Provider
RN	Registered Nurse
UPEI	University of Prince Edward Island

MAiD is when either lethal injection or medication is given by a nurse practitioner or physician when a client is diagnosed with a life-ending illness (Antonacci et al., 2021).

Palliative Care is summarized by the World Health Organization (WHO) as a program that aims to provide the best, holistic quality of life and a natural death for individuals when a cure is no longer possible (Vanderveken et al. 2019).

IPCP is a comprehensive end-of-life program that aims to provide holistic palliative care plans for home care clients by addressing their individual needs and coordinating these needs with an interdisciplinary team (Government of PEI, 2022).

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Abstract

The development of assisted dying programs is growing as over a dozen countries have legalized a form of Medical Assistance in Dying (MAiD). As Canada's MAiD program continues to evolve and become more widely accepted, there is a growing need to understand how it affects the work of palliative care providers (PCPs) and as they plan end-of-life care for their clients who consider MAiD.

In this narrative inquiry research study, I aimed to explore the experiences of palliative care coordinators (PCCs) when their clients consider MAiD as an end-of-life option. After receiving ethics approval, two PCCs who met the criteria were offered to be participants, and participant consent was reviewed and obtained. Two PCCs shared their stories by engaging in a semi-structured interview. Arthur Frank's (2010) narrative inquiry method, dialogical narrative analysis (DNA), guided this study. The stories were analyzed using DNA, revealing five narrative resources common to both storytellers: *the lines get blurred, supporting how they wish to die, I'm not part of that team, the day the IVs go in, and the missing pieces of the puzzle.* The underlying plot, or typology that tied these resources together, was revealed as *nothing in between.*

The findings from this study suggest that these PCCs would support improved accessibility for the client to talk to the MAiD team and increased support from the MAiD team before and after the MAiD procedure. These PCCs would like to see increased collaboration throughout the process and bereavement support provided by the MAiD team for family members after the MAiD process is completed.

Recent literature revealed comparable findings demonstrating a shared experience of palliative care nurses in Canada since the legalization of MAiD. The circulating of these stories

allows the palliative care nurses to share their voice in the new narrative of specialty palliative care nurses as they evolve with the continuing development of MAiD as an end-of-life option.

Chapter 1

Around the world, the development of assisted death programs is growing. Over a dozen countries have legalized a form of MAiD, and others are working to implement similar programs (Ho et al., 2021). Although controversial, medical professionals and the public are interested in this option for end-of-life (Ho et al., 2021). As MAiD evolves, Antonacci et al. (2021) acknowledge the importance of developing working relationships between MAiD providers and palliative care programs to improve care coordination for patients at end-of-life. Considering that the Government of Canada (2018) Framework on Palliative Care in Canada aims to provide a natural death and does not hasten death, palliative care nurses face challenges in caring for patients who request the option of MAiD (Antonacci et al., 2021; Wright et al., 2021). In their research Pesut et al. (2021) discuss how MAiD and palliative care serve the same population and that more collaboration and coordination between the two services makes sense for both end-of-life care providers.

The following paragraphs highlight the law and MAiD, public opinion, the patient experience, the work of palliative care nurses, and the Prince Edward Island (PEI) Integrated Palliative Care Program (IPCP). This provides context for the research questions that guided this study.

The Law and Medical Assistance in Dying

The law supporting MAiD Bill C-14 was first passed on June 17, 2016 (Government of Canada, 2021). This law allows individuals to request either lethal injection or medication from a nurse practitioner (NP) or physician when diagnosed with a life-ending illness (Antonacci et al., 2021). In accordance with Bill C-14, MAiD can only be administered when death is imminent, the person has made an autonomous decision without being pressured, and there is a second

assessment made by an authorized healthcare provider (Government of Canada, 2021). Under this law, people who apply for assisted death must be over 18, have the mental capacity to make decisions regarding their health and be able to provide final consent immediately before the injection (Government of Canada, 2021). The law also states that the person must have an incurable illness, disease, or disability, be in an advanced state, and have unbearable symptoms that are not being alleviated with attempted interventions. Medical professionals felt that the wording of C-14 was unclear in stating death needed to be "reasonably foreseeable" and that it affected the access to advanced requests and mature minors, excluding them from the right to end unbearable suffering (Webster, 2016, p.544; Wiebe, 2023, p.204;). In March of 2021, Bill C-7 was passed to address these concerns.

PCPs were adapting to MAiD in their practice when the Superior Court of Quebec ruled that Bill C-14 violated the rights of patients whose death may not be reasonably foreseeable (Pesut et al., 2021). These authors explained how the Federal government decided to consult Canadians with a broad-based online survey to find common themes of concern regarding MAiD. The results from this survey aided in preparation for changes to Bill C-14. Pesut et al. (2021) discussed the specific criteria for MAiD that were removed, which included the requirement regarding a foreseeable death and allowing for requests from patients whose death was not imminent. Elie et al. (2023) explained how these requests came from people receiving invasive treatments for life-limiting illnesses such as cancer or kidney disease. Their death may not be reasonably foreseeable, but their treatments resulted in further health complications and poor quality of life, motivating them to discuss their end-of-life options. Wiebe et al. (2023) recognized that with these changes to Bill C-14, there was an increase in the requests from people with a diagnosis of chronic pain, fibromyalgia, and chronic fatigue syndrome whose

death may not be imminent. However, because these conditions have no available cure, they requested MAiD. When the Government of Canada (2021) passed Bill C-7 there were changes made to the bill that consider advance requests for those who may lose the capacity to consent by the date of the procedure. This included patients diagnosed with Dementia, Alzheimer's, or a degenerative disease such as amyotrophic lateral sclerosis (ALS). The changes also introduced applications for mature minors and those suffering from a diagnosis of mental health issues (Government of Canada, 2021). Pesut et al. pointed to a critical change in the law that granted the ability to waive the final consent requirement before the MAiD procedure if the patient meets all the eligibility criteria. These authors revealed concerns from care providers before this change that patients decided to have MAiD sooner than intended because of the possibility of losing the ability to consent.

Medical Assistance and Dying (MAiD) and Public Opinion

The questions from a public research poll in October 2020 asked Canadians about their opinions on MAiD and access to MAiD in Canada (Pennings & Reid, 2020). The outcome of this poll showed 77% of those surveyed supported access to MAiD as a fundamental right. When Pennings and Reid (2020) polled Canadians again with questions about the conditions surrounding the decision to have MAiD, the feedback resulted in half of respondents expressing uncertainty about MAiD and caution in their support. These Canadians were concerned that vulnerable populations, such as those with mental illness or physical disabilities, felt pressure to choose MAiD as an option due to a lack of resources and support for their condition. In addition to Canadians' concerns, the Federal government acknowledged the accessibility problem related to palliative care. Seventy percent of Canadians who would choose a palliative care program did not have access to one, and 7 out of 10 Canadians were concerned that with the expansion of the

MAiD program, fewer contributions would go to the palliative care approach (Pennings & Reid, 2020). Dying with Dignity Canada is a national human-rights charity devoted to reducing unwanted suffering and providing Canadians access to all end-of-life care options. Dying With Dignity Canada (2022) provided the results of a national survey that revealed that over 80% of Canadians who responded to the survey support the recent removal of the restrictions on advance requests for MAiD when death is foreseeable. The survey results found that 90% of Canadians who responded and who were over 55 support MAiD.

Patients' Experience with End-of-Life Care

In PEI, clients may receive end-of-life care in the hospital, in the Provincial Palliative Center, in long-term care, in community care, or at home. The Health PEI (2019) palliative care website outlines the services provided to patients in homes or inpatients for people diagnosed with a life-ending illness. These services include education on the disease, treatments, goal setting, and options for symptom management. This site provides access to information on the IPCP. The IPCP is a home care program with a partnership composed of many PCPs. For this paper, PCPs will identify all interdisciplinary teams working with palliative care patients. The PCPs on PEI may include physicians, nurses, social workers, spiritual care, personal care providers, physiotherapists, dietitians, volunteers, and after-hours emergency medical services (EMS) (Government of PEI, 2022; Health PEI, 2022). Each client should have individualized care that includes a palliative care nurse and physician or NP who will lead the team and other PCPs who implement the care plan. Most people choose an in-home death with the IPCP, but some may require a transfer to a hospital (Antonacci et al., 2021; Canadian Institute for Health Information, 2018; Health PEI, 2022). If transfer to a hospital is necessary, the PCP has special units available in the province. The largest is the palliative care center, an independent facility

with ten beds that offers patients and their family members holistic end-of-life care from PCPs. Also, beds are available in Prince County Hospital, Community Hospital O'Leary, Western Hospital, Kings County Memorial Hospital, and Souris Hospital, where palliative services can be provided when hospital transfer is necessary to aid in symptom management (Health PEI, 2022).

Palliative Nurses Working in IPCP

When patients are referred to the IPCP, they have an initial visit with a palliative nurse who often becomes their care coordinator. The IPCP nurse is a registered nurse (RN) trained in palliative care who meets with patients and family members in their homes. These nurses orientate with experienced palliative care nurses and have taken a Learning Essential Approaches to Palliative Care (LEAP) course (Pallium Canada, 2022). The LEAP training, which can be online or in-person, requires modules to be completed independently before attending sessions. These interactive learning modules encompass aspects of care such as palliative medications, care planning, and spiritual support. There are also two sessions guided by experienced PCPs that must be attended to complete the program. The education sessions focus on care for patients with progressive life-ending illnesses and aid these healthcare providers in care planning using a team approach (Pallium Canada, 2022).

With the information from the initial home visit, the palliative nurse assesses the disease progression and develops a care plan for the following days, weeks, or months. The IPCP nurses then use a collaborative approach to aid in the decision-making process for end-of-life care that offers dignity and autonomy to each patient. The IPCP provides a patient and family-centered approach to evaluate their patients while addressing their physical and psychological issues. The

palliative care nurses will provide holistic care, including the patient and their family members in the decision-making team (Health PEI, 2022).

Integrating Palliative Care and MAiD

Ho et al. (2021) emphasized how the palliative care community wanted to maintain a compassionate and holistic approach to end-of-life decisions and intended to provide the education and support needed to address any misconceptions about symptom management. Palliative care nurses offered timely care, symptom control, and education that achieved a natural death with improved communication between patients, families, and PCPs (Ho et al., 2021). While palliative care nurses acknowledged that MAiD may become a part of a patient's requests for end-of-life decision-making, the goal was to continue providing holistic care regardless of MAiD inquiries. Integrated palliative care and MAiD have the potential to work in harmony to support their population of clients in need of symptom management for end-of-life care (Ho et al., 2021; Pesut et al., 2021).

Pesut et al. (2021) identified RNs as the PCPs who spend the most time with patients making end-of-life decisions. Palliative care nurses are increasingly being asked to provide support and assessments for clients interested in exploring MAiD as part of their end-of-life care. Pesut et al. revealed that as palliative care nurses became more comfortable with MAiD, there was an increased openness and discussion about the services required to coordinate and access MAiD. The MAiD nurse coordinator's role was to support the patient and the family members throughout the MAiD process. Pesut et al. stated that in the province of Ontario, MAiD nurse coordinator positions were created to help with the increase in paperwork and to aid in the education, screening, and policy development for MAiD. These nurses were responsible for

ensuring that the patients knew all the care options available at the end-of-life (Pesut et al., 2021).

Currently, there are no MAiD nursing coordinators on PEI at homecare to support this end-of-life decision and offer support for clients and family members considering MAiD as an alternative to a natural death with palliative care. Palliative care nurses develop the care plan for natural death and support and guide patients and family members throughout dying, death, and grief. While both are related to end-of-life decision-making, the goals of palliative care and MAiD differ. This difference may represent a gap in care coordination that may not meet the needs of clients and families at the end of life. However, there is limited research to describe the experience of RNs working in palliative care with patients who choose MAiD as an alternative to palliative care. Understanding the experience of palliative care nurses may reveal how to support clients and families best as they face end-of-life decisions.

Research Questions

In this research study I explored the experiences of palliative care nurses with Medical Assistance in Dying (MAiD) in PEI. The following questions guided the study.

1. What stories do registered nurses who work in palliative care share about their experiences with MAiD?
2. How do the narratives of registered nurses who work in palliative care illuminate the challenges and opportunities of palliative care and MAiD co-existing as options for end-of-life care?

Chapter two will offer a literature review that examines research and findings surrounding MAiD and its challenges for care providers, patients, and families.

Chapter 2

Literature Review

The previous chapter introduced MAiD legislation and its development in Canada. Chapter One also outlined MAiD as an end-of-life option and how it affects the experiences of palliative care providers (PCPs), patients, and palliative care nurses. Chapter two will review current and relevant research related to MAiD and discuss the implications for PCPs, such as MAiD's relationship with palliative care, PCP's observations of MAiD, nursing morals and ethics, and MAiD's relevance to palliative nursing.

Literature Review Strategy

This literature review aimed to examine relevant information on MAiD development in Canada and discuss this subject from the perspective of PCPs, focusing on palliative care nurses and their involvement with MAiD in the practice setting. Articles of interest included MAiD legislation, public influence, program access, and general information about the progression of assisted dying worldwide. With the assistance of the UPEI librarian specializing in nursing research, the broad topic of MAiD was compressed to explore its influence on PCPs and palliative care nursing or nurses. The databases CINAHL, PubMed, and One Search were used to enter terms relevant to MAiD and palliative care nursing. The search terms used were MAiD, Nurse, Legislation, Canada, and Palliative care. Limiters included: peer-reviewed, 2015-current, English language, and all journals. When searching the topic of MAiD as the only search term, the results list was over 12000 articles. When entering nursing, legislation, Canada, and palliative care into the initial search, the list was reduced to under 40 articles. The abstracts of these articles were reviewed. When considering articles for review, challenges of MAiD for PCPs were identified in the study's purpose, the research problem, and the influences of MAiD

on PCPs. After reviewing the abstracts, over a dozen articles were chosen and read in their entirety. Eleven articles from CINAHL, PubMed, and One Search were chosen that address palliative care nursing and how their care planning is affected by patients considering MAiD.

Some connections between the articles include the observations of MAiD by palliative care nurses, the relationship between PCPs and MAiD providers, the experiences of palliative care nurses with MAiD in practice, and the variety of service coordination between palliative care and MAiD programs in Canada. These research studies described the thoughts, feelings, observations, and relevance of MAiD to PCPs and palliative care nurses in their practice setting. Once key information on these topics was extracted from these first articles, grey literature of interest from the newspaper and online data sources offering public information and their evolving views on MAiD was reviewed. There is ongoing research on MAiD, with numerous articles published in nursing journals, but the research on its effect on the palliative nurse in practice is limited. Therefore, no grey literature was added to the final literature review. In the following section, I will discuss connections and themes yielded from the literature search.

MAiD's Relationship with Palliative Care

Wright et al. (2021) shared Canada's two modes of MAiD as prescriptions for self-administered medication or intravenous medication (IV) administered by health providers. The International Association for Hospice and Palliative Care (IAHPC) recognized and respected the rights of each country's government to approve a form of euthanasia or physician-assisted suicide (PAS). However, the position of the IAHPC is "that no country or state should consider the legalization of euthanasia or PAS until has ensured universal access to palliative care services and to appropriate medications, including opioids for pain and dyspnea" (De Lima et al., 2017, p. 1309). According to The World Health Organization (WHO) (2019) palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death.
- integrates the psychological and spiritual aspects of patient care.
- offers a support system to help patients live as actively as possible until death.
- offers a support system to help the family cope during the patients' illness and in their own bereavement.
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated will enhance quality of life, and may also positively influence the course of illness.
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO, 2019, p. 1)

This comprehensive material provided by the WHO was summarized to describe palliative care as a program that aims to provide the best, holistic quality of life and a natural death for individuals when a cure is no longer possible (Vanderveken et al., 2019). Their study maintained that the best quality for end-of-life care included involving family members, lowering stressors, preserving dignity, and pain reduction with symptom management.

In countries where forms of medically assisted death are legal, the palliative care team should not be responsible for implementing these practices (Wright et al., 2021). Most PCPs resist involvement in assisted death (Gerson et al., 2020). Wright et al. (2021) described that at the time of their study, Belgium was the only country found to have an integrated system for

medically assisted dying and palliative care. Gerson et al. (2020) found studies from the United States, Switzerland, and Canada that examined relationships between MAiD and PCPs and how these relationships continue to be complicated. Difficulties have been identified in the collaboration of these two specialties as the practice of MAiD and palliative care have developed individually over time and in different countries. However, more research is needed to describe how assisted dying and palliative care work together (Gerson et al., 2020). Wright et al. explained that some PCPs will not allow MAiD in their practice setting as it conflicts with the definition of natural palliative death. In Canada, many PCPs oppose the MAiD philosophy and how it divides PCPs into those for and those against MAiD (Wright et al., 2021). Ho et al. (2021) and Fernandes (2015) added that the involvement of PCPs in MAiD affected the public perception of palliative care services and may have eroded the trust built in palliative care planning for natural death, comfort care, and symptom management.

Pesut et al. (2021) discussed how Canada as a nation struggles to set up a nationwide process for MAiD that provides education for the providers and patient accessibility. They expressed that a knowledge gap exists for PCPs and the public about which patients meet the requirements for MAiD. While MAiD evolves and becomes more adopted in practice, tensions remain between the PCPs and those who provide MAiD (Pesut et al., 2021). Some palliative care nurses saw MAiD as an acceptable moral decision. Tensions arose from the moral impact of MAiD on palliative care nurses who conscientiously object and the stress they felt when providing care for families throughout the MAiD process. Pesut et al. recommended a larger systems perspective to develop relationships between PCPs and MAiD providers. Ho et al. (2021) suggested that in primary care settings such as hospitals, homes, and palliative care centers, communication was needed to expand informed practice and knowledge of current

policies for PCPs. These authors suggested that lessons may be learned from other countries with a history of assisted dying that have developed more advanced programs coordinating MAiD and palliative care (Ho et al., 2021).

Palliative care nurses were confronted with ethical decision-making concerning their role in the MAiD process (Wright et al., 2021). Their concerns center around the degree to which palliative care nurses were a part of the care plan for patients contemplating MAiD as an option for end-of-life. Palliative care nursing leaders have suggested that anyone participating in the MAiD process should no longer be involved with the palliative program. Even though this view does not have legal standing, it exists in the culture of palliative care nurses across Canada (Wright et al., 2021).

PCPs Observation of MAiD

Although PCPs are experienced with end-of-life care and the practice of natural death, they continue to be immersed in the MAiD process as it unfolds within their practice setting (Ho et al., 2021). These researchers interviewed PCPs to see how MAiD discussions affect their communication with patients and how information from these conversations may be used to address gaps and improve education for the professionals working in end-of-life care settings. They identified concerns about public confusion surrounding the differences between MAiD and PCPs. This confusion may diminish public trust that palliative care delivers a holistic approach to symptom management without accelerating death (Ho et al., 2021). They concluded that professional and governmental standards must support the level of holistic care that palliative programs strive to offer. Ho et al. (2021) also acknowledged how some patients who discuss MAiD are diverted from more holistic, palliative care plans. These researchers considered patient reports of lesser care options when pursuing MAiD. The care plan becomes more of a procedural

matter, pays less attention to the psychosocial issues and suffering of patients and families, and becomes more focused on the quick solution of assisted death (Ho et al., 2021).

In healthcare areas such as home care, hospitals, and palliative care centers, palliative care nurses describe the importance of relationship building between the PCPs and patients receiving end-of-life care (Pesut et al., 2021). Palliative care nurses conveyed that best practice requires a trusting relationship between PCPs and patients to support decision-making when making important end-of-life care plans (Pesut et al., 2021). Schiller et al. (2019) disclosed that because of how services are coordinated in Canada, such as being aimed to provide accessibility to patients, MAiD providers may not have a previous relationship with the patients being referred to them for MAiD service. Pesut et al. (2021) revealed that currently, the PCPs who perform MAiD may have no prior communication with the patient.

There is concern that the public expects the option of MAiD to be understood and accepted by all PCPs (Wright et al., 2021). However, MAiD may only become partially compatible with the philosophy of palliative care nursing as it contradicts the palliative philosophy that promotes a natural death (Wright et al., 2021). Many people expect palliative care nurses to incorporate MAiD legislation into their end-of-life care planning even if it does not meet their moral identity as PCPs (Wright et al., 2021). Pesut et al. (2021) gathered data from across the country (primarily from the provinces of Ontario and British Columbia). The results found no unification between palliative care and MAiD programs in some locations. In other areas, MAiD nursing coordinators, who were not PCPs, worked in an advanced practice role providing the public with education and connecting patients with the PCPs involved in the MAiD plan (Pesut et al., 2021). Creating these coordinated systems is a goal cited in the National Framework for Palliative Care (Government of Canada, 2018). The model that includes MAiD

nursing coordinators requires further support and resources for the healthcare system to adequately accommodate and administer MAiD services in Canada (Pesut et al., 2021).

Palliative Care Nursing Morals and Ethics

Fernandes (2015) discussed her viewpoint as a hospice palliative nurse on the threat of this legislation to the morals and ethics of palliative care nurses. She asserted that the relationship between palliative care nurses and patients, based on trust and compassion, might be compromised if PCPs participate in assisted dying. Fernandes pointed out how most people considered the palliative care nurse's role to be naturally connected to the MAiD program as it involves end-of-life care planning. End-of-life care planning was expected for all patients, whether they had a natural death or an assisted death. When the legislation for assisted dying passed, they hoped that palliative care nurses would maintain their moral clarity, continue to help their patients in a holistic, natural death, and resist involvement in MAiD (Fernandes, 2015). Schiller et al. (2019) stressed that although the legislative system may benefit the accessibility of assisted death for patients, the MAiD law may suppress the ability of PCPs to uphold their morals and make them more inclined to conform to the ideals of others. Schiller et al. provided an example of an ethical conundrum between a patient and a NP. Schiller et al. described an encounter where an NP prepares a patient for MAiD. The patient questioned whether her creator would judge her for receiving MAiD, and the nurse's response was:

> "... 'You? What about me? I am giving the medication!' Although together they had a chuckle about this, the nurse reflected that this question was something that she too had seriously considered" (Schiller et al., 2019, p. 9).

Schiller et al. (2019) stated that with the expanding accessibility of MAiD, palliative care nurses felt a growing obligation to be involved in the procedure. This resulted in challenges for

palliative care nurses to consciously objected to MAiD while they continued to provide holistic care to their patients (Antonacci et al., 2021; Schiller et al., 2019). Antonacci et al. (2021) discussed the results from a nationwide survey of 452 respondents who answered questions about their personal experiences with patients requesting MAiD as an end-of-life option. The survey included three open-ended questions where participants shared their MAiD experiences since the program was legalized. The results included responses from 161 nurses who expressed a lack of psychosocial support from their province or territory, inadequate support for conscientious objectors, a lack of debriefing sessions following the MAiD procedure, and a shortage of counselors to provide debriefing sessions.

PCPs may not be directly involved in implementing MAiD, but they provide support to patients and family members throughout the process (Mathews et al., 2021). In their qualitative research, Mathews et al. (2021) asked PCPs in Canada how MAiD impacted their practice. One nurse they interviewed voiced concerns about “walking a tightrope” (p. 450) ethically speaking, no current mandatory training programs, and not knowing how to respond to MAiD questions from patients and their families (Mathews et al., 2021). The findings of this study suggest that MAiD impacts PCPs in several ways, including their relationships with patients, the use of palliative resources to plan MAiD, emotional and personal challenges, and the ethical dilemmas of how to answer patients' questions about MAiD. In their conclusion, Mathews et al. (2021) express that increased resources are needed to provide all Canadians with effective programs for MAiD and palliative care.

The definition of palliative nursing may be simply stated as aiding in a natural death free from suffering that does not assist or hasten death (Fernandes, 2015). Palliative nurses aimed to continue their work without being challenged to compromise their moral principles by being

asked to participate in the MAiD process. The involvement of palliative care nurses in the MAiD process may damage their morals and ethics (Fernandes, 2015). PCPs were concerned that patient trust may be lessened if they participated in the MAiD process (Fernandes, 2015).

Relevance to Palliative Nursing

Pesut et al. (2021) described the experiences of palliative care nurses dealing with the transition of MAiD as an option for patients at end-of-life. These PCPs were working to adjust to the legislation of Bill C-14 when Bill C-7 passed and allowed assisted death for patients whose death would not be predicted soon. With a healthcare system already faced with limited resources, the changes that came with Bill C-7 complicated care planning issues for palliative care nurses caring for clients needing end-of-life care. Pesut et al. acknowledged the patients' right to plan assisted death but found that PCPs are concerned that patients may choose assisted death sooner than planned for fear of losing the capacity to consent.

With the new Bill C-7, patients do not need to explore their options for end-of-life care, including a palliative program (Ho et al., 2021). Despite not having a requirement to consider a palliative care option, over 80% of those patients who chose MAiD had received some form of palliative care. Over half of those patients who used palliative services did so for over one month before receiving MAiD. A small percentage of clients who requested MAiD withdrew their request when they found that palliative measures worked to manage their symptoms (Ho et al., 2021). This study included palliative care nurses who felt MAiD should only be explored when all other care options have been considered. Palliative care nurses shared their apprehension of MAiD when client suffering was the motivation, and better symptom management may reduce suffering without engaging in MAiD (Ho et al., 2021). The decision to have MAiD is an essential practice consideration as the planning for MAiD can impact the ongoing delivery of

care and what palliative or social support services can remain in place if a patient discusses or chooses MAiD as an option. Further research is required to assess the timing of palliative care and how it affects MAiD decisions (Ho et al., 2021).

Ho et al. (2021) reported an increase in the incorporation of MAiD conversations into the work of palliative care nurses. Palliative care nurses were asked to request MAiD assessments and coordinate appointments for their patients with MAiD providers (Ho et al., 2021). These conversations were free from misinformation or poor guidance in a perfect setting. However, for this to be possible, all team members must have had education and skills related to the MAiD process (Ho et al., 2021). Wright et al. (2021) affirmed that palliative care nurses are expected to accept the MAiD process and information as part of their client-centered care. Antonacci et al. (2021) asserted that palliative and end-of-life care is a unique area of practice and requires all PCPs to have better training and skills to support this practice area. In addition to physical patient care, end-of-life care requires adding coping mechanisms for palliative care nurses to address the psychological stressors of dealing with MAiD. Ho et al. emphasized that PCPs need further education and familiarity with MAiD. They maintain` that PCPs will develop their ability to have more open discussions about MAiD as they learn to navigate the information in policy, law, and culture surrounding MAiD as an end-of-life option.

Palliative care nurses may feel a sense of failure when their patients chose MAiD to end suffering (Wright et al., 2021). In a study by Wright et al. (2021), palliative care nurses were invited to discuss their principles and perceptions of MAiD as an end-of-life option. One of the nurse participants stated that her first MAiD experience was distressing and that there was nowhere to go to express her emotions and no one to share her experience. Another palliative care nurse stated that the legalization of MAiD created a feeling of instability and moral distress

in their practice, and there were separations among staff due to personal emotions and opinions about MAiD (Wright et al., 2021).

Pesut et al. (2021) asserted that palliative care nurses accepted MAiD as an end-of-life option. However, there must be more support for palliative care nurses within programs to coordinate MAiD within healthcare systems. Their findings suggested that despite the challenges that palliative care nurses face, these nurses aimed to provide their population with the resources required to meet their end-of-life needs. PCPs must clarify all end-of-life care options and ensure the patient and family understand them before choosing MAiD. Therefore, "Professional and institutional guidelines need to better support PCPs in maintaining their holistic standard of care as they navigate the legislative and cultural shifts" (Ho et al., 2021, p. 11).

Palliative Care Nursing Exploration of MAiD

The research has revealed several influences that impact palliative care nurses related to MAiD and its effect on their practice. This review has discussed: the philosophy of palliative care as a natural holistic death, patient access to appropriate palliative care, palliative care patients requesting MAiD, relationships between MAiD providers and palliative care nurses, and coordination of services between palliative care and MAiD. The gaps from this review suggest that palliative care nurses want more education and access to palliative care services for clients making end-of-life decisions. Additionally, increased resources for clients who consider MAiD as an end-of-life option, improved communication between the clients and the MAiD providers, and improved coordination of services between MAiD and palliative care are required.

In the next chapter, Arthur Frank's dialogical narrative analysis (DNA) will be described as the methodology for this research study. A discussion of the methods and ethical considerations is also included in the following chapter.

Chapter 3

Methods

The preceding chapters introduce the topic of MAiD in Canada and a literature review examining the challenges this topic has presented for PCPs, specifically palliative care nurses. The following questions guide this study.

1. What stories do registered nurses who work in palliative care share about their experiences with MAiD?
2. How do the narratives of registered nurses who work in palliative care illuminate the challenges and opportunities of palliative care and MAiD co-existing as options for end-of-life care?

This chapter will identify the methodology used in this study and explain why it was chosen. Other elements of the study will be described, including study participants, recruitment strategies, data collection, study setting, data analysis, ethical considerations, and trustworthiness.

Methodology

The experiences of palliative nurses and their experiences with MAiD when providing care for patients at end-of-life were led by the questions above. In this study I listened to the experiences of palliative care nurses to explore how this information revealed ways to improve support for palliative nurses, clients, and families as they face end-of-life decisions. Arthur Frank's (2012) dialogical narrative analysis (DNA) is the form of narrative inquiry chosen as the methodology for this qualitative research study. Riessman (2008) identified narrative analysis and the organizing of narrative data as one segment of narrative inquiry. It refers to a set of methods of data collection that portray texts. This method may interpret the visual, spoken, or

written text to represent specific points to the researcher (Riessman, 2008). This study focused on interpreting the stories of palliative care nurses.

Dialogical narrative analysis is a form of storytelling representing stories from people's life experiences. These stories will shape the tellers' past and future by considering their sense of self and how they express themselves to those around them (Frank, 2012). In this methodology, five commitments create the foundation of the method. Frank (2012) states that the first commitment of DNA is to observe the voice of the individual participant and hear the expression of multiple voices within their story. In any story, the voices of others can be heard as these voices merge to create the narrative. The second commitment of DNA is to be cautious of the monologue, the story of one individual, as it is the gathering of voices for the collective voice that will enable similar experiences to be represented and create the substance that shapes the dialogue. The third commitment of DNA is to consider the extension of the story. Frank realized when listening to stories over many years that people are telling similar stories. As they tell the story, they may make it their own from the borrowed parts from the stories of others. The fourth commitment of DNA is focused on understanding and respecting the participant’s capacity to change. The research may be completed with decided outcomes, but the participants’ story continues and expands even after the study ends. Finally, the fifth commitment of DNA is to continue to consider and respond to what has been heard (Frank, 2012). The listener must "listen” and reflect on all the ways to understand the teller's story. In this ongoing analysis of the stories, Frank asks how people's lives can change when they hear their own stories and the stories of others and how this represents changes in their future relationships.

The following sections will describe the ethical considerations, methods used for recruiting participants, and data collection and analysis.

Ethical Considerations

I received ethical approval from the UPEI Research Ethics Board and the PEI Research Ethics Board (Appendix A). There were minor revisions requested by the ethics committee. These were completed and approved. The interviews were conducted at individual times and locations to ensure the participants' privacy. Before each interview, the participants were given a letter of information and consent form describing the purpose, research questions, and study methodology and methods. The participants were informed of the voluntary nature of the study and that they may withdraw their participation. Polit and Beck (2021) assert that each participant must be informed to make a voluntary decision to participate in the research study with the expectation that all their data will be kept in confidence and they have the right to be treated with courtesy should they withdraw. Participants were provided with a copy of their raw transcript and given up to 10 days to change or remove any information. The last date for withdrawing their information was four weeks following the interview. This is when the interview was transcribed, and analysis initiated. After the data was deidentified, the participants were unable to withdraw their data. Participants were reminded of this in the consent process.

The names of each participant were not identified in the study data. The participants were assigned pseudonyms to identify their data. The data is free of information that could identify the participant, family member, or any specific client or situation, given the small sample size and the nature of the work of the nurses in the IPCP. Care was taken to ensure the security of the data collected from participants. An encrypted flash drive was used to store the audio recordings from the interviews. The recordings and raw transcripts were exchanged between the transcriptionist and the researcher using this encrypted flash drive. Recruitment Strategies

An email was sent to a nurse manager with the IPCP (Appendix B) asking if they would invite the palliative care nurses to participate in this study. The email included information about the research study's aim and two attachments that assisted in recruiting nurses working in the IPCP. The first was an email that invited the palliative nurses to participate in the study (Appendix C). The second attachment was a poster that provided information about the study and the researcher's contact information (Appendix D). In the email I asked the nurse manager of the IPCP to contact the researcher or the research supervisors if they had any questions regarding this research project. There were no questions from the nurse manager. The email requested that the nurse manager forward the email attachments to the palliative care nurses working in the IPCP in the home care office. In the same email I also requested that the recruitment poster with the researchers' contact information be displayed in the office of the IPCP by the nurse manager. Three interested participants contacted the researcher, and they were provided with the information letter and consent (Appendix E) via email to review prior to the interview.

Participants

The participants for this research study were recruited from palliative care RNs who work in the PEI IPCP. These nurses were working or had previously worked in the IPCP for at least one year. A convenience sample, which is sometimes referred to as a volunteer sample, was chosen from palliative care nurses who offered to share their stories of MAiD (Polit & Beck, 2021). Etikan et al. (2016) explain how the convenience sample is practical for choosing members of a population that are available, willing, meet criteria, and are easily accessible to the researcher. Stratton (2021) states that convenience sampling is a non-probability form where the researcher introduces the study to the population, and the participants who offer to be interviewed may come forward. Often used for qualitative research, convenience sampling

selects participants from a specific area (Stratton, 2021). This type of sampling may be biased as the participants may have personal motivation to participate or a desire to promote their opinions (Etikan et al., 2016; Stratton, 2021). Although the analysis results of a convenience sample may only be applied to the participants in the study, one advantage of this type of sampling is that it can be used to develop objectives for further research (Stratton, 2021).

Three participants originally agreed to share their stories. One participant withdrew after the interview and their data was removed. The remaining two participants stories were used to understand their experiences with MAiD. The guiding principle of qualitative research is to sample until no new information is obtained (Polit & Beck, 2021). Cleary et al. (2014) discuss how in qualitative research the number of participants will depend on their expertise and personal experience with the topic. They ascertain that small numbers of participants chosen purposefully should offer rich focused information on the research topic. In this master's research, two participants were sufficient to gain insight into the topic with the understanding that this study could be built on later.

Using a semi-structured interview guide (Appendix F), a pilot-test interview with a RN was completed to estimate the timing of the interview. The interview took approximately 20 minutes.

Study Setting and Interview Process

Participants chose the time of their interviews. All participants accepted the interview location as a room booked on the UPEI campus. The interviews were conducted in person. This allowed for comfort and privacy and minimized interruptions for the participants to talk openly and reflect on their experiences with MAiD in their practice.

The information letter and consent were reviewed with the participant again at the interview. If the participants had any questions the researcher addressed them. When the participants were satisfied that their questions were answered, they read and signed a consent form. A recording device was used for the interview. The researcher has a log of participants' contact information, including email and pseudonyms. This log was password protected, only available to the researcher, and was kept separate from the transcripts.

The interviews began with the question: *Please start by telling me about your role as a RN in the IPCP.* The nurses shared their role as PCCs. This allowed the participants to provide a description of their role in a holistic care plan for their clients. This information becomes meaningful in the following chapter of data analysis. The second question was: *Please tell me a story about a time in your practice in the IPCP when you cared for a patient who considered MAiD as an end-of-life option.* During this portion of the interview, I limited my dialogue to clarify information or seek further related stories. The interviews were semi-structured to allow the nurses to expand their stories during the discussion, as this unfolding of the story reflects how DNA is more focused on speaking with a participant than speaking about a participant (Frank, 2012).

Data Collection and Analysis

When the participant shares their experience, it is the listeners' responsibility to hear the storytellers' point of view (Frank, 2012). According to Polit and Beck (2021) the researcher is also responsible to prepare a checklist of items required for each interview including recording equipment, batteries or chargers, consent forms, notepads, pens, and other supportive items such as water or tissues. With each interview, the data analysis began the moment the participants started to tell their stories. The interviews were audio recorded on a digital recorder. They were

transferred to an encrypted flash drive at the end of the interview. When each participant's interview was complete, notes were taken to remember any thoughts about the interview. The audio recordings of the interviews were transcribed verbatim by a transcriptionist, with all pauses and inflections of the participants being considered. The transcriptionist signed a confidentiality agreement (Appendix G) that outlined the process to protect the transcripts. When the transcriptions were complete the encrypted flash drive was returned to the researcher, the audio was listened to, checked for accuracy, and corrections were made to the transcript. Once the transcribed document was checked and corrections made the transcripts and the audio files were transferred to One Drive, which contains two levels of security authentication.

Each participant was provided with a verbatim transcript of their interview. Participants were invited to give feedback on their transcripts such as making changes or removing any information. Participants were given up to 10 days to change or remove data. None of the participants came forward with any requests for a change in their data. At that time, all identifiers were removed, and the participants were provided a pseudonym, and these were assigned in alphabetical order and in the order in which they volunteered to be a part of the research study.

Documents were password-protected and stored on a UPEI shared drive (OneDrive). UPEI's OneDrive uses multi-factor authentication to protect documents. Only the researcher and their supervisors had access to the transcripts and the shared file. When the study was finished, all data from the encrypted flash drive was deleted and all other study documents, including consent forms, journals, transcriptions, and audio files, were stored in the shared OneDrive. This data will be stored for five years.

The data or "stories" for analysis emerged supported by the semi-structured interview guide used to guide the palliative care nurses who shared their stories of personal experiences

with MAiD in clinical practice. Using Frank's (2012) DNA an analysis guide was developed by Drake (2022) to learn more about the nurses' stories of their patients experiencing early miscarriage. in. The questions from Drake's original analysis guide were modified to reflect the practice of the IPCP nurses experiencing MAiD in practice. Examples of these questions include: *What narrative resources* [described below] *do the storytellers use to shape the story? Whom did the palliative nurses tell their story to? Who were the storytellers that shared a mutual understanding of the story?* These questions were part of the iterative process of repeatedly reading the transcripts and thinking *with* (Frank, 2012) the stories until the narratives emerged from the collective. Frank (2012) describes how narrative analysis brings together stories of people with similar experiences that will shape the collective dialogue, conveying a shared description of the experience. Riessman (2008) describes narrative analysis as a group of methods that interpret related stories. Stories are told to expand on details and can create a more comprehensive picture of a group of individual experiences. The analysis intends to examine how and why the participants share their stories and considers the participant's purpose in telling their stories (Riessman, 2008). The researcher must become immersed in the data and engage in an iterative process of reading and rereading the transcripts (Frank, 2012; Streubert & Carpenter, 2011). Streubert and Carpenter (2011) explain how powerful narratives may be identified when qualitative research analyzes a phenomenon. Through the analysis, the researcher recognized parallels between the participants' statements to describe commonalities in the stories. Frank (2012) suggests that *narrative* and *story* may be used frequently in the same context. For the purposes of this project, stories will be of the individual PCC, and narratives will describe the collective experience of all two nurse participants (Frank, 2010; 2012). Specific PCC stories "can be collected into types of narratives" (Frank, 2010. p. 200). With the stories and narratives,

narrative resources will be revealed as the tools that the individuals use to tell their stories and are common across all stories (narrative threads) (Frank, 2013). The narratives will reveal narrative types as underlying plots that bring together the narrative threads (Frank, 2013). Frank (2012) states the importance of appreciating the storyteller sharing their experience, considering the relationships created by telling these stories, and how the participants' lives are affected by sharing their detailed accounts with others. In Chapters Four and Five I will provide more details of the analysis, including examples from the PCC's stories.

Trustworthiness

Qualitative researchers pursue trustworthiness of their data by confirming that their findings accurately represent the perspective of the participant and not that of the researcher (Polit & Beck, 2021). The goal of qualitative research is to represent the participants' stories accurately. The coherence of these stories and the researcher's interpretation is related to the presence of trustworthiness. The trustworthiness of this research was established using principles of credibility, dependability, confirmability, and transferability.

Streubert and Carpenter (2011) state that credibility is established by prolonged engagement with the data by the researcher and member checking for the participants to confirm that the transcript represents their experiences. In this study I listened to the experiences of each nurse storyteller in an approximately one-hour interview. This interview was conducted on the participant's personal unpaid time. During the interview, the researcher confirmed their understanding of the information being shared. The information was evaluated for accuracy using data triangulation which validates that the information is measuring what it is intended to measure from the interview notes, transcripts, and voice recordings (Polit & Beck, 2021). The researcher and the participant reviewed the data from the interviews, seeking accuracy and aiding

in the credibility and dependability of the data. To support confirmability, the researcher's supervisors reviewed the findings to establish that the interpretation of the data was correct and representative of the participants' voices and not that of the researcher.

Chapter 4

Analysis of Narratives

Frank (2010) explains that narrative analysis is as much the story of what people get caught up in telling as what they may not recognize. In this research I listen to two palliative care nurses who engage in sharing their stories. The nurse storytellers provide familiar examples of when their clients consider MAiD in addition to providing the listener with issues that they may not recognize in their day-to-day practice. Their stories give the reader a glimpse into the practice of palliative care and how these nurses support clients diagnosed with life-limiting illnesses. Their stories unite to create a narrative that will aid in understanding their knowledge and involvement in end-of-life care planning. An interview guide (Appendix B) was followed with a series of opening and probing questions inquiring about the palliative care coordinator's (PCCs) experiences with MAiD. These stories were analyzed using Frank's method of dialogical narrative analysis (DNA). An analysis guide was used to explore stories and how they would address the research questions (Appendix G) to discover the narrative resources within palliative nursing stories (Frank, 2012). Frank (2010) uses the term "dialogical" to express how the voice of the storyteller is never singular. Stories come from multiple voices, and each storyteller will constantly analyze their voice to reflect and adapt their story (Frank, 2010). This guides the storytellers as they attempt to make sense of the stories they tell and hear. What makes narrative analysis unique in an academic context is the time and space the analyst takes to respond to these stories. Frank's version of DNA is unique in that it often contains at least two of three elements: "a story, a storyteller, and a listener." (Frank, 2010, p. 16). The elements of this form of DNA are required as "each allows the other to be the story animates some individual or collective entity or process, and someone tells the story, thereby reanimating it" (Frank, 2010, p. 16). The process allows the story to be broken down into smaller pieces and then, after taking time to analyze,

reassemble these sections to interpret meaning (Frank, 2010). The analysis also considers not just the story and characters who tell it but how their story continues to be told (Frank, 2010).

MAiD from the Perspective of the Palliative Care Nurse in Practice

Frank (2000) describes standpoint as showing the "unique experience" of those who support each other within a culture or group of people who share similar experiences. When I reflect on my practice working with palliative care nurses, I realize they share an intense persistence and dedication to ensuring the final wishes of their clients are being met in the care plan. My experiences shape how I can listen and interpret these nurses' stories.

After graduating from the baccalaureate nursing program, I went to work in long-term care. In this position, I spent time with clients and family members, creating individualized end-of-life care plans that met their needs. Advanced care planning is an area that I was and continue to be drawn to in my practice. Helping clients and family members make these difficult decisions is a valuable and rewarding part of my role. When I moved to home care, I spent time with the palliative program, being mentored by experienced palliative care nurses. During my time with the palliative care program, I listened to these nurses when they discussed MAiD situations with each other and heard the unique challenges they were experiencing in their practice when clients considered MAiD as an end-of-life option. Frank (2010) suggests that the process of narrative will offer people identities and teach people who they are. The stories of the palliative nurses call out to be listened to, which develops my character as a nurse and a researcher, and the storytellers also develop and recognize aspects of their identity as palliative nurses (Frank, 2010).

In my practice, I am also committed to providing end-of-life care plans for clients and families in long-term care and palliative home care. Nurses specializing in end-of-life have

mentored me as I learned to be more proficient in advanced care planning for this population. MAiD is an option for end of life that, since being legalized in 2016, has become more common in society and, therefore, requires increased understanding by PCPs. My nursing colleagues have stated, “The MAiD team should handle this issue” and “Get the MAiD team involved here" when their clients ask questions about having a MAiD death. Antonacci et al. (2021) and Wright et al. (2021) stated that the challenges present themselves because of the differences between the two programs, palliative care planning does not hasten death but promotes a pain-free natural death. So, these statements made by the PCCs, which are also supported by the literature, about the topic of MAiD created my desire to listen to the stories of palliative care nurses to understand what they experienced when their clients considered MAiD. Frank (2010) says that the listener may interpret the stories based on previously knowing the stories. The listeners may become “prejudiced” by the stories they have already heard (p. 94). This prior knowledge may aid in interpreting and is an important basis for any form of understanding, the listener must be open to interpretive possibilities (Frank, 2010). This process requires a shift in thinking and being open to accepting new viewpoints (Frank, 2010). When listening to the stories of these PCCs, I am reshaping the ways that I come to understand their stories and hear what narrative resources they share when telling their stories.

Narrative Resources

Narrative resources are conceptual tools used by the teller to tell stories. These tools guide the listener and the teller in understanding the story by recognizing familiar narratives (Frank, 2010). To avoid limiting the resources of the PCCs, the intention is not to finalize the work or claim to know all possibilities. This will allow the storytellers to get to know themselves and the listener to see consistent and uniform patterns in their dialogue (Frank, 2010). In this

study three PCCs originally agreed to participate in the interview process and share their individual stories of their MAiD experiences from practice. One PCC withdrew from the study and their story was removed. The two remaining PCCs have several years' experience working in healthcare in a variety of settings and have each spent more than two years working as palliative care specialists. Their individual stories become part of a shared narrative that aids in the creation of five narrative resources. These narrative resources create a path to understanding the experiences of a PCC caring for clients and families who may consider MAiD as an option for end-of-life care.

Shaping the Story

Frank (2021) explains how people's narrative resources will depend on where they live, work, socialize, and the stories they feel are important to them. These stories are the ones they are most likely to share with others. It may be difficult to distinguish between a narrative and a story. However, each storyteller contributes to the collective of stories that work together to create significant narratives (Frank, 2010).

Each nurse has varied proficiencies with end-of-life care planning based on their prior nursing roles, background, specific training, and qualifications as PCCs. As storytellers, they develop their nursing stories from their personal experiences in their initial nursing education, their chosen work environments throughout their practice, experiences providing palliative care, and the policies and procedures their manager or institution put in place. The narrative resources heard from their stories include those from the individual PCCs and the shared experiences of both PCCs. Frank (2010) explains the importance of what the listener should reveal and what is appropriate to share, considering the personal nature of storytelling. Several narrative resources were shared by the nurse storytellers and chosen for their relevance to answering the research

questions. The most prevalent narrative resources shared include *the lines get blurred, supporting how they wish to die, I'm not part of that team, the day the IVs go in,* and *the missing pieces of the puzzle*. This chapter will proceed to outline these narrative resources.

***The Lines Get Blurred* Narrative Resource**

Palliative home care offers the client and their family the opportunity to stay in their own home where the people and the surroundings are known to them, providing familiarity and comfort during their final months, weeks, and days of life. When PCCs meet with palliative clients and family members, they exchange knowledge and information describing the PCC's role in end-of-life care. PCCs also described that many clients are not even sure what palliative care is or what their options are around dying and death. Jean describes how she must help them to understand not only palliative care but even to understand the dying process:

> *They don't have a plan to get MAID, but that what they think they are going to do because they, they don't know what palliative care is and They have never seen anyone go through it, they don't know what dying looks like. They don't know what supports are out there. Um, if they, they are very scared of what death is. So when I explain to them what palliative care is and that we are going to support them and we are going to do our best to keep them comfortable and maintain their dignity and that we are going to take care of the family and support the family and that we are gonna to try to help them die where they want, whether that is at home or the palliative care centre or at the hospital. And when I explain what each of those deaths look like and what their options are, when people hear exactly what palliative care is from someone who actually does it, um and they hear and trust me that I have palliated all these people in my career and this is what I do and this is how it goes, then they say, okay I want that. Cause They feel safe, they*

feel that they are not scared of, that death doesn't seem so scary anymore, they know that it's going to be, they are going to be taken care of and their family is going to be taken care of and they are not going to be in excruciating amounts of pain or they are not going to be... by themselves... there is a whole team around them to carry them through that entire journey right until the end. So once people hear that it takes their fear away. So, I do find there is a lot of fear and lack of education around what death looks like. It's Something that no one knows anything about is dying and death. So, I think that's a big gap in our system.

When PCCs come to the client's home for the first time, education is often required to explain what the process of dying looks like and the difference between palliative care and MAiD. Wright et al. (2021) stated that PCCs are expected to accept and share MAiD information as part of their client-centered care. This *lines get blurred* narrative resource demonstrates PCC's priority on educating their clients and family members on the components involved in the palliative care program and how it differs from MAiD as an end-of-life option. This narrative resource supports this PCC's experiences advising and educating clients in the home environment. Gwen describes a client who is confused about the differences between palliative care and MAiD and requires more information about these two subjects:

Some people have the expectation that that is how everyone dies now... that is how everyone is dying these days, so... differentiating to them the difference between palliation and MAID and people are always very appreciative of that information, so it's explaining to people that palliation is dying a natural death... explaining how the process of death works and usually people decline month by month and then week by week and then day by day and then hour by hour and that in those last days they need full total care

so it's making sure the people know what a death usually looks like... and then explaining to them how MAID works.

Gwen says they are often asked questions about MAiD by clients who are unsure if the PCCs are the people who do MAiD or are unsure what the MAiD program is. She provided examples of how they communicate the difference between palliative care and MAiD to the client and that they are two separate options. She describes an example of a discussion where the nurse needed to clarify the client's understanding:

Some people can be very offended by the question so you have to be delicate...I have had to ask people about MAID because the way that they are speaking to me I am not sure if they are referencing to MAID or not... they might mention something like when I get the needle... it is my duty as a health care provider to make sure I completely understand what my client is telling me and that we are totally on the same page... by saying I just want to make sure that we are totally understanding each other... the question I am about to ask you is not me suggesting anything to you but this is what you said, and I will quote it and say I want to make sure you mean medical assistance in dying...they'll say, well I don't know, I don't really know... so then it's providing education to them about the difference between MAID and palliative care....we don't want the lines to get blurred, blurred by what services we provide. Because... our programs are separate programs.

The PCCs are responsible for providing clients with information about the palliative care program. Clients assume that the PCC also has all the information about the MAiD program. Jean shares how they must explain to clients what the palliative care program is and that their focus is on palliative care:

I usually explain to them that the integrated palliative care program is really about providing people support until they have a natural death and that our involvement with the MAID program is limited, which it is. We have not been directed to have comprehensive conversations with people about MAID because we still are very palliative care focused.

The nurse storytellers described how they provide their clients with palliative care education and knowledge about the difference between palliative care and MAiD. These nurse storytellers shared how they take the time to educate their clients on advanced care planning and end-of-life decision-making. They also shared how they support clients in where and how they choose to die.

Supporting How They Wish to Die **Narrative Resource**

Advanced care planning is an integral part of the PCC's role. They discuss with clients and family members the choices available for where and how they choose to die. The clients often choose to die at home with this program if they have support from family. The final days of life with total palliative care require 24-hour care, and staying home requires sufficient family to aid with care and medications. Medications will provide symptom management including pain. The family is educated on how to give these medications. The PCCs will contact or visit the family daily to replenish the subcutaneous medications and assess for effectiveness. Home support workers will also provide personal care for the client daily to assist the family with bathing and repositioning the client. If they do not choose a home death, or do not have the family support required to facilitate a home death, they may go to the palliative care center or hospital for their final days. These decisions are often not made during the initial visit as they require some discussion between the client and their family. PCCs continue to work with clients

on their plan for death throughout the palliative care planning. The two PCCs who shared their stories describe their experiences when clients and family members also brought up MAiD during the end-of-life planning process. Gwen shared an approach to informing clients about MAiD as one of their options:

> *So, people that ask about MAID... I kind of have to be very delicate with people because I have met a few people that were asked about MAID by a different service... they felt that very offensive to be asked if MAiD would be something they would ever be interested in...When people have told me that I have explained to them that no one is trying to coerce you to make any decisions or they are not telling you about this to tell you that's what they think that is what you should do, but MAID is something that is available in our health care system and everyone has the right to know about all the options that are available to them... people deserve to know that and they have the right to know...everyone should get to die how they want to die and have control...that is a very important decision to make and I don't think any client has taken that decision lightly.*

Gwen shares concern when clients may not have knowledge of the MAiD option and further discusses feeling disappointed for clients who do not get their wish to have MAiD.

> *I think legislation is changing to prevent this, but when I hear of someone whose wish was to complete MAID and then it doesn't get to happen for them, it breaks my heart to hear that because I think everyone should get to die how they want to die and have control over how... so whether people lose capacity... that is what it usually would be... I hate hearing about that. Someone who wanted to complete MAID but then didn't get to do it.*

The nurse storytellers share how they coordinate their client’s care with the goal of a natural death while reducing pain and other symptoms. Providers of palliative care have a responsibility to explain all end-of-life options before clients explore the option of MAiD (Pesut et al., 2021). The nurse storytellers acknowledge the client's right to choose MAiD as an option in their practice and provide the information required for the client to access MAiD even in the palliative care unit. Jean explains that although the mandate of palliative care is to support a natural death, they inform people about MAiD, as stated on the application to inpatient palliative care, so clients will understand the option:

> *We do understand that people have choices and that they have options and if they are on our unit...and express the desire to explore MAID they (the palliative care unit) will facilitate it... that discussion.*

The PCCs work with their clients to create an end-of-life care plan. Gwen shares that the personal opinion of the PCC must be set aside to create a care plan that prioritizes the client:

> *Because everyone comes to it with their own backgrounds and preconceived notions and beliefs. I don’t come with any of that. I totally respect and appreciate people that do, and I think they are allowed to have their opinions about it as long as it doesn’t interfere with client care, what a client’s wishes are.*

The PCCs express the importance of their clients choosing how they want to die and respecting their choices. However, these PCCs shared throughout their stories that the philosophy of palliative care program and the MAiD are not the same. They are two distinct services as described in the following narrative resource.

***I'm Not Part of that Team* Narrative Resource**

The PCCs described through the sharing of their stories that they are not a part of the MAiD team. They are often associated with the MAiD team by the clients who expect that these two end-of-life options are connected. The PCCs do not have specific guidelines for how to access the MAiD team when clients request information. The PCCs highlight the disconnect between the two teams. First, Gwen provides examples of information sharing when clients inquire about MAiD:

> *They say are you the person involved in providing MAID or are you the person I would talk to about getting MAID... and I tell them that no, that's not my job, that's not the team I am a part of, that's not the purpose of the program I am a part of but that I can certainly help that person get in contact with the team, that team and I can make a referral to them if they wish...explaining to them how MAID works and that it's not something that I do, it's not something I participate in, it's not part of my program but I am here and available to refer someone that service, to call the MAID team to arrange a visit or to provide the family with the contact information on line so they can contact the team themselves and... have the assessments completed.*

The PCCs explain that they are not formally connected with the MAiD team, but both nurse storytellers have suggested that their clients go to the website themselves to get the contact information to reach the MAiD team. This website has the referral forms for the client to fill out and send to the MAiD team. Gwen has sent the referral form for clients but describes not being familiar with how the process works when the MAiD team receives it:

> *The people who get the referral, I don't really know what goes on in that building. I don't know where it is, I don't know who all in the office is. I have heard kind of rumors of who*

is part of the team...I have heard it's like two nurses and a receptionist maybe that work there, and they are the ones that get the referrals... beyond that I am not really sure how their referral process works.

Jean explains how limited the contact can be between the palliative care team and the MAiD team in practice:

Our involvement with the MAID program is limited... we have not been directed to have comprehensive conversations with people about MAID because we still are very palliative care focused. What I direct them to is on the website... the information and contact numbers there... or... they can speak to their... primary care provider... I don't really have any connection with the MAID team. I have spoken to a couple of them the over the last few months... one thing I was requesting... when I have spoken to them was, because people have a lot of questions about MAID and... I'm not equipped to answer those questions... because I am not an expert on MAID.

The nurse storytellers share their stories of limited contact between the palliative care team and the MAiD team. They offer the client sufficient information to contact the MAiD team but share how the process is not clear. The PCCs shared that when the IVs go in for MAiD is the end of the palliative care plan for a natural death.

***The Day the IV's Go in* Narrative Resource**

As described by one of the nurse storytellers, this narrative resource highlights the story of when palliative care ends and MAiD preparation begins. Until the day the IV is inserted into the arm of their client, the PCCs are actively involved in symptom reduction and the holistic care plan for clients and families. The nurse storytellers shared that they do not put in IVs for the MAiD procedure and that the moment the IV is put in marks the end of the patient's palliative

care plan. From that point on, their end-of-life plan to die is taken over by the MAiD team. One of the nurse storytellers shared their thoughts about the day the IVs go in. Gwen describes that the role of the PCC is to provide quality palliative care until the day the client dies, but one challenge is that the PCC must step back when the IVs for the MAiD procedure are put in place:

> *I provide quality palliative care until the day that the client dies. Nothing changes in the symptom control I provide... my frequency of visits don't change, nothing changes until I, as a palliative nurse, I've been told that I am not to go in and start IV's for someone receiving MAID... so they, the MAID team would ask the home care nurses to go put IVs in but I wouldn't do that just, yeah, I wouldn't do that... so I would see the client up until the day they have their IVs put in... I do find it challenging as a palliative care nurse, is that I am in this job to see someone through to the moment of death and to support that family, so in that last day, having to step back I do find that challenging to do. To not be the able to be the one, but I understand why I can't do that, but it is hard to let another team to come in and take over when I am in this job because I want to see that person through to the moment they die and make sure they have a peaceful death so to kind of give up that control I guess or relationship on the last day I do find that challenging.*

Jean has described contact with the MAiD team as limited, she states she does not put in IVs for MAiD and directs her clients for more information about MAiD to their website:

> *I don't put in IVs for the procedure. I don't really talk to people about it except to guide them to the website... I never had an in-depth discussion like I explained... earlier.*

The nurse storytellers share these similar statements that they do not put in the IVs for the MAiD procedure. However, in the next narrative resource the *missing pieces of the puzzle*, they

reveal that the PCCs will continue providing care after MAiD is completed by extending services to the family in the form of bereavement services.

Missing Pieces of the Puzzle **Narrative Resource**

The nurse storytellers both made references to gaps in knowledge by clients and by themselves in terms of the MAiD program. References to missing pieces of a puzzle were shared in some form by both nurse storytellers. They discuss how they are not connected to the MAiD team and there is little or no communication with the MAiD program. The nurse storytellers use the term *piece of the puzzle* to represent areas where communication and collaboration between the palliative care team and the MAiD team could be lacking. They state that pieces are missing in the MAiD program in the areas that provide support for their clients and family members following the client's death. Gwen shares that this is the way it is and that they believe that no one is looking for input from the PCCs to make any modifications or improvements to the way these programs engage:

> *I feel the decisions are already made on how our programs interact with each other and I don't think anyone is looking for feedback on that. I do wish that there was more collaboration between our teams, and yeah that maybe they'd phone and ask for updates on how the client is doing or I could phone them and give them updates if things are changing. I wish we had that dialogue back and forth... we don't really have any collaboration with them back and forth throughout the process.*

Jean shares an extensive discussion on how the work of the MAiD team could be expanded to provide a more involved, inclusive, and comprehensive role in the client's end-of-life care plan:

Definitely a need for the MAID team to be more comprehensive I guess and more like, accessible in that people have people to talk to and have support for them. There is nothing there now except delivering the service and doing the assessments, that's pretty much all they do as far as I know... the people who are providing it (MAiD) should have the resources to provide... support to people who are getting MAID and that includes answering questions about it, providing support to the families and clients previous to the procedure and after the procedure... because... sometimes after the procedure is done we are then left to kind of pick up the pieces and help these people through that time... when I think it would be more appropriate for the MAID team to be involved in that as well because, because they were there at that moment with the family. I feel like this is kind of a gap that we have right now, and I feel, when I spoke to the MAID team about it, they really didn't seem very concerned about being able to provide that support, to me, that was my impression from them from my conversations with them. That... they didn't feel like it was necessary I guess for them to be able to provide that support... that they were just basically there... to give the medications and end the life and then that's it like... we'll...have the conversation, we'll do the assessments, we'll tell you that you are eligible for it and then we will go and do it. But... a lot of families after the assessments are done, they don't even know who to call when the time comes that they might want it (MAiD). And they ask us like who do we call... they don't seem to know. They don't have that piece of the puzzle and I don't have it. I don't know what to tell them either. So, what I tell them usually is to, I guess you'll just call the office... and ask them what you are supposed to do now. Anyways, I feel like the MAID team needs to be more involved. They need to have their own social workers... to work through these issues with people. They need to

have their own RN's to put the IV's in and to give that support before and after... more... wholistic, because whether or not you have any sort of spiritual beliefs at all, when you end somebody's life they are still human beings... people have emotions and they have concerns and after the person is gone there is bereavement and there seems to be no support for these people whatsoever because having a death from MAID is different. It is not the same as having a natural death and there is a lot of feelings and emotions about, around that and we are not able to provide that support so it would be nice if the MAID team could have their own team of professionals to help people through that... I think it would, it would make it easier if the MAID team would just deal with the MAID issues.

In the missing pieces of the puzzle narrative resource the nurse storytellers describe what client supports they feel are lacking between the palliative care and MAiD services. They both share the desire to have increased involvement and collaboration with the MAiD team.

The above narrative resources shared by the nurse storytellers are recognized as each PCC tells their story, and the similarities are revealed. When considering the narratives above and being attentive to the comparable details in the stories, these nurses share a common feeling of being disconnected from the MAiD program. The quotes provide examples of the lack of connection and coordination of services between the MAiD and the palliative care teams. The PCCs shared from their experiences that when clients request information about the option of MAiD; the PCCs are filling in the gaps in education and care coordination. One important missing piece discussed by a PCC above is the after care. The PCCs go back to the home to support the family members of the client when the MAiD service is completed. What is common for these nurses is the belief that the MAiD program could be expanded to support collaboration between the two services throughout the process.

Stories that circulate among the PCCs

The stories a person remembers are often the same as those shared by the group (Frank, 2010). A narrative habitus, or common stories a group shares, are the ones that stand out to the group. These are the stories that are already circulating. These circulating stories have been illuminated by the narrative resources shared above as common narratives from the nurse storytellers. Storytellers can establish membership to a group depending on the stories they recognize as significant to their specific community (Frank, 2010). The significant stories to these PCCs are shared using five narrative resources described above. These narrative resources highlight their challenges with MAiD in practice and these are also concerns commonly shared between the palliative care nurse's stories from the literature.

Frank (2010) explains how the storyteller may not recognize alternative narrative when telling their story. In the analysis, the listener finds the stories that the teller is now caught up in (Frank, 2010). Being caught up in stories, can help or hinder the storyteller, they can either help them see new ways to tell the story or prevent them from telling the story differently. The nurse storytellers here seek opportunities to offer their clients the best end-of-life care plan. They have identified how that would include seeking more shared resources with the MAiD team. The PCCs revealed in their stories that they do not believe they can introduce a plan of care that includes members of the MAiD team, but both of them mention that the clients would benefit from this type of collaboration.

The stories of the PCCs provided the narrative resources in the above discussion. Their stories reveal areas between the palliative care team and the MAiD team that may be fragmented or lack the degree of collaboration that they believe would best serve their clients at the end of their life. These PCCs provide their clients with a detailed end-of-life palliative care plan but are

not able to support the option of MAiD within their current practice. The following sections will discuss the PCCs' common story and who they share their stories with.

The PCC as a Storyteller with a Shared Story

Frank (2012) asks who tells what stories to whom. He states that medical stories are often shared with other healthcare professionals, but often, they may remain in only one community. When the PCCs share their stories of MAiD experiences from their practice the five narrative resources *the lines get blurred, supporting how they wish to die, I'm not part of that team, the day the IVs go in,* and *the missing pieces of the puzzle* are revealed. These shared resources lead to the underlying plot *nothing in between* that clarifies the common understanding of these PCCs as to what resources are lacking between MAiD and palliative care.

Within the community of PCCs, these nurses communicate with each other about client care plans and other aspects of their role including challenges such as MAiD. When asked if they had shared their stories about MAiD before or with others, these nurses said they had discussed their MAiD stories with the other palliative nurses in the office. The telling and retelling of the MAiD stories among the PCCs within their working community has developed the stories and their relationship to the stories. Frank tells "relationships are constructed around shared stories, and sense of purpose that stories both propose and foreclose" (Frank, 2010, p. 101). The PCCs have developed a trusting relationship from working in a small group and regularly sharing their stories, and it can be assumed that this trust and support helps them to be able to share stories and learn from one another. Frank discusses how stories breathe "life not only into individuals, but also into groups that assemble around telling and believing certain stories" (Frank, 2010, p. 101).

The PCCs are two RNs who volunteered to share their stories about their practice to support this research. The PCCs told their stories using the narrative resources of stories they heard or shared previously with others. Although they are sharing their experiences, the story is not entirely original but is built upon shared narratives (Frank, 2010). When asked to talk about their role as a PCC, each participant gave a detailed description of their role which illuminated who the nurses are in their practice.

Frank (2012) suggests that a group of storytellers that are affiliated will share both common boundaries and understandings of their stories. They will present the stories of the individual storyteller and the stories of the group (Frank, 2010). In their individual stories, the PCCs give descriptions of what it means to provide end-of-life care to their clients. As PCPs, they visit clients in their homes who have been diagnosed with a life-limiting or terminal illness. Often, these clients are in the last months of their lives and require pain and symptom management. These clients and their families require advanced care planning, including identifying goals of care, resuscitation status, health care proxies, and completing a health care directive. Their end-of-life care plan is then coordinated using services available through home care, other health system services, and external resources. The nurse storytellers each shared their individual stories of palliative care planning with a sense of purpose. They also discussed how they shared their stories with each other because they have built a trusting relationship within the PCCs. Developing similar trusting relationships with the MAiD team may offer opportunities for improved communication and coordination between the two teams (Antonacci et al., 2021).

Who is Excluded from the PPC's Story

The PCCs have provided examples of unique challenges that separate them from the MAiD team when dealing with clients at end-of-life. Unlike other providers the PCCs provide detailed advanced care planning and bereavement support for their clients. The PCCs state they are “not part of the MAiD team” and do not directly discuss clients with the MAiD team. The MAiD team and other health care providers (HCPs) work with clients and provide end-of-life care but from different perspectives. These other groups have their own stories to tell, but each of them, including the MAiD providers, may be confined to only their practice to tell stories. The MAiD providers are outsiders to the stories of the PCCs and therefore may not understand the stories of the palliative care nurse. What opportunities could exist for the palliative care nurse and the MAiD nurse to come together to recreate a new set of stories that offers shared understanding?

How do PCCs Hold Their Own

Frank (2010) describes holding one’s own in the story as either “aspiring to a perceived opportunity” (p.177) or “avoiding the threat to the value of the self” (p. 177). According to Frank (2012), people tell their stories often in response to being vulnerable. When the PCCs are telling their story of caring for clients who are at end of life and have questions about MAiD, they tell this story to address their vulnerability. Frank (2012) suggests that this can be instinctive and unplanned, or it may be a deliberate acknowledgment of their feelings and thoughts. When PCCs share their stories, it helps them hold their own by resolving the struggle between opportunities and threats experienced by each storyteller.

The PCCs describe their role in end-of-life care with great thought and detail. They describe that they assist clients and families with pain and symptom management and address individualized care planning needs. Their stories express their confidence and ability to help

clients and families with advanced care planning and education about their preferences for when and where they spend their final moments. Through these stories their confidence and certainty as well as their ability to hold their own in the stories is illuminated. These PCCs reveal confidence in the discussion of their program and value their identity as PCCs. They have noted the boundaries between themselves and the MAiD team by stating that they are not part of that program and that their involvement with it is limited to sending out a referral for their clients who request it. The PCCs are faced with being confident and comfortable in providing comprehensive palliative care but the introduction of MAiD has created a circumstance where they begin to struggle to hold their own because of lack of knowledge of the MAiD program. The PCC become vulnerable because their identity as a provider of palliative care becomes less comfortable, they begin to feel that they may not be able to provide the comprehensive care that is a hallmark of their work. They begin to feel vulnerable, and their stories reflect the response to that vulnerability. The language of being left out, not knowing who to call or what to do, and then finally have to come back and pick up the pieces reflects how vulnerable they are in their practice. The revelation of this vulnerability is both troubling and hopeful in this context. This vulnerability opens up an opportunity to explore how to reduce this vulnerability to be able to tell a different story.

The preceding paragraphs have described how the nurses tell their stories of providing end of life care as part of the palliative care team while co-existing with the MAiD program. Their narrative resources highlight what common tools they use to tell their stories and make sense of their experience. But what is the underlying plot that illuminates their experience? An examination of what typologies exist within their stories will shed some light on this question.

Typologies Revealed from the Stories of the PCCs

Frank (2010) suggests that stories assemble themselves into types. The typology will separate stories into areas of importance or reflect issues that are presented into groups or types. It also shows how an individual is holding their own and in what ways. To be aware of the similarities, the stories must be listened to carefully and focus must be on the entire story. Typologies will emerge with their own life as they are named. The name will describe the story or some part of it. Some stories will fit with the typology, and some will require a new name. This iterative process of naming and renaming continues until the analysis is complete. The typologies are intended to continue even after the research has been completed and are to be brought to life by this researcher or future researchers (Frank, 2010). The two participant's stories and narratives were analyzed using Frank's method as described above. Frank (2010) describes a narrative type as a prevailing storyline where the underlying plot is found. What emerged from listening to the PCCs story was that there was something missing between the work of the palliative care program and the MAiD program; an either/or if you will. There did not seem to anything in between the two options, and this was reflected in the nurse storyteller's choice of narrative resources. The typology that was discovered was the *nothing in between*. Nothing in between will further illuminate the work of the PCC as they navigate end of life options that include MAiD.

Nothing in Between Typology

People tell unique stories, but they compose them by adapting and "combining narrative types that cultures make available" (Frank, 2013, p. 75). Frank (2010) explains that even though each storyteller may describe their experiences differently, there will be stories that persist from one teller to another. These similarities within the narrative establish the plot. There is a

persistent theme within the narrative resources that describe gaps between the care provided by the palliative care program and the MAiD program. The typology *nothing in between* is reflected by prevalent issues between the care provided by the palliative care program and the MAiD program and describes a common experience that includes challenges with understanding, communication, and connection.

The typology evolved from using the iterative process of going back and forth, rereading the data, and finding the commonalities within the resources. Frank (2010) points out that the development of typologies risks putting stories in boxes or limiting what we know by controlling the story. However, typologies can also create a greater appreciation of the story by developing from the creativity of combining the available resources from the combined narrative. Using a typology as a guide, the listener can "hear how these stories are woven together and what changes occur...to hear different threads in the fabric" (Frank, 2010, p. 243). The iterative process of naming specific types takes time but increases the narratives' value by describing the represented shared resources (Frank, 2010). From the combined narrative of the PCCs' stories, the *nothing in between* typology was revealed. Understanding this typology can be aided by considering it in two sections: *nothing in between MAiD and the PCCs* and *nothing in between MAiD and the client.*

Nothing in Between MAiD and the PCCs

The stories of two PCCs describe the issue of lack of communication between the MAiD team and the palliative care team. The general narrative is: "We would like to offer clients more education and resources on the end-of-life care options, but we only have those available in our toolbox. We do not have access to the MAiD program or what their service provides." The PCCs describe their role in providing education and creating a palliative care plan for the end-of-life.

The PCCs describe providing all the information on end-of-life for the client. As discussed earlier, in *the lines get blurred* narrative resource, the PCCs take the time to explain the difference between palliative care and MAiD to their clients. Gwen explains the difference the proper education can make:

> *So, you feel that when they are educated on what palliative care is, they weren't clear before...so I think when, when they're scared, they grasp for some control and MAID is the ultimate form of control they can have over their death and so that is what they reach to. But it might not be appropriate for everyone if they have all the information in front of them. they don't have a plan to get MAID but that what they think they are going to do because they, they don't know what palliative care is and They have never seen anyone go through it, they don't know what dying looks like. They don't know what supports are out there. Um, if they, they are very scared of what death is. So when I explain to them what palliative care is and that we are going to support them and we are going to do our best to keep them comfortable and maintain their dignity and that we are going to take care of the family and support the family and that we are gonna to try to help them die where they want, whether that is at home or the palliative care centre or at the hospital. And when I explain what each of those deaths look like and what their options are, when people hear exactly what palliative care is from someone who actually does it, um and they hear and trust me that I have palliated all these people in my career and this is what I do and this is how it goes, then they say, okay I want that. Cause They feel safe, they feel that they are not scared of, that death doesn't seem so scary anymore, they know that it's going to be, they are going to be taken care of and their family is going to be taken care of and they are not going to be in excruciating amounts of pain or they are not going*

to be... by themselves... there is a whole team around them to carry them through that entire journey right until the end. So once people hear that it takes their fear away. So, I do find there is a lot of fear and lack of education around what death looks like.

Similar stories about educating clients were revealed within the narrative resources. The *lines get blurred* narrative resource shares examples of the PCCs explaining how palliative care works and the differences between MAiD and palliative care. The above quote is an example of how important this education is and how the PCCs are saying that it is up to them, and them alone, to provide this education. Even when the client may be requesting education on end-of-life options the burden of education always falls on the PCCs. The above example shows how important it is that the patient receive this education on palliative care. The typology of *nothing in between* highlights the importance of the need for communication between the two providers. The nurses identified in the *I'm not part of that team* narrative resource share how clients are not well versed in the end-of-life care options and the palliative care nurses provide the education for palliative care, but they must refer to the MAiD team to arrange a visit or start the referral process. Jean explained that there should be more education available when the MAiD team visits families, but nothing is coming from the MAiD team around palliative care education:

If people had more time to consider all of their options and if the MAID people were able to explain to them how palliative care works, then that might help them too to consider to choose palliative care... they don't even explore with them why they are thinking that way or if they realize that they could receive good palliative care through the services that we have here on PEI.

Another area where there is nothing in between MAiD and PCCs is when the nurses are asked by the client how to contact the MAiD team. Because there is no plan in place for the

PCCs to share contact information, Jean describes how in situations where the client wants to contact the MAiD team, they are advising the client to look it up on Google. This comment from Jean supports the *I'm not part of that team* narrative resource*:*

> *They ask us like who do we call... I don't know what to tell them either. So, what I tell them usually is to, I guess you'll just call the office. Look it up on Google and give them a call and ask them what you are supposed to do now. Look it up on Google and give them a call and ask them what you are supposed to do now.*

Even though the palliative nurses find it challenging with MAiD being a separate program, they do everything they can to support their clients. *The day the IVs go in* narrative resource describes how the PCCs provides all care up until the moment the IVs go in for the MAiD procedure. The nurse storytellers share that they have no connection with the MAiD team before or after the MAiD service is provided. Jean's comments support the *nothing in between* typology by sharing where the MAiD team could be more involved and accessible:

> *I feel like the MAID team needs to be more involved. They need to have their own social workers to um, to work through these issues with people. They need to have their own RNs to put the IV's in and to give that support before and after... definitely a need for the MAID team to be more comprehensive I guess and more like, accessible in that people have people to talk to and have support for them. There is nothing there now except delivering the service and doing the assessments, that's pretty much all they do, as far as I know.*

The above quotes provide examples the PCCs shared from the narrative resources: *the lines get blurred* and *I'm not part of that team.* The PCCs share that they would like to see improved contact between themselves and the MAiD team to aid with education and support for

clients. The PCCs also share how the MAiD team could improve their connection with clients. They share how the MAiD team could be more involved by connecting with clients and family members throughout the process of accessing and setting up MAiD.

Nothing in Between MAiD and the Client

The PCCs describe how they believed that the MAiD team could offer improved client communication and support. The nurse storytellers share that they do not have a connection with the MAiD team to support their clients to explore all end-of-life choices. The narrative resources s*upporting how they wish to die* and *I'm not part of that team* convey thoughts of how the PCCs see the two teams as separate. The PCCs who shared their stories said that in their experience any communication between the client and the MAiD team is facilitated by PCC. The PCCs described wanting their clients to die when and where they choose, and this includes educating the clients on how the MAiD team is a different from the palliative care team. The PCCs communicate how their clients have a right to choose MAiD and should die how they wish. The PCCs also share how they have limited contact with the MAiD team, but they continue to share the information they have about MAiD with clients. However, when the PCCs discuss their experiences with client requests for MAiD, they share there is currently no clear way for clients to access the MAiD team directly before or after the assessments are completed. The PCCs are connecting the clients with the referral information and the clients continue to request contact information from the PCCs. The MAiD team does not always continue to communicate with the client to reassess their status after the initial MAiD assessments are complete. The PCCs direct the clients to the website for contact information but would like to have more communication and formal process to offer their clients. While the client may not be the focus of this analysis, the client is the focus of the care offered by the PCCs in this discussion. Gwen shares

what she tells clients who request MAiD contact information from the PCCs. This supports the I'm not part of that team narrative resource:

> *It's not part of my program but I am here and available to refer someone that service, to call the MAID team to arrange a visit or to provide the family with the contact information on-line so they can contact the team themselves.*

Jean provides another example from the nurse storytellers that supports the *I'm not part of that team narrative resource*:

> *What I direct them to, is on the website and that they can... find the information and contact numbers there... I tell them to go to the web page or talk to their doctor about it or their NP... You have to give them something, right.*

The PCCs who shared their stories describe a need to do something to help the client when the MAiD team and the MAiD information are not easily accessible. Several times throughout the interviews, the nurse storytellers discussed finding a way to get the clients what they need despite the gap between them and the MAiD service. This is also an example that supports the *I'm not part of that team* narrative resource. Gwen shares that sometimes the PCCs print MAiD information and forms as the client may not find the website to be easily accessible if they do not possess a computer or the skills to use one:

> *Any forms they (PCCs) printed off were public forms from the website. They only did it because the person wasn't able to, they weren't tech savvy...There was no formal way for us to do that.*

After referring the client to MAiD either by providing them with the contact information or making contact for them, Jean reveals that the client still has challenges contacting the MAiD team. The above example discusses how contacting each team is a separate process and supports

the *I'm not part of that team* narrative resource. The following quote also involves the *missing pieces of the puzzle* narrative resource because throughout the process the nurse storytellers share that they would like to see more involvement and contact between the clients and the MAiD team. Jean reveals that PCCs would like to see the MAiD team communicate with clients they have completed assessments on, before and after the MAiD process.

> *A lot of families after the assessments are done, they don't even know who to call when the time comes that they might want it. And they ask us like who do we call and it's like what did they tell you to do, and they don't seem to know... I would like the stories to be different in the way that they had access to the MAID people, like they had numbers to call, they had people to ask questions to...I feel like the MAID team needs to be more involved.*

The PCCs shared their stories and revealed their thoughts about their perceived lack of communication and connection with the MAiD team. They discuss how they have provided the clients with information to reach out and connect with the MAiD team but the PCCs are not clear on who is on the MAiD team or where they are located. In the typology we are hearing the nurse storytellers share how they attempt to have their clients connect with the MAiD team. The *nothing in between* typology is brought together using examples from the narrative resources providing us with an understanding of the challenges these PCCs face when trying to bring together clients with MAiD.

When asked if they would have liked to see a different ending to their story, one of the PCCs shared how they believe all PCCs would prefer to have the MAiD team more involved when clients choose a MAiD death. This may be an expression of where the *missing pieces of the*

puzzle narrative resource is recognized in the typology. Gwen shares the desire to have coordinated care:

> *I have heard it's like two nurses and a receptionist maybe that work there, and they are the ones that get the referrals... beyond that I am not really sure how their referral process works. I wish that, I do wish that there was more collaboration between our teams, and yeah that maybe they'd phone and ask for updates on how the client is doing or I could phone them and give them updates if things are changing. I wish we had that dialogue back and forth... we don't really have any collaboration with them back and forth throughout the process. Um, I That would be something everyone shares as a feeling.*

Frank (2010) explains that this repeating of *the missing pieces of the puzzle* narrative may be a "stock narrative" (p. 230) as the storytellers both refer to this narrative in their stories. Lack of communication and coordination between the teams could represent an example of a stock narrative and provide an example of how the narrative resources come together. This lack of connection and coordination between the two teams is recurrent throughout the narratives and represents the underlying plot. Other narrative types may continue to be revealed in the future when revisiting these stories, but the typology of *nothing in between* was found to be significant in the analysis of this research.

Holding their own in the Typology

As Frank (2010) described, holding one's own as a threat or a challenge, the typology expresses both for the PCCs. In their role as PCCs, they want to offer a comfortable natural death to their client and make sure education is provided to the client so they can choose the way they wish to die. They have an opportunity to educate the client about palliative care and how they

offer a symptom-free natural death. At the same time, the client may be considering MAiD, but the palliative care team shows concerns about how the MAiD team communicates with the client and the palliative team. The PCCs would like to see more consistent and reliable forms of communication and collaboration between the two teams. They hold their own by working to resolve these challenges within their team and provide the client with everything they currently have available. The typology *nothing in between* explains where the PCCs feel resources are lacking between the two services, and here they are aspiring to what Frank (2010) states as a perceived opportunity by providing all possible resources and providing suggestions to offer more. In providing all resources to their clients, the PCCs aim to provide their client with their desired level of comfort. Being conscious of providing comfort to clients may provide ways to understand and guide future practice for PCCs who have clients considering MAiD as an end-of-life option. Consciousness in comfort may offer insight into how the *nothing in between* typology could be used to guide practice for how MAiD and palliative care teams work together. The concept of how comfort theory could support end-of-life care planning in practice will be discussed further in the following Chapter.

The End of This Story

The nurse storytellers shared their experiences of MAiD in practice when their clients consider MAiD as an option for end-of-life. The stories bring about narratives that are familiar to each other and create the foundation for the five narrative resources: *lines get blurred, supporting how they wish to die, I'm not part of that team, the day the IVs go in,* and *the missing pieces of the puzzle*. These narratives and the narrative type *nothing in between* revealed how the nurse storytellers describe their practice experiences. Their stories disclose how they understood their role as palliative care nurses while attempting to adapt to MAiD as a separate end-of-life

option. Storytelling can show differences between “who is troubled by something, who ought to be troubled, and who has what narrative resources to tell what kind of story about being troubled” (Frank, 2010, p. 29). The nurse storytellers are who is troubled by the lack of resources between their team and the MAiD team. The narrative resources provide examples of how they are troubled, and these come together to create the typology *nothing in between*. The nurse storytellers use their stories to hold their own when they described their MAiD experiences and dedication to providing best care despite any disconnect between the two teams. Frank (2010) asks if sharing the stories will make it more challenging for these storytellers to hold their own. Although the nurse storytellers may continue to experience challenges with MAiD in practice, in their stories they tell how they are currently navigating through the health care system finding ways to support their clients despite a disconnect between teams. The PCCs may not recognize all the work they do to collaborate and communicate for their clients, as they are determined to provide the best possible client outcomes regardless of their client chooses to die.

Chapter 5

Discussion

The PCCs who share their stories provide an understanding of their nursing practice providing care to clients and family members when MAiD is considered an end-of-life option. Two primary questions guide the research:

1. What stories do registered nurses who work in palliative care share about their experiences with MAiD?
2. How do the narratives of registered nurses who work in palliative care illuminate the challenges and opportunities of palliative care and MAiD co-existing as options for end-of-life care.

Detailed narratives were revealed by the nurse storytellers. These narratives revealed common narrative resources from their experiences that may be familiar to other nurses working in palliative care. Five narrative resources were revealed*: the lines get blurred, supporting how they wish to die, I'm not part of that team, the day the IVs are put in,* and *the missing pieces of the puzzle*. From these narrative resources the typology *nothing in between* was recognized and developed. The following discussion will refer to the research findings and use these narrative descriptions to organize this information from the participant's shared experiences with MAiD in practice and compare them to those in the literature.

The Lines Get Blurred Narrative Resource

This narrative resource, *the lines get blurred,* is the first of five narrative resources that were recognized from the common quotes of the PCCs who shared their stories. The PCCs used the words *making sure* when they answered client questions about the differences between MAiD and palliative care. The PCCs want to make sure they understand the client's wishes

about end-of-life and have the available knowledge to support them to make end-of-life decisions. This confirmation is important to the PCCs as they feel the *lines get blurred* between the two programs. The PCCs shared practice examples of when they explained how the two programs, the IPCP and MAiD, differ. Within the PCC's stories, there are examples of the client's lack of knowledge about the areas of dying, death, palliative care, and MAiD. The PCCs acknowledged that it takes time to educate clients and family members on these topics. And, although both PCCs are knowledgeable about the topics of death, dying, and palliative care in some cases, they describe a lack the knowledge when providing answers to the clients regarding MAiD as an end-of-life option. The findings of this narrative resource will be discussed using the two areas of *client's lack of knowledge* and the *PCC's lack of knowledge.*

Client's Lack of Knowledge

The PCCs discuss the importance of educating the clients and family members on end-of-life care planning. Mathews et al. (2021) report how educating clients and the public about the value of palliative care is key to improving its acceptance and access. The PCC nurses communicated that the education levels of clients and family members is lacking in several areas This lack of education is found in the areas of what palliative care is, what MAiD is, and what death looks like. This lack of education is apparent in the narrative resource, *lines get blurred*. The PCCs are trained and experienced in educating clients about palliative care and advanced care planning. The PCCs reveal that client knowledge about what death looks like and the difference between MAiD and palliative care is inconsistent and conflicting. These findings mirror those from the research of Ho et al. (2021), that public confusion exists about the differences between palliative care and MAiD services. Gwen states:

They don't know what palliative care is and they have never seen anyone go through it. They don't know what dying looks like. They don't know what supports are out there.

Other researchers assert the importance of early palliative care referrals to provide end-of-life education and address client concerns (Ho et al., 2021; Pesut et al., 2021). Earlier referrals allow PCCs to be the first source of information and present the information clearly and concisely (Flieger et al., 2020). This decreases the possibility of misunderstanding and misinformation that the family receives about the palliative care program. The PCCs shared that they provide the information in one or more visits and in small amounts that they feel the family can absorb each visit. They continue to complete the care plan in further detail as the family can adjust to their situation and make challenging decisions about dying and death. There are times however that the PCC comes to the home and the clients and family members have received little or inaccurate information and require additional knowledge on death, dying, MAiD, and palliative care. Ho et al. (2021) and Pesut et al. (2021) state that PCCs are increasingly being asked to have these conversations about the MAiD service because the services share the same population. The PCCs shared in their stories that some clients have assumed that the PCC is there to provide them with MAiD and believe the services are the same. The PCCs shared that when they come to the home of a client, they educate them on "exactly what palliative care is" and help them address their concerns about what death looks like. Gwen shares that with this information now they "feel safe... death doesn't seem so scary anymore" because they have built a trusting relationship after addressing the client's fears. Gwen's comments were shared earlier but are stated again to illustrates the importance of this relationship:

I do find there is a lot of fear and lack of education around what death looks like which... is something we all do in the end... that no one knows anything about is dying and death.

Terzakis and MacKenzie (2019) discussed families' lack of preparedness and education and how it interferes with their abilities to recognize appropriate end-of-life options for their loved one. Family members may be in denial and therefore not prepared to provide their loved one with the care they require. Family members state a "deep uncertainty about what symptoms to expect and what death would look like" (Terzakis & MacKenzie, p. 27). These authors described how including family and helping them be prepared for the death of their loved one requires a collaborative interdisciplinary team of HCPs.

Each nurse storyteller's story has unique elements. However, regarding the client's lack of knowledge both PCCs shared similar experiences of how the client and family were not well informed about the topics of death, dying, palliative care, and MAiD. When discussing the MAiD team's involvement, the PCCs express how they would like more collaboration with the MAiD team so that they could provide their clients with more information.

PCCs' Lack of Knowledge Related to MAiD

HCPs who provide end of life care should be equipped with the knowledge that they need to aid them in understanding and addressing the grief and emotions of the client at end-of-life (Antonacci et al.,2021). Ho et al. (2021) suggest that improving the education level of professionals will improve their ability to have difficult discussions about MAiD as legal and cultural issues continue to evolve. Antonacci et al. (2021) also list one of the challenges for HCPs as public and professional confusion about the difference between MAiD and palliative care. They recommend the need to focus on the specific HCPs who work with MAiD, as this end-of-life option presents unique challenges. Also, HCPs require more education and support to ensure all Canadians have access to high-quality and compassionate care regardless of their choice to have a natural death or MAiD (Antonacci et al., 2021).

The literature suggests that additional support and education is required to increase MAiD proficiency and competence for HCPs (Ho et al., 2021; Mathews et al., 2021). The PCCs acknowledged that the MAiD resources are limited and, at times, unavailable to them in practice (Ho et al., 2021). However, despite lack of resources, the nurse storytellers in this research continue to provide the education and support for their clients to reach their end-of-life goals through the IPCP. Mathews et al. (2021) suggested that more resources to support PCPs would positively influence the relationship between MAiD and palliative care programs. They recommend several training areas to expand knowledge: communication, ethical decision-making, and increased awareness of the legal criteria required for MAiD eligibility (Mathews et al.). Establishing these educational resources for PCPs will increase the capacity for the two programs to coexist as end-of-life options (Mathews et al.).

The stories of the PCCs who participated in this research illuminated that they provided their clients and families with high-quality end-of-life care. Their stories reflect their day-to-day work in making care plans that reflect the client and families' wishes. The education and care they provide is developed from prior nursing experience and their specialty as palliative care nurses. Their stories may not reflect explicit knowledge of MAiD processes as it is not part of their program, but they were able to identify that while they are experts in palliative care, they have limited understanding of the MAiD program and the options available within that program. Jean stated earlier but it was worth repeating that it would be advantageous for clients to have the MAiD team be more involved in the education process:

> *People have a lot of questions about MAiD... I'm not equipped to answer those questions... I am not an expert on MAiD, and I feel like the people who are providing it should have the resources... that includes answering questions about it.*

Both nurse storytellers acknowledged their expertise in provided quality palliative care, however, their knowledge of MAiD and the processes surrounding it, created challenges for them. Compounding these challenges was that their clients also did not understand the difference between the palliative care program and the MAiD program, or even the process of dying and death. PCCs found themselves not only helping to navigate dying and death for the client and family but also navigating the topic of MAiD with limited resources.

***Supporting how they wish to die* Narrative Resource**

The second narrative resource established in the analysis was *supporting how they wish to die.* As discussed earlier, the PCCs offer end-of-life education and advanced care planning with each client as part of their role. One key aspect of the PCC role is to aid the client in choosing how and where they wish to die. The client may choose to die at home, a palliative care center, or the hospital and may choose a natural death or MAiD. The analysis of the PCCs' stories discovered that when the client requests information about MAiD as an end-of-life option, these PCCs explain to their clients how MAiD is available through a separate program from palliative care. The nurse storytellers shared that they have little knowledge of how the MAiD team communicates with their clients once approved for the MAiD program. Pesut et al. (2021) share that as palliative care nurses become more open to involvement with MAiD, discussions will increase around what services are required to coordinate with palliative care. The PCCs want to increase palliative care services to those considering MAiD and express the importance of knowing how the client wants to die while maintaining the best possible palliative care to reduce suffering until the day they die, regardless of their choice of how they die (Pesut et al.). Pesut et al. foresee that the programs will be improved by building trusting relationships over time. These relationships can be developed using consistent attempts to communicate and

educate all stakeholders. MAiD nurse coordinator positions were created in the province of Ontario with success to help with administration of programs (Pesut et al.). The MAiD coordinators are responsible for to making sure clients have all appropriate information about end-of-life options (Pesut et al.). The stories shared by the PCCs here suggest, and are supported by the literature, that the client's dying wishes could be supported by finding ways to improve collaboration between palliative care and the MAiD team.

Terzakis and MacKenzie (2019) explain how the use of collaboration with an interdisciplinary team can help the client and family prepare for death. The PCPs in their research shared how they use advanced care planning to educate their clients on the end-of-life care options available. Their goal is to respect the client's personal beliefs and acknowledge their choice of where they wish to die by educating the client and family about end-of-life options (Terzakis & MacKenzie). The results from the PCCs in my research suggest that they support not only the client's dying wishes and how they choose to die but also by finding ways to become educated about the MAiD program and creating opportunities to collaborate more with the MAiD team.

I'm Not Part of that Team **Narrative Resource**

The *I'm not part of that team* narrative resource is the third narrative resource identified by the analysis. Both PCCs used this statement in their stories to convey that they are not a part of the MAiD team when talking to their clients. The PCCs provided examples of when they must explain the difference between their programs and how they can refer the client to MAiD or tell them where to find the information. The nurse storyteller's share that they are not clear exactly who is on the MAiD team or exactly how the referral process works. They explain to the client and family that they, as PCPs, are part of a plan for natural death and that the MAiD process is a

separate team to be contacted for assessments and approval. Several of the research studies referenced in this research have provided examples of the confusion between the two programs and the lack of public knowledge on these end-of-life options (Antonacci et al., 2021; Ho et al., 2021; Pesut et al., 2021).

Pesut et al. (2021) explained how the integration of MAiD and palliative care is different in each province. Some areas have informal exchanges, while others have fully integrated programs. Those fully integrated programs have different organizational guidelines to follow within each of their provincial healthcare systems. However, MAiD and palliative care programs who are working together to coordinate care remain independent services, based on guidelines from the Federal government. The benefits described by those who participate in a fully integrated program suggest that PCPs are the best people to provide end-of-life care planning and offer palliative care to clients until death (Pesut et al.). The focus is on the best care in the final days of life instead of how the client chooses to die. Their research concludes that the best way to integrate these teams is through relationship building between PCCs and MAiD providers. In this study, the PCCs have had similar discussions about how they do not have direct contact with the MAiD providers. Jean shares:

> *I haven't had a connection in a really long time. I don't really have any connection with the MAID team. my contact with the MAID team right now, it is very limited.*

Gwen shares a similar experience connecting with the MAiD team:

> *I would just help them get in touch with each other (the client with MAiD). Um, but other than that the only contact I would have with the MAID team would be sending a referral over to them.*

This lack of contact may impact the continuity of care between programs. Jean shares that there is no “formal way” to communicate with the MAiD team:

> *I would like the stories to be different in the way that they (clients) had access to the MAID people, like they had numbers to call, they had people to ask questions to.*

Pesut et al. (2021) suggests that although there must remain some distance between the two programs, palliative care plan for a natural death and MAiD, communication and education between all stakeholders will build relationships that enhance end-of-life care planning.

The day the IVs go in **Narrative Resource**

The narrative resource *the day the IVs go in,* explains how the PCCs experience caring for their palliative client until their final day of life. The point when the intravenous for the MAiD procedure are inserted and they are ready to have MAiD is the moment that palliative care ends and the MAiD process begins. The PCCs discussed their feelings on that final day of caring for their clients. One PCC shared that it is hard to give up that control because they expect to care for their clients until death as part of the palliative program and they would like to be with them at the end, but research suggests that PCPs should not be involved in implementing assisted death (Pesut et al., 2021; Wright et al., 2021). Wright et al. (2021) studied two hospice palliative care sites. One site allowed MAiD on the premises, and the other did not. The palliative care nurses in this study held to a separate philosophy of a palliative natural death. They are not involved in the MAiD process. However, they continue to provide palliative care for their clients until the time the patient leaves the site, or the MAiD team comes to provide their service. The nurse storytellers in this study share the same commitment to care for their clients until the day the IVs are put in. One of the nurse storytellers shared that they recognize this as the time their role of palliative care is over, and the MAiD team has taken over for the final moments of the

client's end-of-life plan. This PCC also reveals a lack of closure for them when they step away for the MAiD team to step in. There is a missing piece for them in their role of supporting the client and family through the dying and death process.

The Missing Pieces of the Puzzle **Narrative Resource**

The *Missing Pieces of the Puzzle* Narrative Resource represents the challenges PCCs face related to lack of education and knowledge as well as closure for them related to the MAiD program. The nurse storytellers each used the term piece or pieces to describe gaps between the programs. The terms "missing pieces" and "pick up the pieces" were used by nurse storytellers when discussing how their practice encounters the MAiD team. The PCCs shared how they and the MAiD team could be collaborative in the care planning for the patient's death and the bereavement process. Both nurse storytellers shared their thoughts about working together to provide bereavement services for their clients. They suggested that they believe this is one of the areas the MAiD team could improve their service by having social workers involved with their clients.

The PCCs state that despite attempting to reach out to the MAiD team they have minimal contact with them except to send out the referral. Jean shared their frustration with the MAiD team telling the PCCs "You can always contact us" but when it is time to access the service the information is not clear. For example, they would like to see increased communication around client information such as updates or changes in status. Jean shares:

> *If I had a contact, I would just send them their name and phone number and say these people have questions for you could you please address them... They could just contact them themselves and really, they should be doing that anyways. They should be, if somebody has had MAID assessments done and has said this is something I may want to*

have in the end there should be somebody from the MAID team checking up on them anyway.

The quotes analyzed in this research suggest that two nurse storytellers believe there is a need for increased access and improved communication between the palliative care team and the MAiD team. Throughout the analysis one of the PCCs consistently shared that they would like the MAiD team to take to care of everything related to MAiD. While the other PCC shared that they would like to see the programs expand to be more integrated.

Palliative care teams and MAiD teams have the potential to work together to support their end-of-life population (Ho et al., 2021; Pesut et al., 2021). Mathews et al. (2021) acknowledged that while there is a need to increase care coordination, palliative care access and services must be preserved while making room for the MAiD program. Pesut et al. (2021) discusses how both programs must increase their ability to share expertise. When palliative care and MAiD work together with a functional knowledge of each other's practice, it provides better quality service to the client (Pesut et al., 2021). The nurse storytellers in this research expressed a desire to see increased communication and collaboration between the MAiD team and PCCs as well as clients. They suggested that more collaboration with the MAiD team is needed to fill in the missing pieces and work through issues with clients before and after the procedure. The nurse storytellers also express the desire to increase care for clients considering MAiD as end-of-life option. They express the need for increased communication and service coordination as they navigate through the challenges of accommodating their client's requests for MAiD.

Nothing in Between Typology

As Frank (2010) described, stories will persist from one teller to another. The typology *nothing in between* is an example of similar narratives that establish the plot (Frank, 2010). The

persistent narrative from this research analysis is the gap between the MAiD and the palliative care program. The PCCs discuss the common issues that stand out in their practice. These include needing more support, contact, and coordination with the MAiD team. The typology evolved from the iterative process of going back and forth, rereading the data, and putting together the PCCs common concerns noted in the narrative resources. These topics were put into two categories: *nothing in between MAiD and the PCCs* and *nothing in between MAiD and the clients.*

The PCCs in this study shared their experiences with MAiD in practice. Each participant describes areas of the MAiD program that they feel are a challenge to them as a PCCs. One area discussed frequently by all PCCs was the lack of client education about end-of-life care. The palliative care nurses are responsible for educating their clients about their program, but the research finds they are also expected to know about the MAiD program because the two share the same end-of-life population (Ho et al., 2021; Pesut et al., 2021).

One nurse storyteller stated that if the clients have all the information, they need to decide how they want to die, MAiD may not be their choice. The nurse storytellers told us that clients and families are not necessarily informed about MAiD or palliative care. This was told using the narrative resources of *the lines get blurred*, *supporting how they wish to die, the day the IVs go in, I'm not part of that team*, and *the missing pieces of the puzzle.* The underlying plot informs the typology of *nothing in between* revealing that there are several gaps that create challenges for the palliative care team that have impacts (real or potential) on the MAiD team, and most importantly the clients and families navigating dying and death.

Current practice has the PCCs providing end-of-life education and answering questions about dying and death with the client and family. Nurse storytellers illuminated that

understanding of each other's programs would support the MAiD team, could make clients aware of good quality palliative care options before choosing MAiD, and PCCs could make clients aware of MAiD as one option for end-of-life. The nurse storytellers acknowledged that at this point, they believe that neither team is equipped or prepared to offer this education and that this should be further explored. Although the focus of the analysis is on the story of the palliative care nurse's experience of MAiD in practice, the client is their focus for care. The *nothing in between* typology revealed the nurse storyteller's thoughts about the relationship between MAiD and their practice as a palliative care nurse. The PCCs discuss how they feel disconnected from the MAiD team and are not able to provide the support that is needed for clients considering MAiD as an option. The PCCs are directing their clients to the website and telling them to discuss MAiD with their provider, but they would like to see a more formal communication process set up between clients and the MAiD team.

Both nurse storytellers describe a gap between their role in providing palliative care and MAiD and a need for something in between both teams. The nurse storytellers are aware of this gap because, with palliative care, they have a fully accessible program for their clients. They understand the process for clients to access the palliative care team, yet when clients want to know more about MAiD, they do not have the same confidence in accessing the service and therefore do not necessarily feel they are supporting their clients as they prefer to do. The nurse storytellers also shared that they believed that client's access to the MAiD team may not be as streamlined as the process to access palliative care. The findings suggest that consideration could be given to ways to fill in the gaps and increase access and support for both programs. Ho et al. (2021) discuss the lessons that may be learned from other countries with more advanced coordination between palliative care and MAiD programs. When PCPs work with the MAiD

team it can influence how people perceive their services and affect the trust in the palliative philosophy of a natural death (Fernandes et al., 2015; Ho et al., 2021). Wright et al. (2021) and Ho et al. share concerns about how involved the palliative care nurses should be with the MAiD care plan as it can add to public confusion between what the two services provide. When MAiD is discussed, it can move the care options away from the holistic approach and become more of a procedure (Ho et al., 2021). The PCCs in this research described building a trusting relationship with their clients when developing their end-of-life care plan. Pesut et al. (2021) reiterate that best practice requires this trusting relationship to support the end-of-life decision making process.

Finishing the Journey with Clients and Families

From the first visit when the client is admitted to the palliative care program, the PCCs provide the client and family with end-of-life support and education. These PCCs are specialists in end-of-life and strive to achieve a peaceful planned natural death for their clients However, MAiD is a legislated end-of-life option for all Canadians and PCCs find themselves with clients requiring information and education on this service as well. The PCCs explain to clients and family that they are not part of the MAiD team and refer them to the MAiD service. The PCCs continue to provide high quality care for their clients until the day the IVs are put in for MAiD. After the MAiD service has visited the home and MAiD is completed the PCCs return to provide their client's family members with bereavement services.

Nurse storyteller, Jean, described being told by colleagues how they "do as much as they possibly can" for their clients to help them communicate with the MAiD team even with no formal process in place. Both PCCs work together to provide bereavement services to their clients. Jean shares:

After the procedure is done, we are then left to kind of pick up the pieces and help these people through that time.

The findings from this study suggest that these PCCs would support improved accessibility for the client to talk with MAiD team and more support from the MAiD team before and after MAiD including improved ways for PCCs, clients, and family members to communicate with them. These nurse storytellers share that they would like to see increased collaboration throughout the process and more bereavement supports provided by the MAiD team for the family members after the MAiD process is completed.

The theory of comfort may provide insight into ways that MAiD and palliative care can collaborate to provide comfort to their shared end-of-life population. Kolcaba (1994) shares how the concepts of comfort theory when offered together have the potential to support the goal of holistic client comfort. To meet the desired level of comfort, Kolcaba's theory suggests that comfort measures be provided simultaneously to produce a greater overall comfort effect. This may provide opportunities for the PCCs to meet their clients end-of-life comfort needs, whether they choose a palliative natural death or MAiD.

Conscious Comfort

Kolcaba's mid-range theory of comfort was developed in the 1990s and used in describing comfort to measure relief, ease, and transcendence (Kolcaba, 1994). Lin et al. (2023) describe Kolcaba's Comfort Theory as the most universal theory used to measure comfort elements. Vicdan (2020) shares Kolcaba's definition of comfort, "helping the needs of an individual, providing tranquility and an expected result within physical, psychospiritual, social and environmental integrity towards overcoming the problems" (p. 30).

The PCCs in this research discuss how much client education and communication is needed to help their clients navigate through questions about MAiD and its distinction from palliative care as an end-of-life care option. The narrative resources highlight these issues shared by the nurse storytellers. They include *making sure to understand because lines get blurred, supporting how they wish to die, I'm not part of that team, I don't put in the IVs,* and *the missing pieces of the puzzle*. These highlighted areas offer opportunities for PCCs to promote improved comfort measures for clients at end-of-life. Kolcaba (1994) uses a conceptual framework for comfort that may guide PCCs in supporting the health care needs of their clients by addressing the intervening variables. Using Kolcaba's comfort theory may offer insight into how the typology of *nothing in between* could be addressed by using her framework to guide practice and improve communication between the MAiD team and the palliative care team.

Kolcaba (1994) maintains that overall comfort will be increased by focusing on three elements of comfort theory: relief, ease, and transcendence. The concept map of comforting measures at end-of-life illustrates how PCCs can set goals to provide their clients relief, ease, and transcendence. These goals aim to enhance physical, psychospiritual, environmental, and social comfort (Kolcaba, 2003). A modified example of the concept map for comfort comforting measures at end-of-life may be viewed in Appendix H.

Although Kolcaba's mid-range theory of comfort is described as a complicated concept, this theory aims to provide an overall feeling of pleasure and increased satisfaction. These feelings may increase confidence in decision-making and facilitate healing or aid in a peaceful death (Lin et al., 2023). In palliative care, comfort measures aim to reduce anxiety for PCCs, clients, and family members by helping them make difficult decisions about their end-of-life plan. Kolcaba's theory may offer insight into how what was revealed by the nurse's stories may

be able to inform nurses' practice to meet client's comprehensive care needs and help to set goals to achieve overall comfort.

The concept map of comfort measures at end-of-life (Appendix H) offers a way to present a detailed example of comfort measures that could be implemented for a client who is at end-of-life to meet their individual comfort needs by providing relief, ease, and transcendence. Each of these areas are reached by addressing a client's physical, psychospiritual, environmental, and sociocultural comfort needs. The conceptual framework modified for comfort at end-of-life (Appendix I) is an illustrated example of how applying comforting interventions can move the client towards health-seeking behaviors and achieving a peaceful death (Kolcaba, 2003). Open discussions about how to achieve client comfort measures may offer opportunities to develop relationships between the palliative care team and the MAiD team by increasing their opportunities to support client care.

In this chapter I discussed the findings from the shared experiences of the nurse storytellers. I expanded on the five narrative resources: *the lines get blurred, supporting how they wish to die, I'm not part of that team, the day the IVs are put in,* and *the missing pieces of the puzzle* in my study and how they relate to the literature. The typology *nothing in between* was established as the underlying plot of these resources that persisted from the analysis of the narratives. The findings from nurse storytellers also highlight some of the same narratives can be found in the literature review including:

- lack of knowledge by clients about palliative care,
- lack of knowledge by clients about dying and death
- lack of knowledge by clients about the difference between MAiD and palliative care
- lack of communication between MAiD teams and palliative care teams

- how improved relationships may improve care and increase the potential for these teams to work together to plan end-of-life care.

This chapter provided an opportunity to discuss the findings from this research analysis and present literature to support the shared experiences from the stories of the PCCs. Kolcaba's comfort theory was described as a theory that may offer opportunities for the MAiD team and palliative care team to connect using the common goal of overall client comfort at end-of-life. The next chapter will summarize this research and discuss the limitations, implications, and recommendations for future practice.

Chapter 6

Summary, Limitations, Implications, and Recommendations

Chapter six will be the final chapter concluding my thesis. In this chapter I will summarize the research study, discuss the limitations, implications for theory, implications for education, implications to practice, and present recommendations for future research.

Summary

This research study began with an introduction to the topic of MAiD. This opening discussion presents the law and MAiD, public perception and views, the experiences of clients and nurses, and a description of how the PEI IPCP works. This information supports the development of research questions exploring the shared experiences of the palliative care nurses who work in the IPCP program with clients who consider MAiD as an end-of-life option. A literature review was then performed regarding the subject of MAiD from the perspective of PCPs (PCPs) focusing on the involvement of palliative care nurses. Some fundamental topics from the review include palliative care and its philosophy of a natural death, access to palliative care services, clients who request MAiD, the relationships between PCPs and MAiD providers, and the coordination of services between palliative care and MAiD. The result of the review determined that more research is required to explore the knowledge and perspective of palliative care nurses with MAiD in practice (Mathews et al., 2021; Ward et al., 2021). To explore this gap in knowledge, Arthur Frank's (2012) dialogical narrative analysis (DNA) was chosen as the form of narrative inquiry to serve as the methodology. DNA is a form of storytelling that allows the teller to consider their sense of self. Frank's method is committed to representing life experiences and was used to explore the stories of palliative care nurses. Frank (2012) states that the foundation of his method is committed to:

- observing the voice of the storyteller and the multiple voices within
- be cautious of the story of one individual as we must listen to the collective voices
- consider that stories come from the borrowed parts of others stories
- understand that the PCCs story has the capacity to change over time
- consider and reflect upon all the ways to understand the story as people's lives, relationships, and stories change over time.

After ethics approval was obtained from the PEI Ethics Board (Appendix J) and the University of Prince Edward Island (UPEI) Ethics Board, PCCs were recruited from the nurses working with the IPCP in PEI. Two PCCs volunteered to share their stories. I supported a comfortable sharing environment for the nurse storytellers by choosing a quiet location in a booked room at UPEI where they were away from their workspace and free from interruptions. I reviewed the consent form with the PCCs and reminded them that they have the option to withdraw from the research. I was conscious of my personal movements and focusing on maintaining eye contact with the participant during the interview. This study presented minimal risks to participants. The researcher did not observe any signs of distress during the interview sessions that would require rescheduling or debriefing.

The interviews were recorded and after each interview I took notes on anything that stood out to me about the subject or their story. The interviews were transcribed verbatim by a transcriptionist. My supervisor, Dr. Patrice Drake, reviewed the transcripts with me. All information that could identify the participant, client, or family member was removed from the transcribed interviews. My supervisor and I independently reviewed the interviews and selected significant quotes from each participant. We compared our selections and found them to be synonymous.

The interviews and the individual quotes from them were read and reread in an iterative process to let the narrative resources emerge from the data (Frank, 2020). Narrative resources are conceptual tools used to tell stories by the teller. These tools guide the listener and the teller in understanding the story by recognizing familiar narratives (Frank, 2010). Five narrative resources *the lines get blurred, supporting how they wish to die, I'm not part of that team, the day the IVs go in,* and *the missing pieces of the puzzle* were chosen and reviewed by my supervisor and co-supervisors. These narrative resources lead to the discovery of the typology *nothing in between* which represents the PCCs discussion on lack of resources and support between the palliative care services and the MAiD service. The discussion following the analysis shared literature that supported the nurse storytellers by confirming their experiences and highlighting how MAiD programs and palliative care programs have improved their coordination by developing improved working relationships.

Limitations

This study has several limitations that may influence findings. Throughout the study I navigated these possibilities to add to trustworthiness.

In my nursing practice I work with the PCCs on a regular basis and may have preconceived ideas about how MAiD affects palliative care. The PCCs have worked with me in the past and this also may have affected the information they choose to share or not share in the interview process. Frank (2010) expresses how the listener may become caught up in one version of the story. Sometimes this may be a legitimate form of the story but one which the listener has become too familiar with. This can be considered as a caution to the validity of the listeners awareness and response to the stories (Frank, 2010). The analyst listens to multiple stories about similar experiences and finds ways to connect the stories. Frank (2010) expresses that putting too

much emphasis on the verification of stories may pose limits to the analysis of their data. For this research the data was validated by reviewing the notes, transcripts, and voice recordings to see if the information was measuring what was intended (Polit & Beck, 2021). Although as the researcher I may have preconceived ideas about the research topic, the research process and data triangulation were implemented to limit the impact of this.

There are some other limitations of this research that should be considered. To begin with, the sample size of two PCCs is small, and as a result may not represent the opinions and perspectives on MAiD by all palliative care nurses. These two nurse storytellers shared several narrative resources but also had diverse perspectives. Mathews et al. (2021) discuss how in their study conscious objectors declined to identify themselves and that there may be a stigma that creates this hesitation. The nurse storytellers of this study requested not to be identified based on religious or moral perspectives of assisted dying. To respect this request the topic of moral identity has not been discussed in this research. This area still remains as an important research area to be further investigated. HCPs describe ethical and professional dilemmas around MAiD, especially around the time that the procedure should be implemented in the end-of-life plan (Mathews et al., 2021).

The nurse storytellers did not have prior knowledge to the questions. Mathews et al. (2021) state that providing the questions in advance may have allowed the participants to have developed more comprehensive responses.

Additionally, the first passing of MAiD was in 2016. Although policies have been developed, this law is relatively new and there have been recent updates to legislation. This does not provide enough time for our healthcare organization to develop and implement policies for these changes surrounding the practice of MAiD and how it relates to palliative care planning.

Also, MAiD policies are developed provincially, this leads to a variation in how palliative care programs are working with their MAiD teams across the country. This may cause the results to be less relatable as the nurse storytellers are PCCs from one province.

Implications for Practice

Despite the controversy surrounding the topic of MAiD there remains limited research in how palliative care nursing experiences MAiD in their practice. The stories from the PCCs in this research study suggest that recommendations may be made that can influence practice and future research.

When clients and families face end-of-life decisions nurses and other health care professionals need to consider the challenges involved. The client and family may require education and support from their health care provider or palliative care program to develop the care plan. The PCCs are in the position to provide high quality palliative care for their clients by initiating the assessment process and setting up the support required to keep the client at home. The role of the PCC is not currently to support the MAiD process, but they find themselves in a position that requires them to be involved. There is currently no national guidance to set the standard for collaboration between palliative care programs and MAiD programs. Each province has their own policies and procedures for how they work to coordinate palliative care and MAiD services to their clients (Pesut et al., 2021). Developing a system of care coordination between these two programs may benefit the PCCs, client, family members, and the MAiD providers. Other Canadian provinces, like British Columbia and Ontario have implemented a more advanced system of care coordination between palliative care and MAiD (Pesut et al., 2021). In these areas where MAiD nurse coordinators practice, they perform an advanced practice role of providing education to HCPs and the public, developing policies, and connecting HCPs involved

when clients choose a MAiD death (Pesut et al., 2021). These programs may offer support to develop and strengthen the care coordination between these two programs in PEI. Improved collaboration may allow the PCCs to focus on their care plan for a natural death while providing support for their clients who consider the option of MAiD.

Implications for Theory

Khan (2017) expresses that nursing has contributed a unique body of knowledge to the healthcare profession. Nursing theories are developed from practice to guide nursing and set the structure for everyday practice (Khan, 2017). Developed in the 1990s, Katharine Kolcaba's middle range Comfort Theory (Kolcaba, 1994) has been continually modified to meet advancements in healthcare. This theory aims to determine comfort needs and establish the interventions required to meet the level of comfort desired by the patient and family. According to Kolcaba (1994) the three distinct types of comfort include relief, ease, and transcendence. She elaborates on these needs being reached by using each in the individual contexts of physical, psychospiritual, environmental, and sociocultural. I have expanded the concept map of comfort measures at end-of-life by adding comfort concepts that the IPCP addresses for home care clients when making an advanced care plan (Appendix I) and simplified the conceptual framework for comfort at end-of-life by focusing on concepts (Appendix J) that address the client needs as faced by the PCPs Using comfort interventions, supported by the health care institution, the goal is to have the client realize a state of relief, ease, and transcendence (Vicdan, 2020). This process aims to apply the chosen health seeking behaviors and support a peaceful death. Using this middle range theory to address the needs of clients diagnosed with a life-ending illness offers an opportunity to further develop use of the theory by end-of-life care providers. Using Comfort Theory to guide this research may offer opportunities for the palliative care team and the MAiD

team to enhance their working relationship by collaborating to achieve desired comfort measures for their shared population of clients making end-of-life decisions.

Implications for Education

The implications for education resulting from this research may influence clients, families, PCPs, student learners, and other health care providers that are involved in the end-of-life care planning process. Increased awareness may change public perception to allow for the recognition that palliative care is a plan for a natural death and MAiD is a separate option for end-of-life care. Expanding the understanding of how these two programs work and providing education to the HCPs involved aims to decrease the confusion between how MAiD and palliative care services operate. Sharing research findings through journals and conferences will contribute to the increased level of education for HCPs. I will present these findings locally, regionally, and internationally at any opportunity that presents itself.

It is imperative to establish a way to disseminate findings to the PCPs and MAiD providers in PEI as well as the other provinces who are trying to deliver enhanced end-of-life services. With improved education and awareness of these programs we may change the current perception of palliative care and MAiD and create a new awareness of how these programs can communicate. The end goal will be to provide quality end-of-life options that are better understood by everyone.

Recommendations for Future Research

The results from this research may be significant for the planning and implementing of future research in narrative inquiry to expand on the stories of the palliative care nurses and their experiences with MAiD in practice. The two PCCs interviewed highlighted comparable concepts in their discussion. These concepts described opportunities to increase education and

coordination of services between palliative care and MAiD. These teams work with the same end-of-life client population who required specialized services in dying and death. The literature suggests that improving education for both PCCs and the MAiD team will improve their working relationships with each other and their clients. Also, working to provide comfort measures to this population may give these teams a common framework to follow in creating care coordination. Opportunities exist to invite storytellers from different geographical locations to participate in narrative inquiry and share their stories. PCPs will benefit from the practice experience and knowledge that is being used and shared in other provinces as Canada navigates the ever-changing MAiD legislation as an end-of-life care option.

Dissemination of Findings

The study findings will be shared through an oral thesis defense and will be presented in a public presentation at the UPEI Faculty of Nursing for nursing students and faculty. Once the examining committee has approved the thesis and final revisions are completed, it will be submitted to Island Scholar. A manuscript article will also be prepared for publication in a peer-reviewed journal. Also, opportunities to present this research at local, regional, and national conferences will be sought out.

Ending With Gratitude

This study explored the stories of two PCCs and their experiences with MAiD in PEI. Two PCCs shared stories of experiences when their clients consider MAiD as an end-of-life option. The PCCs discuss moments of hesitation in their approach to handling MAiD in practice and they each have individual ways to cope. Their stories share the common experience of lack of connection between the palliative care team and the MAiD team. These nurse storytellers discuss examples from practice and highlight ways that the MAiD team could offer increased

support to end-of-life care planning. Future research may clarify what supports would allow these two services, who work with the same population of clients at end-of-life, to better coordinate.

I am grateful for the narratives shared by these nurses and how this dialogue offers the potential for change in practice. These nurses are the specialists in end-of-life care, and they offer insight into how other PCCs may perceive MAiD in practice. There stories may inspire future practice by considering how palliative care and MAiD working together could contribute to enhanced end-of-life care. I am grateful for this opportunity to provide a potential new narrative to palliative care nurses experiencing challenges with MAiD in practice, I am appreciative of the storytellers and the stories they have shared.

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Appendix A
Ethics Approval

Health PEI
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PEI Research Ethics Board

16 Garfield Street
PO Box 2000, Charlottetown Prince Edward Island. Canada C1A 7N8
www.healthpei.ca

Date: August 23, 2023

Rebecca MacLure
322 Lower Malpeque Road Charlottetown PE
C1E 1S8

Dear Rebecca;

Comite d'ethique de la recherche de l'I.-P.-E.

16, rue Garfield C.P. 2000, Charlottetown ̂Ile-du-Prince-Edouard, Canada C1A 7N8
www.healthpei.ca

RE: Project Title: ***Medical Assistance in Dying (MAiD) from the Perspective of the Registered Nurse Working in Palliative Care***
Principal Investigator: Rebecca MacLure

The above noted study was granted conditional approval on August 14, 2023. Thank you for providing the revised documents listed below;

- \- Email Summary of changes
- \- Revised Full Proposal (with tracked changes);

• Appendix E: Information Letter & Consent Form

I am pleased to advise you that full approval has been granted for the above noted study. This study was reviewed according to ICH GCP guidelines and will require an annual report and request for re-approval to be in place prior to August 23, 2023.

Notification of closure is required once the study is completed or terminates early. The "Continuing Review Reporting Requirements"; the "Reporting Study Closure and/or Early Termination"; and the "Request for Annual Approval" forms can be found on the Health PEI website under the PEI Research Ethics Board link.

ATTESTATION: This Research Ethics Board complies with Division 5 of the Food and Drug Regulations, the ICH Harmonized Tripartite Guidelines: Good Clinical Practice, and the Tri-Council Policy Statement.

Sincerely,

Name: Kathryn Bigsby, MD, FRCPC Title: Chair, PEI Research Ethics Board

Tel/Tel.:902 569 0576 *healthpei.ca* Fax/Telec : 902 368 6136

Appendix B

Email for Nursing Manager of the Integrated Palliative Care Program (IPCP)

Hello (Nurse Manager of Nursing for IPCP)

My name is Rebecca MacLure. I am a Master of Nursing Student with the University of Prince Edward Island Faculty of Nursing.

This email is to share information about a research project I am conducting for my master's program. The study is titled *Medical Assistance in Dying (MAiD) from the Perspective of the Palliative Registered Nurse*. This research aims to ask palliative care nurses who work in the Integrated Palliative Care Program (IPCP) to share their experiences with MAiD. The study has received approval from the UPEI Research Ethics Board and the PEI Research Ethics Board. This research will contribute to understanding the experiences of palliative care nurses working with patients considering the option of MAiD for end-of-life care.

I request your permission to access the palliative care nurses who have worked or are working in IPCP to participate in this study by sharing their experiences with MAiD. I attached an email invitation to be sent to registered nurses in the IPCP program. I would appreciate it if you would forward it to them. I also attached a recruitment poster to be displayed on the wall in their work area.

I would appreciate your support in conducting this research. Please feel free to contact me with any questions. You can also contact my supervisors:

Dr. Patrice Drake
mpdrake@upei.ca
902-566-0757

Rianne Carragher MN NP PhD(c),
rcarragher@upei.ca
(902) 620-5193

Thank you,

Rebecca MacLure BScN, RN
Master's Student, Faculty of Nursing at UPEI
rmaclure@upei.ca
902-218-2719

Appendix C

Email Invitation for Nurse Participants

Research Title: Medical Assistance in Dying (MAiD) from the Perspective of the Palliative Registered Nurse

Researcher:

Rebecca MacLure BScN, R.N., Master of Nursing Student, UPEI Faculty of Nursing

Supervisors:

Dr. Patrice Drake, Associate Dean (Interim), Assistant Professor, UPEI Faculty of Nursing

Rianne Carragher MN NP Ph.D.(c), Assistant Professor, UPEI Faculty of Nursing.

I am a registered nurse and a master's student at UPEI Faculty of Nursing. I would like to invite nurses who currently work or have worked in the PEI Integrated Palliative Care Program (IPCP) to participate in this study. This research will explore the stories of palliative nurses and their experiences with patients who consider MAiD as an end-of-life option.

Palliative nurses who choose to be in the study will participate in an interview about their experiences with MAiD in their practice within the IPCP. If you would like to participate in this study or have any questions about the study, please contact Rebecca MacLure at **rmaclure@upei.ca** or (902) 218-2719. You may also contact my supervisors, Dr. Patrice Drake at (902) 566-0757 or **mpdrake@upei.ca** or Rianne Carragher at (902) 620-5193 or **rcarragher@upei.ca**.

Thank you,

Rebecca MacLure BScN, RN

Master's Student, Faculty of Nursing at UPEI

rmaclure@upei.ca

902-218-2719

Appendix D

Study Recruitment Poster

University of Prince Edward Island Faculty of Nursing

Medical Assistance in Dying (MAiD) from the Perspective of the Nurse Working in Palliative Care

Are you currently working, or have you worked with the Integrated Palliative Care Program (IPCP) as a registered nurse?

I am a registered nurse and a master's student at UPEI Faculty of Nursing. I would like to invite nurses who currently work or have worked in the PEI Integrated Palliative Care Program (IPCP) to participate in this study. This research will explore the stories of palliative nurses and their experiences with patients who consider MAiD as an end-of-life option.

Palliative nurses who choose to be in the study will participate in a 30 to 60 minute confidential interview about their experiences with MAiD in their practice within the IPCP. If you would like to participate in this study or have any questions about the study, please contact Rebecca MacLure at rmaclure@upei.ca or (902) 218-2719. You may also contact my supervisors, Dr. Patrice Drake at (902) 566-0757 or mpdrake@upei.ca or Rianne Carragher at (902) 620-5193 or rcarragher@upei.ca.

Thank you,
Rebecca MacLure BScN, RN
Master's Student, Faculty of Nursing at UPEI
rmaclure@upei.ca
902-218-2719

Appendix E

Information Letter and Consent Form

Study Title: Medical Assistance in Dying (MAiD) from the Perspective of the Palliative Registered Nurse

Researcher:
Rebecca MacLure BScN, RN
Master of Nursing Student
UPEI Faculty of Nursing
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902-218-2719

Supervisors:
Dr. Patrice Drake, RN
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902-566-0757

Rianne Carragher MN, NP, PhD(c)
UPEI Faculty of Nursing
rcarragher@upei.ca
902-620-5193

You have been invited to participate in a study that asks for the stories of registered nurses who currently work in the Integrated Palliative Care Program (IPCP) or have worked in the IPCP about their experiences caring for patients who consider MAiD as an end-of-life option. Your support is important for this study to be a success.

End-of-life decisions are important to patients, families, and those who care for them. Palliative care nurses report challenges in caring for patients and their families when they request the option of Medical Assistance in Dying (MAiD). Even though this option for end-of-life care is becoming more frequent, there is limited research to describe the experience of registered nurses working in palliative care with patients who choose MAiD. Patients and palliative care nurses report challenges in their experiences related to MAiD requests, and these challenges have been reported to affect patient outcomes for end-of-life care.

This study is recruiting palliative care nurses willing to share stories about their experiences caring for palliative care patients who request MAiD. We are interested in all points of view.

The results of this study will be used to support my thesis to complete my Master of Nursing.

Purpose

The purpose of this research is to hear and understand the stories of palliative care nurses caring for patients who request MAiD. I believe these stories will provide an opportunity to better understand their experiences and increase their confidence in providing care for patients and families as they make end-of-life care decisions.

Study Procedures

If you agree to participate, you may participate in one or more interviews with Rebecca MacLure.

These interviews will be recorded and then transcribed. The transcriptionist will sign a confidentiality agreement. Your name and other identifying characteristics will not be included in the transcribed interview.

Each interview will take about 30 to 60 minutes. This will be on your own personal time.

After your interview(s) have been transcribed, anything that could identify you, your patient, or their family members, will be removed from the transcript. This document will be shared with you so you can clarify or remove any part of the information you have shared. You will have ten days from receiving your transcript to provide feedback to me.

Benefits

You are not expected to receive any benefit from participating in this research study. The study findings may help other palliative care nurses and the nursing profession to improve care practices related to palliative care and MAiD.

Risks

There are no anticipated risks if you choose to take part in the interview. It is possible that our discussion may raise uncomfortable memories or feelings. You do not need to answer any questions that you are uncomfortable with. Participants will be offered an option for a debriefing session if any distress has emerged from their interview session. Debriefing will be available through the Employee Assistance Program (EAP) available free to all employees and family members of those working for Health PEI.

Voluntary Participation

Your participation in this research project is completely voluntary.

Freedom to Withdraw

After agreeing to be in the study, you can decide to withdraw. If you do decide to withdraw, all your information will not be included in the study.

The last date to withdraw your information will be four weeks after the interview. This is when the interview will have been transcribed and analysis initiated.

Confidentiality & Anonymity

What you say during the interview will be kept confidential within the law by investigators.

Direct quotes from the interview may be used in final reports and presentations. Still, they will be stripped of your identity. Your story will be presented with the stories of other registered nurses.

The interview will be audio recorded. A transcriptionist will transcribe the information. Only the researcher and their supervisors will have access to the transcripts.

The analysis and findings of this study will form the foundation for my emerging program of research. There may be a benefit in re-examining the findings from this study in future work in this field. If so, the University of Prince Edward Island Research Ethics Board and the PEI Research Ethics Board will first review the study to ensure the information is used ethically.

Additional Contacts

If you have any questions about the project, you can contact Rebecca MacLure, rmaclure@upei.ca 902-218-2719.

You may also contact my supervisors:

Dr. Patrice Drake, UPEI Faculty of Nursing
mpdrake@upei.ca
902-566-0757

Rianne Carragher MN NP Ph.D.(c), UPEI Faculty of Nursing
rcarragher@upei.ca
(902) 620-5193

This study has been reviewed for its adherence to ethical guidelines and approved by the University of Prince Edward Island Research Ethics Board and the Prince Edward Island Research Ethics Board. If you have any questions regarding your rights as a research participant, you may contact the Prince Edward Island Research Ethics Board at 902-569-0576 or the University of Prince Edward Island Research Ethics Board at 902-620-5104.

I understand the information I have been provided about this research study. I have had time to review the study information and research questions. I have enough information to decide whether to participate in this study. I am willing to participate in the interview.

Do you understand that you have been asked to be in a research study? Yes No

Have you read and received a copy of the attached information sheet? Yes No

Do you understand that you are free to leave the study at any time? Yes No
(Without giving a reason or without penalty)

Has the issue of confidentiality been explained to you? Yes No

Do you understand who will have access to your study records? Yes No

Who explained this study to you? ___________________________

Signature of Research Participant: ___________________________

Name of Research Participant (Printed Name)

Date: ________________________________

Signature of Investigator: ____________________________________

Date: _______________________________

adapted from Dr. Patrice Drake, 2022

Appendix F
Interview Guide

Thank you for agreeing to participate in this interview. Your input is essential and invaluable to this project.

The purpose of this interview is to document your experience of patients who consider *medical assistance in dying or* MAiD as an end-of-life option. I am using a research methodology called narrative inquiry. Narrative inquiry uses stories to understand experiences.

This interview is comparable to a conversation and should take no more than 30-60 minutes to complete. Also, I may contact you a second time to revisit this first interview and further clarify your experience. I am audio-taping the interviews to ensure that what you say is accurately documented.

There is no right or wrong answer as this is your story and your experience. Tell me in the way that is most comfortable for you.

Do you have any questions about the consent?

No – Thank you. We can sign the consent and I will give you a copy. I would like to remind you that you can withdraw your consent at any time.

Yes - [Answer any questions or concerns] I would be happy to review the consent with you and answer any questions you may have about the project. When you are confident that your questions have been answered, you can decide about participating and sign the consent.

If there are still issues or concerns – Thank you for your time. If you change your mind, please feel free to contact me.

Once informed consent has been obtained

I am going to start to audio-record now. You may ask to have it turned off at any time during the interview if you would like a break. Please remember you do not have to answer any question you are uncomfortable with.

Audio-recorder on

I will begin with a question. Please ask if you want to have the question read again.

Opening questions

1. Would you please start by telling me about your role as a registered nurse in the integrated palliative care program (IPCP)?
2. Please tell me a story about a time in your practice in the IPCP when you cared for a patient who considered MAiD as an end-of-life option.

Probing Question

3. Is this your first time sharing this experience? How long have you waited to share this story as you have just told it?
4. How might others tell this story differently? Do these stories make it easier or harder to tell your story?
5. Would you have liked to have had a different ending to the story?
6. Would you have told this story differently at a different point in your career?

Final Question

7. Is there anything else you would like to share that we have not yet talked about today?

Audio-recorder off

Thank you for your time and for sharing your story. I would like to contact you again to revisit this interview and clarify any questions that may arise as I work on my study. Your responses are confidential, and you cannot be identified; however, after I interviewed other nurses, there may be other questions I wanted to ask you that I did not in this first interview.

adapted from Dr. Patrice Drake, 2022

Appendix G

Confidentiality Agreement for Transcription

I, the undersigned, agree not to discuss, share, or transmit (i.e., electronic files) the information learned from transcribing one on one interviews with anyone other than Rebecca Maclure, UPEI Master of Nursing Student of the *Medical Assistance in Dying (MAiD) from the Perspective of the Palliative Registered Nurse* study.

The encrypted flash drive containing the completed password protected transcripts will be returned to the researcher and any electronic files will be deleted from my computer 30 days (about 4 and a half weeks) after giving it to Rebecca MacLure, UPEI Master of Nursing Student.

I have been given a copy of this agreement for my records.

Transcriptionist Signature ____________________ Date ________________

UPEI Master of Nursing Student signature ____________________ Date ______________

Appendix H

Analysis Guide

Consider

- Why did I want to study the experiences of palliative care nurses with MAiD?
- What did I know about the day to day of the nurse who works with patients at end-of-life?
- I needed to listen to the stories that call out to be told.

Needed to begin with the narrative resource questions.

- What narrative resources do palliative care nurses use to shape the story?
- What narrative resources shape how I, as the listener, understand the story?
- How were the narrative resources shared between different nurses?
- What are the limits of resources for palliative care nurses?

Asked the primary resource questions to see what may influence the creation of new resources.

- What stories are already circulating?
- What was familiar about those stories (recognizable characters, plot lines, genre choices, and common metaphors)?
- If there were other narrative resources available, would the story have been different?
- Would the palliative care nurses have had the opportunity to pursue a different storyline?
- What prevented alternative narrative resources from being pursued or introduced?

How did/do the stories circulate within the group?

- Whom did the palliative care nurses tell their stories to?
- If palliative care nurses practice in a closed system, how do they tell their stories? What codes do they use?

How are the storytellers linked or what are their affiliations?

- Who were the palliative care nurses that shared a common understanding of the story?
- Who did not understand the palliative care nurses' stories or who was rendered an outsider?
- Who was excluded from the "we" who share the story?

What did the stories tell us about the storytellers?

- How did the story teach the palliative care nurses who they are?
- How did the palliative care nurses use the story to explore who they might become?
- I need to remember that stories are made up of stock identities.

What was at stake by telling the stories?

- How did the palliative nurses hold their own in the story by telling the story in the way that they did?
- How did the stories convince the palliative care nurses of who they needed to be and what they had to do to hold their own?
- I must remember that holding one's own is a response to being vulnerable.
- What made palliative care nurses vulnerable?

What typologies or narrative types are revealed to us for this project?

- An iterative process of using the questions above.
- Re-reading of both transcripts and answers to the above questions to do the following:
    - Understand how the available range of narrative resources limits the storytellers.
    - Assess how well served palliative care nurses are by their stories.
    - Determine how typology helps palliative care nurses hold their own.
    -

What is the ending of THIS story, knowing that there are others to be told?

- Write an appreciation for the story and the storytellers.
- Who does this story bring together and who is moved outside by the story (and what is the consequence of this)?
- Recognize the power of imagination to affect people's storied lives.
-

*Adapted from Frank, A. W. (2012). Practicing dialogical narrative analysis. In J. A. Holstein & J. F. Gubrium (Eds.), Varieties of narrative analysis (pp. 32–50). Sage. https://dx.doi.org/10.4135/9781506335117.n3

adapted from Dr. Patrice Drake, 2022

Appendix I

Concept Map of Comforting Measures at End-of-Life

Modified from Kolcaba (2003)

Kolcaba (2003) describes how using a visual guide to view holistic care aids in the definition of comfort. She shares how comfort is patient focused and it is a complex process to attempt to reach comfort in all areas simultaneously. Each cell is interconnected and by developing a pattern of care, comfort needs may be assessed in all three types and contexts. Kolcaba uses the interventions not only for advanced directives but also for healing and recovery. Although reaching a state of comfort in every cell would be rare in healthcare settings, the goal is to improve the level of comfort from the patient's baseline.

Table 1

Concept Map	Relief – specific comfort needs met	Ease – state of contentment	Transcendence – rise above the challenge
Physical	Chronic disease issues and symptoms being managed by PCPs.	Therapies continue with pharmacological and non-pharmacological strategies. When clients and family members receive education on MAiD and palliative care options it aids in overall contentment.	Symptom control using methods provided may relieve physical challenges. When clients choose Goals of Care for end-of-life they rise above this difficult decision-making challenge.
Psychospiritual	Anxiety related to decline in health is relieved by providing resources and guidance for clients and family members.	Encourage discussion and education for decision making for difficult end-of-life decisions (funeral home/burial/cremation)	Anxieties decrease when patient and family are supported in ACP with mental health and spiritual supports.

Environmental	Being removed from noisy, cold, busy area of home, LTC, or hospital to quiet place of home or palliative care center for final moments provides relief.	Support chosen space and reassessed comfort measures to promote peaceful environment.	Patient supported in **chosen**, peaceful environment with comfort needs. Choosing perhaps to die at home with family at their side.
Sociocultural	Addressing cultural or traditionally sensitive care required to surround client and family with their chosen people and customs to provide relief.	Find out how family is available to support cultural, language or financial barriers. A natural death may be more accepted in some cultures.	Challenges are reduced when nursing supports are in place and spiritual needs are met for the end-of-life care plan.

The following definitions expand on the concepts used in the table above:

Relief

- specific needs are met such as pain, comfort is experienced in the sense of relief.
- provide relief as a result of client and family coming together to make the advanced care plan.

Ease

- comfort for ease of mind; for example, addressing anxiety.
- providing the client and their family with education about what is palliative care and what is MAiD.

Transcendence

- the state of comfort achieved when patients can rise above health care challenges.
- enhanced with decision-making processes that include loved ones.

Physical

- bodily sensations, homeostatic mechanisms, and immune function.
- providing symptom management for end-of-life.

Psychospiritual

- pertaining to internal awareness of self, self-esteem, identity, sexuality, meaning of life, relationship to higher being.
- comfort with choices and the comfort of family members with those choices.

Sociocultural

- interpersonal, family, and societal relationships, finances, teaching, health care providers etc.
- traditions, rituals, and religious practices that may be part of end-of-life practices.

Environmental

- external background of human experience that impacts the patient's quality of life.
- providing a comfortable environment for the time of death.

Appendix J

Conceptual Framework Modified for Comfort at End-of-life
Modified from Kolcaba (2003).

Kolcaba (2003) describes how nurses identify and design comfort interventions for patients and their families when developing a care plan. The PCCs use advanced care planning (ACP) to develop comfort interventions and communicate with patients and family members ways to achieve the goal of desired comfort and a peaceful death. Kolcaba (2003) suggests that institutional support is required to aid nurses in setting and achieving the health seeking behaviours chosen by the patients and their family members.