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How do Palliative Care Registered Nurses Apply Concepts of Ethical Decision-Making When
Caring for Patients who Request Medical Assistance in Dying?

An Interpretive Descriptive Qualitative Study

By

Lauren Kopchek

A Thesis
Submitted to the Faculty of Graduate Studies
through the Faculty of Nursing
in Partial Fulfillment of the Requirements for
the Degree of Master of Science in Nursing
at the University of Windsor

Windsor, Ontario, Canada

2020

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January 15, 2020

DECLARATION OF ORIGINALITY

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ABSTRACT

Changing international legislation is challenging views about the ethics of assisted dying and palliative care. In 2016, assisted death was decriminalized in Canada and termed, Medical Assistance in Dying (MAiD). In the midst of this happening, Canadian palliative care nurses began the process of trying to make sense of new rules, scope of practice, government regulations related to MAiD, and its fit with the philosophy of palliative care which seeks to not hasten death. Limited Canadian studies have explored nurse experiences with assisted dying, and even fewer were completed after the legalization of MAiD. The international literature indicates that nurses who are involved in assisted death experience emotional and/or ethical distress. While provisions for conscientious objection is available for Canadian nurses, it is not known how palliative care nurses experience the ethical decisions associated with MAiD. This study explored the ethical decision-making experiences of Ontario palliative care nurses related to MAiD. The study findings highlight patient autonomy as the foundational principle upon which palliative care nurses make decisions. Additional education, support, and ethical decision-making training for palliative care nurses related to MAiD is emphasized.

DEDICATION

I wish to dedicate this to my husband, Dave. Thank you for pushing me when I needed it, your support means the world to me.

ACKNOWLEDGEMENTS

I've intuitively known that I would make a difference and contribute to the nursing profession. Although, my path varied throughout the years, there was always a pull to pursue or try new things during my career. I want to thank my advisor, Dr. Pfaff for helping me realize the love of research. Your insight, knowledge and guidance has been inspirational and I appreciate everything you have done.

To my thesis committee, Dr. McMurphy and Dr. Freeman, thank you for encouraging me throughout this process. I will be forever grateful for the knowledge and expertise that allowed me to complete my thesis.

To the Faculty of Nursing, thank you for all your help and support during my academic career.

To my parents whose love and support continue to amaze me. Your unconditional love has allowed me to spread my wings and make a difference in this world. To the nurses who care for patients who face daily struggles related to life limiting diagnoses, I did this study to make a difference in the care we provide to our patients. I want nurses to have the support and education needed to provide the best care possible to their patients. Finally, to the palliative patients I have cared for, you have given me the ultimate gift - to live each day to the fullest. Thank you.

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CHAPTER 1

INTRODUCTION

A momentous decision in 2015 by the Supreme Court of Canada resulted in the decriminalization of physician assisted dying throughout Canada (Government of Canada, 2016). Bill C-14, an act to amend the criminal code, came into law on June 17, 2016 (Parliament of Canada, n.d). Medical Assistance in Dying (MAiD) is the term used in Canada to describe the administration or provision of a substance by a doctor or nurse practitioner when administered to hasten a person's death (Dying with Dignity, 2015). The Canadian umbrella term, MAiD, includes both Physician Assisted Suicide/Death (PAS/D) and euthanasia. PAS/D encompasses the act of a medical doctor providing a lethal dose of medication that a person self-administers at a time that is determined by the person (Abrahao et al., 2016; Denier, Dierckx de CasterlÃ, De Bal, & Gastmans, 2008); Government of Canada, 2016). Euthanasia requires the active participation of a healthcare provider to deliver the lethal dose of medication when the patient is unable or unwilling to self-administer (Abrahao et al., 2016; Denier et al., 2008; De Lima et al., 2017; Government of Canada, 2016).

MAiD is an ethically charged topic for many Canadians and remains worrisome for many health care professionals, including palliative care nurses. In the wake of Canada's legislation, health care organizations had little time to develop policies and procedures for MAiD, and there was limited international literature available to guide its integration. In the case of palliative care nurses, the legislation directly conflicts with the palliative care philosophy to not hasten death (World Health Organization, 2016). The position statement of the International Association for Hospice and Palliative Care (IAHPC) argues against any participation in acts that unnaturally accelerate death.

Many palliative care experts assert that access to quality palliative care must be provided before assisted death is discussed (De Lima et al., 2017). Petrillo and colleagues (2017) reported that individuals who express uncontrolled symptoms of pain or suffering are often not aware of palliative care services and therefore ask for an assisted death (Petrillo et al., 2017). According to De Lima and colleagues, (2017), much of the world's population does not have access to palliative care, and this is greatest in areas of low-income individuals (De Lima, et al., 2017). Patients often present to the healthcare system in the latent phases of their disease and disease progression may be too far advanced to receive symptom management (De Lima et al., 2017). In turn, patients may feel the need to turn to an assisted death for fear of uncontrolled symptoms or a painful death (De Lima et al., 2017). Petrillo and colleagues (2017) argue that it is imperative that palliative care be implemented and equally accessible to all individuals.

For the above reasons, participation in a medical act that causes death may cause moral and ethical distress among palliative care nurses who respect adherence to the tenets of palliative care practice. This ethical distress may lead to nurse burnout and absenteeism, which in turn can affect employee retention. In a recent Canadian study, Ontario palliative care nurses reported the need for comprehensive policies, education and debriefing for nurses related to MAiD (Freeman, Pfaff, Kopchek, & Liebman, 2019). They also overwhelmingly requested training for ethical decision-making related to MAiD (Freeman et al., 2019). This thesis describes the literature, conceptual framework and methods used to explore how palliative care registered nurses (RNs) apply concepts of ethical decision-making when caring for patients who request MAiD.

Significance of the Issue

The Carter versus Canada case was heard by the Supreme Court of Canada and led to the decision to change the law regarding euthanasia. Current Canadian end of life practices, such as

palliative sedation and withholding medical treatments/withdrawing life sustaining measures were reviewed by the Supreme Court judges (Government of Canada, 2015). These legal practices are performed under strict guidelines for palliative patients who fit the criteria for use. Although some individuals view the practice as having an effect of hastening death, strong societal consensus view these practices as being ethically acceptable (Government of Canada, 2015). The Supreme Court examined evidence from ethicists and found no ethical distinction between assisted death and other end of life practices that were currently used (Government of Canada, 2015). Furthermore, the judge found that some Canadian physicians did find it ethical to perform an assisted death, and they would do so if the law allowed it. Therefore, the trial judge concluded there was no societal consensus that MAiD was ethically acceptable, but that an informed, competent adult with a terminal illness should have his or her wishes respected (Government of Canada, 2015). The unanimous decision spoke loudly and clearly across the globe that Canadians are viewing death and dying in a progressive manner (Government of Canada, 2017).

Although legislated in Canada, PAS/D is a controversial global issue. The process of assisting an individual to die is not specific to Canada, and in fact, only a few countries have legalized. They include the Netherlands, Switzerland, Belgium, Albania, Luxembourg, Columbia and seven states in the U.S. (Echlin & Gentles, 2015; Petrillo et al., 2017). There are numerous countries throughout the world that do not agree with assisted death and in fact, the practice is illegal in Asia, Africa, Latin America (excluding Columbia), most of Europe and many states in America (Echlin and Gentles, 2015). International arguments against legalizing assisted death are ongoing. Concerns relate to protecting vulnerable populations, such as children

and the elderly, logistical debates regarding how to determine the suffering, and what constitutes a terminal diagnosis (Echlin & Gentles, 2015).

To qualify for MAiD in Canada, a person must be 18 years of age, have a serious or incurable illness, disability or disease, endure physical or psychological suffering that is intolerable as per the patient, and death is deemed foreseeable (Dying with Dignity, 2015). The Netherlands allows assisted death for persons younger than 18 years of age; whereas, Canadian law states that individuals must be over 18 years of age to be eligible (Stokes, 2017). Some individuals argue that a patient under 18 is vulnerable and cannot make this decision (Stokes, 2017); however, others contest that there is no legal age of consent, as long as the patient can make a choice based on knowing the risks and benefits of MAiD (Stokes, 2017).

Since the legalization of MAiD, 803 cases occurred between June 17, 2016 and December 31, 2016 in Canada, excluding Quebec, Yukon Territories, Nunavut, and the Northwest Territories (Government of Canada, 2019). The number of MAiD deaths has risen to 2,614 deaths as of Dec 31, 2019 (Government of Canada, 2019). The majority of MAiD provisions (93%) were performed by physicians with only 7% provided by nurse practitioners. Settings in which dying occurred include: hospitals (44%), homes (42%), long term care facilities (5%), Hospice (4%), and other settings (4%) (Government of Canada, 2019).

In Canada, RNs may exercise their right to conscientiously object to participating in any or all process of MAiD. Conscientious objection relates to respecting a patient's wishes and autonomy, but also recognizes a person's right to not participate in an assisted death if an individual so chooses (Baker, Sharpe & Lauks, 2016). In Ontario, the College of Nurses of Ontario (CNO) supports conscious objection; however, the nurse must transfer care of the patient

requesting MAiD to another provider and not pass judgement on the patient in any way (CNO, 2016).

Since the passing of the legislation for assisted death, little research in Canada has been completed to determine the impact of this legislation and the participation in MAiD on the profession of nursing, particularly palliative care nurses. Nurses spend a large proportion of time with patients and are often approached by patients to discuss wishes about dying, including having an assisted death (Van Bruchem-van de Scheur, Van der Arend, Van Wijmen, Huijjer Abu-Saad & Ter Meulen, 2008). Palliative care nurses have varying views, opinions, and beliefs that may differ from patients regarding MAiD (Freeman et al., 2019). Current literature supports that this may create ethical and moral dilemmas for palliative care nurses (Freeman et al., 2019; Young, Rieger, & Thorpe, 1993). Therefore, additional research is needed to identify the ethical issues nurses face when caring for patients requesting MAiD, and how they make ethical decisions. Results from this study will allow workplaces to institute resources, such as education, moral support, and policies that support nurses when caring for patients who request MAiD.

Purpose of the Study

The primary purpose of this qualitative study was to understand how palliative care RNs apply the concepts of ethical decision-making when caring for patients who request MAiD. This study used Greipp's (1992) model of ethical decision-making to better understand *how* nurses make ethical decisions related to MAiD by identifying factors that theoretically influence ethical decision-making. The research was also proposed to support policies and practices related to ethics and MAiD for palliative care RNs who work within settings that provide MAiD as a health care service.

Research Questions

The primary research question was:

1. How do palliative care RNs apply concepts of ethical decision-making when caring for patients who request MAiD?

A secondary research question was:

2. What are the educational needs of RNs related to ethical decision-making and MAiD?

CHAPTER 2

CONCEPTUAL FRAMEWORK

Greipp's Model of Ethical Decision-Making

Greipp's (1992) model of ethical decision-making is a general systems theory that explains the ethical interaction between the nurse and the client with an ethical framework and ethical nursing principles at the centre. Greipp's (1992) model is universal, and as such, it can be used in any setting for identifying areas of difficulty in making ethical decisions (Greipp, 1992). To date, there are no published articles that use an ethical decision-making model to guide nursing practice when deciding to care for persons who request assisted death. The model allows the nurse to identify personal and patient psychosocial variables that influence the decision-making process (Greipp, 1992). The structure within this model allows the nurse to identify and analyze factors that influence skill development in ethical decision-making (Greipp, 1992). The model's theoretical background is based on general systems theory and is comparable to the work of Leininger and the theory of transcultural caring (Greipp, 1992). The major concepts of Greipp's model are described in the subsequent paragraphs.

Ethical Framework

At the centre of Greipp's (1992) model (see Figure 1), the nurse has knowledge or situational information pertaining to a clinical experience. The knowledge can be obtained from several sources such as professional or personal experience. Based on this, the nurse will have views and/or opinions about an ethical concept and will begin to work outwards utilizing the guiding principles of ethics for nurses. The ethical framework presented in the middle of Greipp's (1992) model provides guiding principles used by nurses. The principles included are autonomy, beneficence, non-maleficence, and justice. According to the Canadian Nurses Association (2017), ethical nursing practice reflects the following: safety, compassion,

competent and ethical care, the promotion of health and well-being, respecting informed decision-making, dignity, privacy, confidentiality, justice, and accountability. These ethical principles are also inherent to the practice of nursing as articulated by the CNO, which is the regulatory body for Ontario RN's.

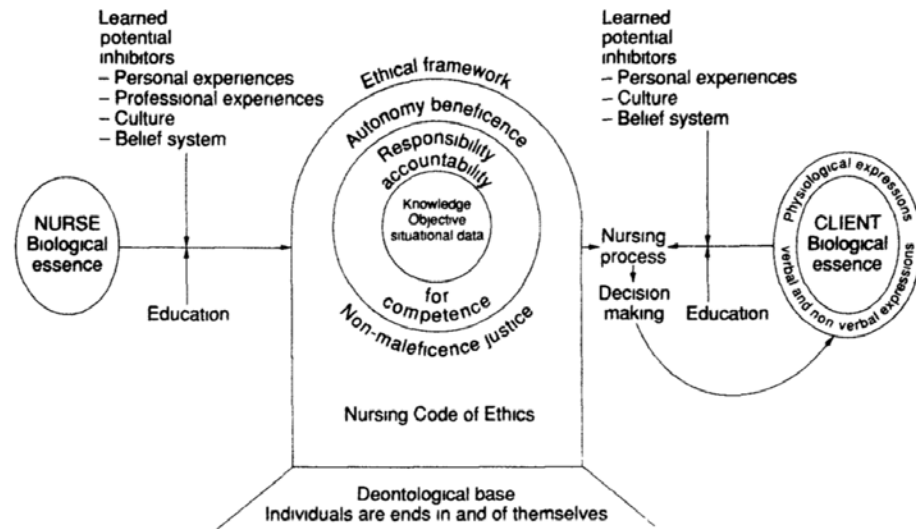
According to Greipp (1992), professional knowledge needed for practice includes objective situational data. When the nurse contemplates ethical situations, such as the decision to participate in an assisted death, the individual must consider the guiding principles of autonomy, beneficence, non-maleficence, and justice. The nurse, however, may be at a disadvantage when trying to use this ethical framework if education in ethics is lacking. For example, if the nurse is unfamiliar with ethical issues related to assisted death, they may lean towards learned potential inhibitors, such as the belief system. Therefore, the model highlights potential inhibitors that violate basic ethical principles and bypass the framework (Greipp, 1992). On the other hand, the model showcases the reality that psychosocial factors have an influence on the nurse and the client in the decision-making process (Greipp, 1992). Further, education provided to the nurse and client can influence the decision-making of the individual (Greipp, 1992).

Learned Potential Inhibitors

Griegg (1992) defines the learned potential inhibitors as the nurse and client's way of thinking according to factors such as personal and professional experiences, culture, and belief systems. Every individual has a set of morals, values and beliefs that are influenced by culture, work, or life experiences (Griegg, 1992). The visual representation of the model depicts the nurse and patient on opposite sides of the diagram. Education, decision-making and the nursing process are concepts that may influence the patient or nurse when making a decision. For example, the nurse reflects on their feelings towards assisted death/dying and uses past work

experiences, personal beliefs, or religion to form an opinion about assisted death/dying. The nurse may oppose assisted death/dying due to religion and/or a strong belief in allowing an individual to die naturally. However, the nurse may incidentally learn something new from the patient that results in the opinion of the nurse regarding assisted death/dying changing. New knowledge can change the decision of an individual even with learned potential inhibitors (Griep, 1992).

Figure 1 Griep's model of ethical decision making



CHAPTER 3

LITERATURE REVIEW

Search Strategy

A review of research was completed regarding nurses' values, attitudes, and beliefs toward assisted death and dying. Inclusion criteria included English as the primary language, full text articles, qualitative and quantitative studies. In order to obtain all relevant articles, no restriction was placed on the year of publication. Exclusion criteria included studies that focused on physicians, nursing students, or any other healthcare professional. With the assistance of a librarian, electronic databases used in the search included the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, Proquest, the Cochrane Database of Systematic Reviews, and Medline. Research articles, journals, editorials, and one book was utilized in the literature review (Echlin & Gentles, 2015). In addition, grey literature such as professional associations, government websites, and opinion articles were included in the literature review. Key words used in the searches included, *physician assisted death*, *medical assistance in dying*, and *physician assisted suicide*. Boolean search phrases included "physician assisted death and nursing"; "euthanasia and nursing"; "attitudes of nurses and euthanasia"; "physician assisted death and ethics"; "nurse experiences with physician assisted suicide and physician assisted death". A total of 32 articles were selected and reviewed. The 32 articles consisted of qualitative and quantitative research, two systematic reviews and one meta-synthesis of qualitative research. Their reference lists and bibliographies were further reviewed for any relevant research articles that were missed. As a result, six additional sources were found and used in the final literature review.

Findings

The literature was summarized into four themes: (1) terminology, (2) nursing and assisted death, (3) palliative care perspectives, and (4) ethical and moral issues.

Terminology

The review of the literature demonstrated that countries use various terms and definitions to define and describe concepts related to medically assisted dying. Currently, the Netherlands, Switzerland, Belgium, Luxembourg, and specific states in the United States (U.S.) offer physician assisted death or PAD (Stokes, 2017). In the U.S., PAD refers to a physician assisting a patient to end one's life by means of prescribing a lethal oral medication that the patient self-administers (Stokes, 2017). The term euthanasia is another term utilized in the U.S. to describe the process by which a physician administers the lethal medication to the patient, resulting in his or her death (Stokes, 2017). The European Association of Palliative Care (EAPC) defines assisted dying as a combination of voluntary euthanasia and PAD (Radbruch et al., 2015). Voluntary euthanasia can be described as a physician administering medication to end an individual's life, and PAD is viewed as a physician helping a patient to die by providing drugs for self-administration (Tomlinson, 2014). According to Van Der Maas and colleagues (1996), PAD and physician assisted suicide (PAS) is used in the Netherlands and refers to a physician prescribing or supplying drugs with the intention to enable the patient to end his or her life. . It should be noted that some U.S. states do not use the terms PAD or PAS as they are perceived to have a negative connotation. For example, the Oregon department of Human Services stopped using the term PAS in 2006 and began calling it, the Oregon Death with Dignity Act (Dying with Dignity, 2015). For consistency and clarity, the term MAiD will only be used when referring to the Canadian context. Assisted death and/or dying will be used for international studies.

Nursing and Assisted Death

In a meta-synthesis of the qualitative literature related to nurse perspectives, Elmore, Wright and Paradis (2016), revealed that nurses believe that it is of utmost importance that people receive or have access to palliative care regardless of wanting or not wanting assistance with dying (Elmore et al., 2016). Nurses expressed needing adequate time for discussing assistance with dying and stated that the lack of staffing and team support resulted in feelings of guilt, anxiety, and failure, due to the inability to spend adequate time discussing the needs of patients (Elmore et al., 2016).

Denier and colleagues (2009) completed a qualitative study that explored the experiences of nurses in Belgium who cared for patients who requested assistance in dying. Denier et al. (2009) reported that nurses described the experience as being difficult at an organizational, practical, and emotional level. Nurses described the assisted death process as being intense and wanting to ensure the actual process was performed correctly so that the patient had a peaceful and dignified death (Denier et al., 2009). On an emotional level, nurses stated that the process was “grave and difficult” no matter how organized the actual process is (Denier et al., 2009). Nurses reported time and transparency being significant factors, as they allowed patients to discuss their concerns and wishes regarding the assisted death (Denier et al., 2009). However, nurses still found that when the act of assistance in dying was hidden in any way, the actual care process was difficult due to the inability of nurses to discuss anything with patients and or families (Denier et al., 2009). Openness, time needed to care for patients, and clear policies aided in contributing to a more positive experience for nurses associated with assistance in dying (Denier et al., 2009).

Other factors that may make it difficult for nurses to care for and participate in assisted death included: religion, geographical location, speciality, and level of education (Evans, 2015). According to Evans (2015), religion is an important factor in all countries, and it must be considered in decisions and policies. Inghelbrecht, Bilsen and Mortier (2009) conducted a nationwide cross-sectional questionnaire in Belgium and found that Catholic nurses had lower rates of acceptance related to assisted death as compared to those who were neutral or had no religious affiliation. Nurses have varying faiths and beliefs that may affect whether one will participate or oppose assisted death (Inghelbrecht et al., 2009).

A nurse's workplace was found to be a factor in terms of whether a nurse was in opposition or favoured assisted death (Evans, 2015). A cross-sectional study by Tepehan, Ozkara and Yavuz (2009), found that 62% of intensive care nurses and cardiac care nurses in Turkey supported the legislation of assistance in dying. These findings may suggest that ICU and CCU nurses were exposed to more palliative patients and/or encountered more requests from patients wanting an assisted death, as compared to nurses who work in other areas such as, pediatrics or obstetrics (Tepehan et al., 2009).

Knowledge and education are factors that influence nurses' perspectives toward assisted death. Level of education was examined by Inghelbrecht et al., (2009) and Evans (2015). Nurses with higher levels of education were more prepared to assist in administering a lethal dose to a patient in comparison to diploma nurses (Inghelbrecht et al., 2009). This finding may be attributed to the fact that degree nurses have the ability to critique and criticize research which allows the nurse to make an informed decision about nursing actions (Finkleman & Kenner, 2012). However, the research findings stated that further research needed to be conducted to identify why and if there is a correlation related to nurse's level of education and willingness to

participate in assisted death (Evans, 2015). Two studies reported that some nurses are not aware of the difference between palliative sedation and assisted death (Abrahamo, et al., 2016; Laporte-Matzo, & Kennedy-Schwarz 2001), suggesting that nurses need additional education related to palliative sedation versus assisted dying.

Palliative Care Perspectives

Nurses who practice palliative care may have a difficult time providing care to those involved in the process of assisted dying as it contradicts the philosophy of palliative care. Palliative care encompasses symptom management, quality of life, psychological, spiritual and existential well-being, disease management, social support, and bereavement care (Smith, Goy, Harvath, & Ganzini, 2011). The Canadian Hospice Palliative Care Association position statement does not view euthanasia or assisted death as part of quality end-of-life care (Canadian Hospice Palliative Care Association, 2010). There are nurses who agree with assisted death and have speculated that a main reason for patients seeking an assisted death is to avoid poor quality of dying or symptoms related to the disease progression (Smith et al., 2011). However, it is also argued that patients who consider assisted death are not aware of palliative care and/or do not have access to palliative care services (Smith et al., 2011).

Studies indicate that palliative care nurses who have participated in assisted death indicate various struggles when doing so. A descriptive, nonexperimental study conducted by Young, Volker, Rieger and Thorpe (1993) reported that up to 44% of nurses stayed in the room when an assisted death was performed, 29% of nurses stayed in the room despite disagreeing with the provision, and 24% of nurses disagreed with assisted death and did not participate (Young et al., 1993). This demonstrates that nurses have varying opinions and values that influence the decision to participate in the provision of MAiD.

In Harvath and colleagues' (2006) study, palliative nurses in the state of Oregon identified numerous challenges but also experienced positive opportunities when caring for patients who requested assistance in dying. Oregon was the first state in the US to legalize medical assistance in dying and therefore, this was one of the few studies that discussed palliative care nurses' experiences with assisted death. Positive factors that arose included increased opportunities to discuss end of life wishes or fears of death and dying. In addition, improved attention to pain and symptom management was observed (Harvath et al., 2006). Nurses expressed positive outcomes when they were able to have open and honest conversations about assisted death (Harvath et al., 2006).

Ethical and Moral Issues

Harvath et al.'s (2006) study revealed ethical dilemmas encountered by hospice workers. This is the only known study to directly report issues related to ethical decision-making among palliative care nurses. It is limited because these views are combined with those of other disciplines. The study found that nurses experienced ethical dilemmas and moral distress related to the perceived increased responsibility to manage end of life symptoms and balancing patient autonomy. Nurses voiced concerns, such as legal ramifications, professional responsibilities, and internal struggles related to whether assisted death was appropriate to practice within a palliative care setting. Furthermore, missed opportunities for addressing a patient's spiritual wellbeing were revealed. Nurses explained that patients go through a process when death is near, and that healing and closure can occur for patients and/or families during this time. When patients choose an assisted death, they may lose out on spiritual transformation or closure (Harvath et al., 2006). Some nurses felt they failed the patient if the symptoms weren't managed well, and the person choose assisted dying instead of a palliative care approach (Harvath et al. 2006). In addition,

nurses experienced varying views related to a patient's autonomy and the right to choose assisted death over palliative care (Harvath et al., 2006). Nurses expressed accepting the individual's decision to choose an assisted death, but also wanted to uncover the reason why a patient chose an assisted death versus a palliative approach (Harvath et al., 2006). Some nurses had conflicting ideas as to whether it was right to try to potentially sway an individual away from an assisted death (Harvath et al., 2006).

Elmore and colleagues' (2016) meta-synthesis provides an in-depth analysis of nurses' moral experiences related to assisted death; however, the review did not include any Canadian studies. Rather, it reflected international literature where legislation varies, and the perspectives of nurses who work in a variety of care settings were used. The findings revealed that nurses are moral agents who care deeply and perceive a responsibility of caring for patients and families who are contemplating and/or receiving an assisted death (Elmore, Wright, & Paradis, 2016). Feelings of distress related to the inability to relieve intense suffering and/or not meeting patient or family's needs were emphasized (Elmore et al., 2016). Nurses struggled morally about crossing ethical boundaries between pain management and hastening death in relation to palliative care versus assisted death. In addition, contextual factors such as the nurses' environments in which they worked led to moral distress. Factors such as, length of time spent with patients, quality of interactions with physician's related to involvement of care were variables identified by nurses.

Literature Summary

No published Canadian research has been conducted that directly discusses the impact of MAiD and the ethical decision-making of palliative nurses since legislation was passed June 17, 2016. The 26 included articles reported international perspectives from eight countries, yet only

eight had legalized PAD/S. Much of the literature discussed why individuals choose assisted dying. Some of the reasons included having control over one's death, fear of death or suffering, loss of dignity, loss of bodily functions, burden on family, and financial implications (Baker et al., 2016; Chambaere et al., 2010; Smith et al., 2010). Two studies reported that assisted dying may be anti-ethical towards palliative care, and that it may contribute to missed opportunities for spiritual transformation and concern that vulnerable populations, such as the elderly, may be coerced by family or even nurses (Harvath et al., 2006; LaPorte et al., 2001). The literature also reports that nurses experience difficulty in their workplaces, whether or not they agree with the legislation (Elmore et al., 2016; Harvath et al., 2006; Smith et al., 2011).

Nurses require debriefing and emotional support around assistance with dying (Elmore et al., 2016). Nurse's attitudes, beliefs and values are aligned with the professional code of ethics, which may be a strong determinant to a nurse choosing to participate in an assisted death (Elmore et al., 2016). Elmore and colleagues (2016), revealed that nurse's struggle with ethical decision-making related to the autonomy of the patient. However, it is not known why or what factors are attributed to this, and further research is required. It is clear that nurses' views regarding MAiD are underrepresented, and yet nurses spend the largest amount of time with patients and families at the end of life (Terkamo-Moisio, et al., 2017). There is a strong need for research to be completed that explains how Canadian palliative care nurses are making ethical decisions about participating in MAiD. The findings will support quality palliative care and nurse well-being by identifying the ethical decision-making practices and educational supports needed by Canadian palliative nurses.

CHAPTER 4

METHODS

This section discusses the research design, setting and sample, data collection, data analysis and ethical considerations to protect participants.

Research Design

Established qualitative standards were used throughout the study to ensure rigor and trustworthiness (Lincoln & Guba, 1985; Thorne, 2016). While other qualitative traditions seek to generate new theories or metaphors, an interpretive descriptive method allows the researcher to identify or answer problems related to a specific issue in the nursing field (Thorne, Reimer Kirkham, O'Flynn-Magee, 2004). As previously described, Greipp's (1992) model of ethical decision-making guided the study. Concepts explored included: ethical principles, learned potential inhibitors such as, personal experiences, professional experiences, and the culture and belief systems of the nurse and patient. Participants described how they apply concepts of ethical decision-making as it related to MAiD. The investigator elicited and interpreted participants' knowledge of ethics and their perceived support needs related to ethical decision-making and MAiD.

Sample and Setting

Purposive sampling was used to identify palliative care nurses who work in Ontario, Canada and have experiences related to MAiD that can inform the research questions (Thorne, 2016). Participants were recruited by e-mail from a database of palliative care registered nurses who had participated in a larger study (n = 22) and who had agreed to be contacted for future research (Freeman et al., 2019). Male and female RNs who self-identified as working in palliative care in Ontario, Canada were eligible to participate. The researcher applied a maximum variation approach to recruit participants who lived in different areas of Ontario and

worked in a variety of palliative care settings (Thorne, 2016). Participants were selected if they lived in rural or urban communities and if they worked in hospital, community or long care facilities to maximize the diversity of participant's experiences. In addition, participants were selected if they had firsthand experience with MAiD or exposure to MAiD in some clinical context. Sampling ceased once the researcher determined that enough data had been obtained in order to answer the research questions and when data redundancy was evident (Thorne, 2016). Constant data collection and analysis was implemented throughout the study to ensure various perspectives and/or new information was included to gain additional knowledge or insight related to the study (Thorne, 2016). The final sample included ten participants.

Ethical Considerations

Ethics clearance was obtained from the Research Ethics Board at the University of Windsor for a larger study that involved palliative care nurses. A request to revise was approved to add the student investigator, and this request also included the semi-structured interview schedule that was used in this study (See Appendix A). Careful selection of the interview questions was made to mitigate psychological and social harm (Kaiser, 2009). A letter of consent and confidentiality was sent via email to participants prior to telephone interviews being conducted. Participants were informed of the types of audiences with whom the research might be shared (Kaiser, 2009). All identifying information was removed during the data cleaning process and data were stored in a password protected laptop and shared only with co-investigators and research assistants who helped with data transcription.

Data Collection

Interview questions were piloted to obtain feedback before the interviews were conducted. Semi-structured interviews took place via telephone and were digitally recorded.

This reduced distractions for the interviewee and participant (Carr & Worth, 2001) and captured the live narrative of the participant. Examples of questions included: (1) What are the deciding factors that influence you to participate or not participate in MAiD? (2) When you are faced with an ethical issue related to MAiD, what ethical principles do you apply? (3) How do you manage ethical dilemmas in the workplace? (4) How does ethics guide your practice related to the MAiD? (5) What education do you feel is important or imperative to nurses regarding MAiD? Prompts based on Greipp's model (1992) were used to encourage in-depth and meaningful responses related to the theory.

Data Analysis

Data analysis took place concurrently with data collection. An iterative reasoning approach was used when sorting the data (Thorne, 2016). Transcripts of the interviews were carefully reviewed. Data were sorted using broad-based coding so that common themes, ideas, and patterns could be grouped (Thorne, 2016). In addition, ideas were jotted down during and after the interviews, and when reviewing the transcribed audiotapes (Thorne, 2016). Microsoft Word processing system was used to organize themes and a separate file was used to capture important quotes from participants (Thorne, 2016). A constant comparative analysis was used during the analysis (Glaser & Strauss, 1967).

Reflexivity

As a palliative care nurse, it was important for me to pay attention to my own beliefs and assumptions throughout this study. I have worked in the community and acute care settings and have witnessed firsthand how MAiD affects nurses. I witnessed fellow colleagues struggle with the decision to participate in MAiD, and when doing so, many ethical dilemmas arose throughout the process. First and foremost, the palliative care philosophy opposes the idea of MAiD, and I

needed to explore my own thoughts, feelings, values, and beliefs. This created personal conflict and required ongoing reflection throughout the study. I created a personal diary to keep track of my feelings and opinions. I remained open minded to participants' own thoughts and feelings by putting myself in their shoes. Established qualitative standards were used throughout the study to ensure rigor and trustworthiness (Thorne, 2016). Participant reflections were reviewed throughout the study with my supervisor, and this supported the identification and verification and identification of the themes.

CHAPTER 5

FINDINGS

The palliative care nurses worked across four sectors. Participants were employed in acute care (n = 3), hospice care (n = 4), long term care (n = 1) and community care (n = 2). Participants worked in urban settings (n=9) and rural areas (n=1). Six participants reported having participated in the provision of MAiD and four had not. Only one palliative care nurse in the study identified themselves as disagreeing with MAiD. Overall, the findings suggest that the palliative care nurses considered the ethical principle of autonomy before other concepts when deciding to participate in MAiD. The findings are categorized using Greipp's (1992) theoretical framework

Application of Ethical Decision-Making

The core concepts of Greipp's (1992) ethical framework most influenced palliative care nurse decision-making related to participating in MAiD, with autonomy emerging as the single overarching ethical principle followed by justice and non-maleficence. Participants had difficulty expressing why and how they came to make an ethical decision. The author prompted/reviewed the CNO Ethical Framework (CNO, 2019) and used Greipp's model (1992) to enrich the responses. For example, Participant Seven made the decision to participate based on patient autonomy, but had a difficult time identifying if other factors, such as religion, personal beliefs, or professional experiences influenced their decision.

Autonomy. The majority of participants (n=7) made it clear that despite personal feelings about MAiD, it was ultimately up to the patient to make a choice regarding MAiD. *“There are things that I don't agree with, but it's not about you. Autonomy is a big factor, you're not the one dying”* (P2).

Participant Five stated very simply, *“If that’s the patient’s choice, then I’m all for it.”*

Justice. Two participants described the principle of justice as influencing their decision to participate in MAiD. According to the Canadian Nurses Association (2017), nurses uphold the principle of justice by upholding human rights, equity, fairness, and promoting the public good. A lack of universal access to palliative care was reported as a source of confliction.

“I don’t know, it’s not that I don’t agree with it, because I feel that people can have their own choices and reasons for pursuing, but I guess I just felt that if people could have access to early palliative care then maybe there wouldn’t be as many MAID requests.... Palliative care is all about not wanting people to feel like they want to die. It’s giving people comfort to continue until the time comes” (P7).

One participant struggled with the justice of the law: *“Just because its law, doesn’t mean it’s right existentially” (P1).*

Non-maleficence. Only one participant indicated a personal conviction to do no harm as the deciding factor for participating in MAiD.

“Thou shall not murder, bottom line for not choosing to go ahead with MAiD. I’ve watched people die for nine years, sometimes two or three times a shift. It makes you really have to evaluate that. Everyone has to have a bottom line and if they don’t, they just shift as the culture or law shifts (P1).

Non-maleficence falls under the ethical principle of accountability. If a nurse decides that the request for care conflicts with his/her own personal values, then the nurse must provide safe, compassionate care until alternative care arrangements can be made (CNA, 2017).

Understanding ethics. Despite relying on the principle of autonomy for decision-making, the data revealed that participants struggled to understand/explain the concepts of ethics,

personal beliefs, and values. In fact, prompts were needed to define and describe the terminology. Participant Four commented: *“I don’t think nurses know the difference between values and ethics.”*

Several participants commented about a lack of reflection on ethics.

“I don’t think a lot of people in general know what their values are, what makes them who they are. I think people can recognize when they’re having an ethical dilemma when you start talking about a situation and its psychosomatics. If there are no ethics, there are no values” (P6).

Not all individuals were familiar or conscious of how they used ethical concepts in everyday nursing practice. An account of that finding is summarized below:

“I haven’t really thought about my personal beliefs related to MAiD. I haven’t even really thought about it because it’s supposed to be about the patient’s choice. I’m there to assist the patient. I give the patient’s the facts or refer them back to the family doctor but nothing else because I don’t know how to have those conversations” (P8).

Learned Inhibitors

The professional and personal experiences of palliative care nurses influenced nurses’ decisions to participate in MAiD. Positive and negative experiences influenced nurse attitudes and decision-making toward MAiD, and emotional conflict was evident among most participants.

Professional experiences. Participants indicated that witnessing patients suffer in the end stages of dying affected how they viewed death and dying.

Participant Two stated: *“I’ve seen really good deaths, but really bad deaths. I feel like those overall experiences have made me feel comfortable with MAiD. My experience seeing*

people hooked up to machines or tubes, I feel like it takes away the dignity from the person. I think it's a brave decision to make when choosing MAiD."

Participant Nine shared a broader perspective on death and dying: *"There's so many diagnoses when you know the outcomes are not pleasant. I've watched so many terrible outcomes, but I've seen beautiful things too and that's why I do understand the perspective."*

Several participants spoke of stress related to family conflict regarding MAiD: *"The one difficult case I can remember, was when a patient decided not to tell the family that they were going to go through with MAiD. That was a tough case to go through, the family was devastated"* (P7).

Participant Four shared this recollection of family conflict: *"The understanding of the patient needs finally changed their mind, the family finally understood what the patient wanted, and the patient wanted to choose their own death."*

Organizational factors such as work support, job demands, and policies were identified as inhibitors to ethical decision-making related to MAiD. Lack of support from fellow colleagues and/or workplaces influenced palliative care nurses' decisions to participate in MAiD: *"I think you should know that the institution's decision to not participate in MAiD was hugely influenced by the staff, by the nurses at the institution"* (P1).

These factors made it difficult for nurses to ask questions or learn more about MAiD. If MAiD was not openly discussed in the workplace, nurses felt scared to ask questions or participate in MAiD for fear of being judged or criticized by colleagues or employers. Participant Three described this account:

"I'm not sure how to bring about a change, the damage has been done, it's been treated so hush hush-its taboo. I can't even email anything out to staff without the manager's

approval. A nurse tried to offer education to others about MAiD and it was denied by the manager.”

Participants reflected on having adequate staffing so that exceptional care can be provided to patients who are in the end stages of dying. When staffing was inadequate, nurses felt rushed and concerned about providing care that was ‘sub-par’ as they could not attend to the needs of patients and families. Staff also expressed distress when employers did not inform them when a patient was to undergo MAiD: *“Usually staff express distress when they aren’t informed that the patient is undergoing MAiD. Staff like to know these things before hand and be able to provide the proper care”* (P6).

Participant Nine shared a similar experience: *“I showed up to the person’s home thinking I was just going to start an IV and it turned out being an IV I had to start due to MAiD. I had no warning that this was what I was going to do.”*

Personal experiences. Surprisingly, not one participant identified religion or faith as factors that influenced decision-making to participate in MAiD. Some participants reflected on personal experiences of loved ones who died and described seeing good versus bad deaths. A good death included patients who did not physically or emotionally suffer throughout the trajectory of the disease and/or in the end stages of dying. A bad death was viewed as a patient who suffered physically and/or mentally throughout the illness or end stages of dying. An account of this can be seen in this recollection:

“We had a son die at seventeen months and they asked how much longer they wanted to work on him, and I said, ‘He’s been through hell so let him go’. We also have a daughter who has an autoimmune disease and if the time comes, I know she will choose quality over quantity” (P5).

Moral Residue

Participant's verbalized feeling ethically conflicted when making a decision to be involved with MAiD: *"Ethical dilemmas, do we do this or not do this? Every day, it's a struggle because you have so many people involved"* (P4).

"You don't get a sense of what it is until you are doing it. It hits you harder than you think when going through it (P10)".

"We see things that are not always right in the field and what do you do with that information" Who do we report these things too? If you keep seeing these things, then it will lead to burnout and it can get to your soul" (P6).

Participants did not discuss conscientious objection directly but commented on others judging them based on the decision to participate in MAiD. Participant 10 recalls this in the following account. *"Nurses looked at me like they did when people participated in abortion and they were mad at me. I simply said, it's not about you, it's about the patient."*

Not applying an ethical framework was associated with moral and personal conflict for the palliative care nurses who participated in this study. Participant Seven discussed the 'moral residue' that is left after palliative care nurses witness practices in the field that may be wrong: *"Nurses might not know how it's affecting them and so you kind of just keep doing what you're doing. I just think the buildup of moral residue over years of practice, it can be hurtful to a person"* (P7).

A significant aspect of 'moral residue' was witnessing improper MAiD practices. Examples of improper MAiD practices included physicians speeding up the ten-day waiting period and/or concluding a patient was competent when nurses assessed that they weren't. An account of this is summarized in the following quote:

“We did have a case last week actually where the patient was assessed, and the physician cleared the patient as being competent and the staff on the floor felt that was incorrect. We felt that should have been reviewed in a case review afterwards” (P6).

Four of the ten participants expressed internal moral conflict as a result of witnessing “bad practices” of MAiD. *“It just seems that these rules and guidelines put in place by the government aren’t monitored that closely. I don’t know how often they review cases here and when I asked someone on the committee, they said they hardly meet at all” (P6).*

Participant One commented: *“I’m always a little weary of somebody bending the rule or you know doing backdoor MAiD; this happens when doing palliative sedation when the person didn’t even qualify for palliative sedation.”*

Participants described the moral conflict they experienced when witnessing patient distress related to decision-making: Participant Eight shared the following: *“That’s another thing I’ve had. Patients can’t just wait in the hospital until they decide what date their going to have MAiD. So, they feel pressured to pick a date because maybe they can’t go home or don’t have enough assistance (P8)”*.

Education and Support

Knowledge deficits related to MAiD and ethics in general negatively influenced palliative care nurses’ overall ability to make ethical decisions. Participants shared many educational needs, such as legislation rules and/or guidelines, legal ramifications for nurses, and ethical training. Participant Eight commented on this subject: *“We need more ethical training. Everyone is focused on skills and not the real conversations (P8)”*.

The ability to answer questions and have conversations related to MAiD was emphasized by nurses. Nurses didn’t know what they can or can’t say to patients without feeling like they are

coercing the patient to make a decision regarding MAiD. *“I didn’t think my opinion was important, I was there to assist the patient. Maybe I should be able to talk more about MAiD, but I just pawn off the conversation and say, ask your doctor. I don’t know how to have those conversations with a patient (P10)”*.

Participants indicated that having formal and informal debriefing before and after the provision of MAiD is imperative to ensure any emotions, feelings, and questions are addressed:

“I hear distress from nurses when there is family conflict, the patient is not able to speak for themselves or the process of debriefing before or after MAiD is not done (P5)”.

“Having a debriefing before and after MAiD is done would be helpful. Not just the individuals involved, but everyone on the floor” (P7).

Some palliative care nurses commented on not feeling like a part of the healthcare team when physicians discussed MAiD with patients, and that no discussion took place before or after the procedure amongst the healthcare team. This created feelings of angst when managing patient and/or family’s concerns. One participant reflected on incorporating self-reflection in the moment and after an ethical event to explore and talk about ethical dilemmas: *“I don’t think it’s a basic for every human to be self-reflective. You have to know where you stand and why. Where are these feelings coming from?” (P2)*

Nurses felt rushed and stressed when not provided adequate time, education and/or support when deciding whether or not to participate in MAiD. The community palliative care nurses reported that access to online education, pamphlets and/or support from management would be helpful when participating in MAiD. Participant Eight reviewed a scenario that occurred amongst nurses:

“The care providers didn’t prepare the organizations to go ahead and start doing MAiD. No mandatory education or information was provided for the nurses. The education we were provided with, consisted of a simple checklist and we were required to just go out there and start doing it. We were not always made aware in advance that a referral was for MAiD. Often, we wouldn’t be prepared when walking into a patient’s house.”

One participant requested topics related to compassion fatigue, resilience training, and incorporating self-reflection when educating nurses regarding MAiD. Furthermore, the palliative care nurses who worked in acute care settings shared that access to an ethicist or ethical consultant would be helpful.

CHAPTER 6

DISCUSSION

This study is the first Canadian study to qualitatively explore the ethical decision-making perspectives of palliative care nurses in the wake of MAiD legislation. The findings of this small qualitative Canadian study are largely consistent with those reported in the international literature; however, new and conflicting findings, specifically related to palliative care nurses did emerge. This chapter presents a discussion of the literature related to current findings, nursing implications for research and practice, followed by limitations of the study.

Ethics and Ethical Decision-Making

Ethical considerations in the context of MAiD include various perspectives on the nature of suffering, autonomy, dignity, and death. Autonomy of the patient maintains the right to self-determination and is a principle nurses adhere to worldwide (CNO, 2019). When the Supreme Court of Canada legalized MAiD, one of the main arguments was a competent individual should be allowed to make a medical decision on their own (Government of Canada, 2016). Autonomy and perceptions of what constitutes a good versus bad death was evident in the findings and literature. Different views of death and/or suffering can affect a nurse's decision to participate in the provision of MAiD.

Palliative care nurses expressed difficulty verbalizing why and how they made a decision. Prompting and probing was needed during the interviews to understand why and/or how palliative care nurses make decisions related to MAiD. According to Berghs and colleagues (2005) nurses can feel a loss of words when trying to indicate how they felt about an ethical situation, but they are able to participate in reflective practice. End of life decisions require complex decision-making that involve the inclusion of patients, families, and the healthcare team

(Berghs et al., 2005). Formal processes, such as ethical decision-making models or systematically working through a framework can help palliative care nurses with decision-making; however, ethical principles taught in nursing may be too theoretical and not true guidelines of what actually occurs in the nursing field (Berghs et al., 2005). Therefore, ethical frameworks or guidelines need to be more contextual and practice-based to illuminate nurses' attitudes towards MAiD, or any other ethical dilemma (Berghs et al., 2005).

LaPorte et al., (2001) report that nurses are able to express emotions towards assisted dying but may not understand how emotions and values form the basis of ethical principles. This qualitative study revealed similar findings. The participants readily expressed their emotions, but they were challenged to identify specific ethical principles related to their decisions. As reported by Miller and colleagues (2004), nurses do have different attitudes and beliefs about assisted death. Religion, personal and professional beliefs are factors identified by nurses that influence how one makes a decision to participate or decline MAiD (Miller et al., 2004). In this study, nurses did not identify religion, culture, or faith as a deciding factor, despite being prompted.

Patient and Nurse Involvement in Decisions

Consistent with the literature, participants in this study indicated that patients and families ask nurses questions related to MAiD and palliative care. Bruchem-Van et al. (2008) reinforced the reality that among all care providers, nurses spend the majority of time with patients and families and, as a result, answer questions related end of life decisions. The findings of this study indicate that palliative care nurses are not involved in the initial conversations that physicians have with patients in which they discuss MAiD. As a result, nurses are left out and unable to bring forth any concerns or questions that the patient may have. Nurses advocate for their patients and spend the majority of the time with patients, hence, it is imperative that

palliative care nurses are involved with every aspect related to MAiD. Findings also indicated that palliative care nurses may not be prepared to respond to these questions. That is, palliative care nurses reported that organizations did not openly discuss MAiD processes and procedures with the nurses. Therefore, palliative care nurses were afraid to ask questions and/or voice issues related to MAiD for fear of being centered out. This is problematic because if a nurse has fears or unanswered questions pertaining to assisted dying, the issues may continue to be ignored, resulting in poor patient care and increased costs to the public (LaPorte et al., 2001).

Dierckx, Denier, De Bal and Gastmans (2010), assert that nurses need to be part of the decision-making process. The study participants continuously voiced concerns about not being a part of the decision-making, and this resulted in feelings of angst or being uncomfortable discussing MAiD. The palliative care nurses also reported that feeling uncomfortable with the provision of MAiD was related to educational gaps and fear of legalities. This is consistent with LaPorte and colleagues' study (2001) that reported nurse feelings of anger, fear, or guilt when deciding to engage in and assisted death.

Education and Emotional Supports

Nurses require education and clear policies to competently perform their roles and responsibilities related to MAiD (Pesut et al., 2019). According to the CNO (2018), nurses' roles include educating clients without encouraging MAiD, supporting patients and/or families, and inserting an intravenous line (IV). In this study, palliative care nurses overwhelmingly voiced knowledge deficits related to MAiD that may have contributed to their decision-making related to participation in MAiD. Participants reflected on needing more education about ethical decision-making, the process of MAiD, roles, competencies specific to nurses, documentation, and having conversations with patients and/or families. Past studies confirmed that nurses want

to know how to support families during and after the provision of MAiD, how to improve communication skills and many want additional continuing education in palliative care (Campbell & Black, 2013, Dierckx et al., 2010; Freeman et al., 2019).

The emotional support of palliative care nurses is a moral imperative for all organizations that provide MAiD. As revealed in this study, palliative care nurses face moral and ethical dilemmas in their daily work. When ethical values clash internally overtime, moral residue can ensue, particularly when nurses have no safe outlet for reporting issues that are morally distressing. As revealed in the findings, palliative care nurses expressed witnessing ‘bad practices’ of MAiD.

Palliative care nurses require a pathway or safe haven to aid in dealing with moral residue. According to Radbruch and colleagues (2005), many nurses feel more capable in managing the physical versus psychological aspects of providing end of life care. Furthermore, lack of nurse agreement regarding a patient’s decision to participate in MAiD can cause distress in the nurse-patient therapeutic relationship (Radbruch et al., 2005). Nurses also express feeling a heightened sense of duty and/or obligation when caring for patients who were nearing death, regardless of the patient receiving palliative care and/or MAiD (Elmore et al., 2018). Nurse distress associated with engaging in assisted dying may also result from feeling obliged to the patient and/or not being able to transfer care to another healthcare provider due to size of the organization or living in a rural area (Miller et al., 2014).

MAiD legislation in Canada allows healthcare providers to engage in conscientious objection to participating in the provision of MAiD (Government of Canada, 2019). At the time data were collected in this study, rules and regulations around MAiD were still being formulated by provincial regulatory bodies throughout Canada, and these bodies report varying

responsibilities and roles surrounding MAiD (Pesut et al., 2019). The decision to participate in MAiD for a nurse has to be informed, reflective, and not based on prejudice or fear (Browne & Russell, 2016). In Ontario, conscious objection allows a nurse to not participate in the provision of MAiD as long as the decision is not conveyed to the patient, and an alternate care provider can be found (CNO, 2018). In this study, only one nurse reported working in a rural area, and one nurse conscientiously objected to MAiD; however, the findings indicate that moral distress was experienced by the majority of palliative care nurses.

Although the current study is only able to describe the psychological and moral impact of MAiD on palliative care nurses over a short period of time since its legislation, countries that have decriminalized MAiD indicate that nurses struggle morally and emotionally over a period of time (Denier et al., 2009). Studies from around the world indicate that nurses have many formal and informal roles when participating in assisted dying (De Bal et al., 2006; De Beer et al., 2004; Denier et al., 2010; Dierckx de Casterle et al., 2006). Dierckx and colleagues (2010) stress the importance of nurses talking to colleagues as a form of emotional and psychological preparation prior to an assisted death. Debriefing allows nurses to discuss feelings, emotions reviews cases, which results in better patient care (Harvath et al., 2006). Formal versus informal debriefing is a necessary means of support that was validated in this study and throughout the literature (Harvath et al., 2006; Smith et al., 2011). Nine participants revealed that debriefing is not always done and that it is essential to nurse well-being. While informal debriefing may include a nurse talking to fellow colleagues in the clinical setting, formal debriefing includes a structured process of trained individuals to assist the nurse in exploring one's own thoughts and/or feelings related to a distressing even (Royal College of Nurses, 2020).

Hospice Palliative Care and MAiD

Access to palliative care, prior to the provision of MAiD, was a theme found throughout the literature (Smith et al., 2011; Harvath et al., 2006). Palliative care needs to be offered in the early stages of a life altering diagnosis so that patients have the necessary support and guidance when dealing with a pending poor prognosis (Petrillo et. al., 2016). In this study, palliative care nurses voiced concerns over accessibility and timeliness of palliative care, and they supported the need for access to palliative care despite patient's request for MAiD. Accessible and timely care is an example of the justice principle that nurses adhere to when caring for patients. Further policy development needs to be implemented to include all patients have the right to palliative care and/or MAiD.

Harvath et al., (2006) similarly reported nurses having concerns that a lack of access to palliative care may lead patients to choose MAiD as a last resort due to poor symptom management and limited access to palliative care. Interestingly, few palliative care nurses viewed palliative care to be at odds with MAiD. The literature suggests this is more of a conflict for nurses working in a hospice setting versus acute care setting (Harvath et al., 2006). The view of dying as a natural process, neither prolonging nor hastening death, are common beliefs held by individuals working in hospice palliative care settings (Campbell & Black, 2013), and a philosophy of hospice palliative care (WHO, 2016)

CHAPTER 7
SUMMARY OF IMPLICATIONS FOR PALLIATIVE CARE
NURSING PRACTICE

This study explored how palliative care nurses apply concepts of ethical decision-making when caring for patients who request MAiD. The findings and discussion offer the following brief recommendations for nursing practice in the areas of education and workplace culture.

Palliative Care Nurse Education

Palliative care nurse education is needed in the areas of (a) ethics training, (b) legislation, regulations, policies, and procedures about the provision of MAiD, (c) communication with patients and families regarding MAiD and (d) inclusion of palliative care nurses throughout the entire MAiD process.

- a. Ethical training should include an ethical framework or decision-making model that allows nurses to work through ethical dilemmas. Participants stated that the basics of ethics is taught in school but that working through an ethical dilemma in the workplace is not always consciously practiced. Thus, it is recommended that comprehensive ethics training related to MAiD be provided by palliative care nurse employers and schools of nursing. Ongoing interaction with theory and practice indicates that current theoretical models of ethics are not user friendly and that they be more practice-based approach, and include values clarification (Berghs et al., 2005).
- b. Palliative care nursing employers should assess the specific educational needs of staff related to legislation, practice regulations, and organizational policies and procedures. Organizations are encouraged to implement additional relevant and accessible educational resources such as in-service education and/or online learning. Funding for

continuing education and use of trained ethical consultants are suggested in order to support nurses.

- c. Communication training is required to engage palliative care nurses in meaningful conversations with patients and families regarding. While post-graduate palliative care courses such as Learning Essential Approaches to Palliative Care (LEAP) and Comprehensive Advanced Palliative Care Education (CAPCE) are available, these education classes focus on a palliative care approach and do not address how to answer questions or concerns from families and/or patients related to MAiD, its processes, and how to support patient/family decision-making. Nursing employers are encouraged to offer case-based continuing education to enhance professional and therapeutic communication techniques among palliative care nurses surrounding MAiD.
- d. Palliative care nurses need to be included in all discussions with patients and/or families related to MAiD. Thus, further formulation of education needs to occur so that all parties of the healthcare team can work together to ensure continuity of care.

Supportive Work Culture

Pesut et al., (2019) highlight the importance of identifying and supporting the emotional work of nurses; otherwise, nurses face moral distress and/or patients suffer from poor quality of care. The findings of this study and the literature emphasize the moral residue, as well as the cumulative emotional effects on nurses when they see repeated instances of death and suffering (Laporte et al., 2001; Pesut et al., 2019). Part of a palliative nurse's profession is to care for individuals who endure suffering, and this often can create moral distress (Laporte et al., 2001). As a call to action, emotional and psychological support systems need to be available and accessible for palliative care nurses at all times.

A supportive work culture should include access to informal and formal support systems for palliative care nurses. This should include a bioethicist, a clinical practice consultant with expertise in the provision of MAiD, and time for formal and informal debriefing. Informal and formal debriefing strategies may include, but is not limited to talking to fellow colleagues, team meetings and/or structured interdisciplinary meetings to perform case reviews.

Study Limitations and Future Research

This study included a small sample of palliative care nurses who work in Ontario, Canada, therefore transferability of the findings is limited. Few participants had engaged in a medically assisted death; therefore, their views about deciding to participate in MAiD reflect on hypothetical MAiD scenarios, not the actual experience. Only one participant worked in a rural area which poses a limited view of palliative care nurse experiences. In rural settings, limited human resources may result in difficulty for a nurse to consciously object, and access to palliative care may also be limited. Therefore, additional perspectives of rural nurses are needed.

Due to the nature of the topic, very few Canadian articles were available to interpret the findings of the palliative care nurses who participated in this study, and time restraints precluded the researcher from engaging participants in member checking. Although this study focused on palliative care registered nurses, future studies should include registered practical nurses, and nurse practitioners who are also involved in providing MAiD, although with differing scopes of practice. A larger study that combines quantitative and qualitative methods would provide generalizable evidence about how palliative care nurses make decisions about MAiD. It was evident that palliative care nurses have varying views and opinions about death and dying, as well as what constitutes suffering. Further insight from a patient's perspective of what constitutes

suffering may be helpful, and how suffering impacts a patient decision to seek MAiD is suggested.

Although Greipp's (1992) model of ethical decision-making framework was helpful for understanding nurse decision-making, the issue could also be illuminated by applying a feminist ethics of care or a feminist ethics of relationship lens. According to Koehn (1998), women work through ethical dilemmas by building empathy and trust and considering the views of all parties involved in the dilemma. Gilligan (n.d.) explores how people construct moral conflicts and choices, specifically the way individuals make choices and decide upon actions. A feminist view may help to identify how and why palliative care nurses, a predominately female cohort, make ethical decisions. Finally, future studies that inform practice support for palliative care nurses who conscientiously object to MAiD are needed.

Conclusions

To date, this is the only research study that revealed how palliative care nurses in Ontario, Canada apply concepts of ethical decision making when caring for patients who request MAiD. Ethical decision making by participants coincided with Greipp's ethical decision-making model. Participants clearly indicated that making a decision to participate in MAiD is complex. Patient autonomy was a central ethical principle. Additional guidance/ethical training is needed by front line staff who are involved in the provision of MAiD. To prevent moral residue, resources and support are needed for palliative care nurses caring for patients receiving MAiD. Supportive workplace policies for palliative care nurses who engage in patient and family end-of-life decision making in the wake of MAiD legislation is a moral imperative for all organizations who are involved in the provision of MAiD.

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[sc/documents/services/publications/health-system-services/medical-assistance-dying-](https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/medical-assistance-dying-interim-report-june-2018/medical-assistance-dying-interim-report-june-2018-eng.pdf)

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APPENDIX A: INTERVIEW QUESTIONS

Preamble:

Thank you for participating in the quantitative survey and for agreeing to participate in a follow-up interview. The findings of the quantitative study suggest that nurses have very divided perspectives about MAID. In this qualitative study, we would like to understand why this is the case. We would also like to understand how palliative care nurses apply ethical principles when working with patients who request MAID

Did you receive and review the Letter of Information for Consent that was sent to you? Do you have any questions about the research study before we proceed to the consent process?

Consent:

I will review the Letter of Information again with you and invite you to ask any questions.

- Do you consent to participating in this interview? (If no, thank participant)
- Audiotaping of your interview is voluntary and you may withdraw any time by requesting that the taping be stopped. Your name will not be revealed to anyone and your audio-recording will be kept confidential and used only for the purpose of this study. Do you consent to audio-recording? (If no, inform participant that you will take notes).

Interview Questions:

I will ask several questions. In addition to answering the questions, I invite you to share any other information from your experiences that might be helpful in informing the research. You may choose to not answer any questions that you prefer not to. Please feel free to tell me this and there will be no judgment on my part.

Insert demographic questions here....

- Where working?
- Participated in MAID? Work with other palliative care nurses and/or nurse practitioners who participate in MAID?
- Years working in nursing? palliative care?

Not all nurses experience the same situation in the same way, and a situation that causes conflict, uncertainty or distress for some nurses may be straightforward for others.

1. The decision to participate or not participate in MAID is a very ethical one. What has influenced your decision to participate or not participate in MAID? Do you use a framework, structure or specific process when making an ethical decision? -

Thank participant then indicate you wish to dig a bit deeper....

2. Decisions about participating in MAID can be influenced a person's application of ethical principles such as autonomy, beneficence, non-maleficence, and the nursing code of ethics. I will briefly review some

ethical principles/values to help our discussion, and then ask for your perspectives.

Define autonomy, beneficence, and non-maleficence.

- How do you (or do you) apply these principles in your practice as a palliative care nurse?
 - How have they or might they influence your decision about participating in a medically assisted death?
 - Should one be prioritized over the others in palliative care nurse decisions about MAID?
3. How do you prioritize your sense of duty, responsibility and accountability as it relates to MAiD? What do you think are some of the consequences of participating or not participating in MAiD for patients and palliative care nurses? How has this influenced (or not influenced) your decision to participate in MAID?
 4. The CNO identifies several ethical values as being important in providing nursing care (examples, client wellbeing, client choice, respect for life, maintaining commitments, truthfulness, fairness). When two or more ethical values apply to a situation, but they support diverging courses of action, an ethical conflict or dilemma exists. How do you apply these values to decisions about MAID?
 5. Tell me about any other factors that have influenced your attitudes and values about MAID (probe for inhibitors - personal and professional experiences, culture, and personal beliefs). How have your

relationships/interactions with patients and families influenced your views and attitudes about MAID?

6. What supports are most needed by palliative care nurses? Think about organizational, educational and professional supports.
- What education do you feel is important or imperative to nurses regarding MAID? - probe communication and ethics training; if they agree, what specifically is needed?
 - Are you provided any support (prompt types of support such as emotional, organizational, education) in the workplace in regards to MAID? If so, what is it? If not, what kind of support do you feel nurses need in regards to MAID? - probe debriefing, conscientious objection.
7. Before we close, do you have anything else you would like to add?

This concludes the interview. Thank you again for participating. You may withdraw your responses now and up until one week from today. This will be *[provide date]*.

Please contact Dr Pfaff if you would like to do so. Her contact information is on the Letter of Information. Do you have any questions or further comments before we end our call?

APPENDIX B: LETTER OF INFORMATION FOR CONSENT



LETTER OF INFORMATION FOR CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: **The Attitudes, Values, Beliefs and Experiences of Hospice/Palliative Care Nurses and Nurse Practitioners with Medical Assistance in Dying: A Qualitative Follow-Up Study**

You are asked to participate in a research study conducted by Kathryn Pfaff, PhD, Dr. Laurie Freeman, PhD, Dr. Linda Patrick, PhD, Dr. Kathryn Edmunds, PhD, Lauren Kopchek, BScN, RN, and Ms. Jordyn Liebman, from the Faculty of Nursing at the University of Windsor. Parts of the study will be used to support the thesis component of Lauren Kopchek's Master's of Science in Nursing degree.

If you have any questions or concerns about the research, please feel to contact Kathryn Pfaff at 519-253-3000 extension 4977 or by e-mail at kpfaff@uwindsor.ca.

PURPOSE OF THE STUDY

This is a follow-up qualitative study that we are conducting to better understand the attitudes, values, beliefs and practice experiences of palliative care nurses and nurse practitioners (NPs) in Ontario since the legalization of Medical Assistance in Dying (MAID) in Canada. The findings of our quantitative study suggest that palliative care nurses and nurse practitioners have either strong positive attitudes toward MAID as a health care service for palliative care patients **OR** they have strong negative attitudes toward MAID. This study will help us to understand these findings, along with the supports needed by Ontario's nurses and nurse practitioners as a result of the legislation.

PROCEDURES

If you volunteer to participate in this study, you will be asked to participate in an interview that will take place over the phone. It will last approximately one hour. It will be audio-recorded but you can still participate if you prefer not to be audio-recorded.

POTENTIAL RISKS AND DISCOMFORTS

This research does not involve any physical risks, but it is possible that you may feel uncomfortable or experience negative emotions when remembering and sharing difficult experiences that you may have encountered regarding MAID. You also may be concerned that your employer is aware of your attitudes and values about MAID. If you require support as a result of participating in this study, there are resources listed at the end of this document that you are encouraged to access.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

There are no direct benefits associated with participating in this study. The information gathered in these interviews will help us to understand what influences palliative care nurses' and nurse practitioners' attitudes about MAID, their decisions about participating in MAID, and how organizations can best design policies that support the needs of patients, families, palliative care nurses and NPs in Ontario.

COMPENSATION FOR PARTICIPATION

There will not be any compensation for participating in this study.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. We commit to maintaining the confidentiality of your information; however, there is always a chance that computers can be hacked. If you consent to audio-recording, your data will be electronically deleted after it is transcribed and checked for accuracy. Your real name will not be connected with any of your responses. Pseudonyms will be used for all participant quotes and we will not report any quotes that may make you or your organization identifiable. The transcripts will be stored in a password-protected computer. Only members of our research team will have access to your transcripts. Data will be kept indefinitely for potential use in future studies.

PARTICIPATION AND WITHDRAWAL

Audiotaping of your interview is voluntary and you may withdraw any time by requesting that the taping be stopped. You may withdraw from this research study up to one week after participating in your interview. You may do this by contacting Kathryn Pfaff using the information provided on the previous page. After one week, you will be unable to withdraw as we will be in the process of combining your data with the data of other participants. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A summary of the research findings will be posted on the University of Windsor's scholarship website by August 31, 2019.

Website access: <https://scholar.uwindsor.ca/>

SUBSEQUENT USE OF DATA

These data may be used in subsequent studies, in publications and in presentations.

RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

Date

Supportive Resources

In the event that you perceive psychological distress or concern about your emotional well-being, the following resources may be helpful:

1. Your Employee Assistance Program (if available in your organization)
Provides confidential support for workers
2. Mental Health Helpline
Service is 24/7

1-866-531-2600
3. Distress and Crisis Ontario
Service is 24/7
416-486-224

For questions about nursing practice questions related to MAID, please visit:

- <http://www.cno.org/en/trending-topics/medical-assistance-in-dying/>
- <http://www.cno.org/en/trending-topics/medical-assistance-in-dying/medical-assistance-in-dying--faqs/>
- <http://www.cno.org/en/trending-topics/medical-assistance-in-dying/medical-assistance-in-dying--additional-resources-and-references/>

APPENDIX C: LETTER OF CONSENT FOR INTERVIEW



LETTER OF INFORMATION FOR CONSENT TO PARTICIPATE IN RESEARCH (Interview)

Title of Study: **How do Palliative Care Registered Nurses Apply Concepts of Ethical Decision Making When Caring for Patients who Request Medical Assistance in Dying?**

You are being asked to participate in a qualitative research study conducted by **Lauren Kopchek**

If you have any questions or concerns about the research, please feel to contact Lauren Kopchek at (519) 253-3000 ext. 7484.

PURPOSE OF THE STUDY

This qualitative study is a follow-up to the on-line survey that you completed in October, 2017. The purpose of this study is to better understand how the attitudes and experiences of RNs influence support or lack of support for Medical Assistance in Dying (MAID) in Ontario. It will also explore the professional and organizational supportive needs of palliative care RNs regarding MAID.

PROCEDURES

If you volunteer to participate in this study, you will participate in a telephone interview that will last approximately 45 minutes to an hour in length. You will share your thoughts about several questions, and will be invited to offer any additional information that you feel is important to share.

POTENTIAL RISKS AND DISCOMFORTS

This research does not involve any physical risks, but is possible that you may feel uncomfortable or experience negative emotions when remembering and sharing difficult experiences that you may have encountered regarding MAID.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

By participating in this follow up interview phase of the research, you may increase your self-awareness of your values and beliefs about MAID. You may also feel empowered by sharing your attitudes and perspectives. The information gathered in these interviews will also help the researchers understand and communicate the support needs of palliative care RNs and NPs, and nursing policies and practices that guide MAID in Ontario.

COMPENSATION FOR PARTICIPATION

There will not be any compensation for participating in this study.

CONFIDENTIALITY

We will maintain confidentiality of your information. All recorded data will be deleted immediately after it is transcribed. You will not be identified with your data and it will be stored on a password-protected computer. Only Kathryn Pfaff, Lauren Kopchek and trained members of our research team will have access to the database. Data will be kept for potential use in future studies. Once it is no longer needed, it will be electronically deleted.

PARTICIPATION AND WITHDRAWAL

You can choose whether or not to participate. If you do participate, you may refuse to answer any questions you don't want to and still remain in the study. You decide whether or not to be audio-recorded, and can ask that your responses be deleted at the completion of the interview. You won't be able to delete your recording after transcription, as we won't be able to identify your data once the data analysis begins which will be approximately one week after your interview.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A summary of the results of this research will be made available on the University of Windsor research site (www.uwindsor.ca/reb). It is anticipated that these results will be available in June, 2019. Links to any publications that arise from the research will be made available on the Faculty of Nursing's website.

Web address: <http://www.uwindsor.ca/nursing/>.

Date when results are available: June, 2019

SUBSEQUENT USE OF DATA

These data may be used in subsequent studies, in publications and in presentations.

RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

Date

APPENDIX D: LETTER OF PARTICIPATION



Dear Palliative Care Colleague,

Thank you for your commitment to nursing research. We were able to reach you because of you granted permission to the College of Nurses of Ontario to share your contact information for the purpose of research when you last renewed your license to practice.

We are writing to you to invite your participation in a research study entitled: **How do Palliative Care Registered Nurses Apply Concepts of Ethical Decision Making When Caring for Patients who Request Medical Assistance in Dying?**

Participation in MAID has potential to create moral and ethical distress among hospice palliative care nurses. Although the Ontario Ministry of Health and Long-Term Care allows for healthcare providers to decline involvement in medically assisted death, nurses must transfer care to a colleague who is willing, and has the knowledge, skill, and ability to provide care (College of Nurses of Ontario, 2016).

Not all hospice palliative care nurses feel conflicted about engaging in medically assisted death and it is unclear why this is the case. Because palliative care practitioners experience higher levels of emotional burden than those who work in other settings (Rokach, 2005), it is important to understand the attitudes, beliefs, and practice experiences of hospice palliative care nurses and NPs. Your perspectives may help develop policies and practices that address how to best integrate MAID, and how to support the professional practice needs and psychological wellbeing of palliative care nurses and NPs.

Your participation would involve completing a 45 min to hour in length telephone interview that will be audio recorded.

Your participation is both voluntary and confidential. A follow up email will be sent to confirm the date and time of the telephone interview.

We appreciate your consideration of this research project. The study has received ethics clearance from the University of Windsor. If you have questions about the study, please feel free to contact either of the researchers listed below.

With kindest regards,

Kathryn Pfaff, PhD, RN
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