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When Patients Ask to Die: The Role of Nurses in Medical Assistance in Dying

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Abstract

Canadians older than 64 years now outnumber persons under 14 years and are increasingly living with chronic illness heightening the importance of palliative and end of life care. Nurses have significant involvement in end of life care which, in Canada, may now include assisted death. This study used interpretive description, a qualitative methodology, to explore the perspectives of nine palliative care nurses regarding best practices in care related to MAiD. The analysis produced three overarching themes of: (a) **Business as usual** which reflects participants' perspective that MAiD is an aspect of existing practices in end of life decision making in palliative care; (b) **Nursing role within MAiD** discusses the importance of patient centred care and includes assessment, liaison, intervention and bereavement; and (c) **Support for Nurses to Provide MAiD Care** reflecting the support required for nurses providing this care and includes (a) palliative education required, (b) conscientious objection to MAiD, and (c) give and take of the final intervention. Best practices for end of life nursing care may be better aligned using the concept of patient directed death. The findings from this study can inform nursing best practices related to MAiD in order to support patients' experience of a 'good death'.

Keywords: Medical assistance in dying; MAiD; assisted death; nursing; role; support

Co-Authorship Statement

Contributions to this paper were made by the advisory committee: Dr. Lorie Donelle,
Dr. Sandra Regan and Dr. Ken Kirkwood.

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Chapter 1

Introduction and Background

Palliative care and issues surrounding end of life are increasingly a concern of Canadians. In the middle of the twentieth century, Canadians aged 14 years and younger outnumbered older people; but now, for the first time in history, persons aged 65 years and older outnumber persons aged 14 and under (Statistics Canada, 2016). Among this aging population, chronic illness including cancer and progressive diseases of the heart, lung and neurological systems constitute the leading causes of death in Canada (Statistics Canada, 2015). In fact, more than half of Canadians will experience life-threatening illnesses, frequently with debilitating and distressful symptoms that lead to a loss of function and ability to care for themselves (Canadian Hospice Palliative Care Association, 2013; Statistics Canada, 2015). Within the context of an aging population with an increased incidence of chronic illness and associated symptoms that impact quality of life, a new legislation legalizing assisted death within Canada has been passed.

There is growing awareness among health care system leaders, care providers and patients regarding the need for quality palliative care for those facing these life threatening illnesses (Canadian Hospice Palliative Care Association, 2013; Paetkau et al., 2011). Palliative care is understood to be "... an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization, n.d. para. 1). End of life care is a component of palliative care and refers to care of people who are in decline and who are deemed to be terminal, or dying in the foreseeable future (Canadian Institute of Health Research,

2011). Even in the context of quality palliative care, some people find their physical and/or psychological suffering intolerable and consequently individuals have chosen to hasten their own death with assistance from a physician (Steck, Egger, Maessen, Reisch, & Zwahlen, 2013). The choice for assistance to die became a legal option in Canada for competent, adult, terminally ill patients in 2016 so long as they have been provided with information for available treatment options to relieve their suffering (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3). Even though Canadians may now legally consider “medical assistance in dying” or MAiD, as this has come to be known, as an option when faced with a terminal illness, the role and the perspectives of members of the multidisciplinary team beyond physicians and nurse practitioners is largely unknown.

While polarized opinions of support and opposition exist on the topic of MAiD, general public opinion polls in the last decade have consistently shown that the majority of Canadians are in favour of some form of assisted death for terminally ill patients (Ghose, 2014). Ipsos-Reid (2014) found that 84% of Canadians feel that a doctor should be able to support the wishes of a terminally ill, competent, adult who is suffering unbearably and who wants to end their life. This public support of assisted death included individuals who identified as disabled, who identified as Roman Catholic, groups that are typically considered to be opposed to MAiD out of concern for vulnerable persons, or contradiction to their faith (Ipsos-Reid, 2014).

The request for assisted death in Canada has been before the Canadian judicial system for over twenty-five years. In 1993, Susan Rodriguez, a 42 year old woman with a diagnosis of amyotrophic lateral sclerosis (ALS) (a progressive and life limiting disease

that leaves cognitive functions intact but leads to progressive paralysis and pain, and given a prognosis of less than a year of life) requested the right to end her life. At that time, medical assistance in dying was not a legally sanctioned intervention for end of life care; Ms. Rodriguez petitioned the courts to request assistance to end her life at a time of her choosing and with the help of a qualified physician. After a highly publicized process, Ms. Rodriguez lost her case in the Supreme Court of Canada for her right to assisted death (Beaudoin & Marshall, 2016). The fact that the judges were split in the decision to legalize physician assisted death by 5-4 suggested that decriminalizing assisted death had considerable support.

Nineteen years later, in 2012, the Supreme Court of Canada debated the issue again, and in 2015 provided unanimous support in favour of assisted death for the families of Kay Carter and Gloria Taylor (Butler & Tiedemann, 2015). Ms. Carter suffered with spinal stenosis which is a disease that causes progressive pain and mobility limitations while leaving cognitive functions intact. She travelled to Switzerland in 2010 to access assisted death. Ms. Taylor suffered with symptoms from amyotrophic lateral sclerosis (ALS) (Butler & Tiedemann, 2015). Ms. Taylor had received a court order allowing her an assisted death but passed away before she chose to act upon this (CBC News, 2012). Legislation that amended the criminal code to allow for the provision of MAiD followed in 2016 (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3). The intervention – medical assistance in dying (MAiD), is defined in Canadian legislation as “**(a)** the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or **(b)** the prescribing or providing by a

medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death” (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3, s. 241.(1)). A person qualifies for MAiD when

“(a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada; (b) they are at least 18 years of age and capable of making decisions with respect to their health; (c) they have a grievous and irremediable medical condition; (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3, s. 241.2 (1)).

No research exists in Canada on the nursing role in MAiD from the perspective of palliative care nurses. The purpose of this research is to explore the nursing role in assisted death (MAiD), in the Canadian context.

Terminology

Different terms are used to describe the medical hastening of a patient’s death. *Euthanasia* is often the term used to describe the active role of a physician who would administer the lethal medication (Georges, Onwuteaka-Philipsen, & van der Wal, 2008; Norwood, Kimsma, & Battin, 2009; Norwood, 2007; van Bruchem-van de Scheur et al.,

2008; White, Wise, Young, & Hyde, 2009). *Physician assisted suicide*, or *physician assisted dying* are often used to describe the passive role of a physician; a physician prescribes a lethal dose of medication to a consenting and terminally ill person who would then self-administer the medication at the time of their choosing (Harris, 2014; Jannette, DeWolf Bosek, & Rambur, 2013; DeVeer, Francke, & Poortvliet, 2008; Voorhees, Rietjens, van der Heide, & Drickamer, 2014). The term *MAiD* in the Canadian legislation allows for both passive and active forms of assisted death. The general term ‘assisted death’ is used in this paper in reference to patients wanting medical assistance to die; and the term *MAiD* will be used when discussing the act of assisting death specifically within the Canadian context.

This study focuses on the role of Registered Nurses (RNs); a protected title that requires licensing from the College of Nurses of Ontario (CNO). The protected title Nurse Practitioner (NP), specifically named in *MAiD* legislation, differs from that of the RN. The NP is an extended class of registration that gives NPs authorization for controlled acts in addition to the scope of practice of an RN; including communication of a diagnosis, prescribing or dispensing of medication; and now determining eligibility for, and provision of *MAiD* (*Regulated Health Professions Act*, 1991, SO 1991, c. 18).

Existing Legislation Regarding Assistance to Die

In the United States, physician assisted death was legalized in the state of Oregon in 1997, with Washington State following in 2009, and more recently Vermont, California, Colorado and District of Columbia (Cable News Network, 2017); Belgium and the Netherlands legalized euthanasia in 2002; and Luxembourg legalized assisted death in 2009 (Dalhousie University Health Law Institute, n.d.). Common criteria used in considering eligibility for assisted death include: age of majority or the ability to provide

competent consent; capacity to consent; diagnoses of serious and incurable disease; pain and suffering that cannot be relieved; the request for assisted death is informed and made of free will (Steck et al., 2013). Consistent across most practices is that the patient must make the request for assisted death both verbally and in writing; have completed two separate medical evaluations, and observe a specified period of reflection (Dalhousie University Health Law Institute, n.d.). In all locations where assisted death is legislated, physicians hold the authority to prescribe and to administer medications for assisted death except for Canada, where Nurse Practitioners also have the authority for this controlled act (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3). Common responsibilities for professionals who provide the assisted death intervention include observing that all eligibility criteria and conditions are completed, and engaging in one or more consultations with other members of the health care team and the patients' family about the nature of the patients' request unless this last point is opposed by the patient (Dalhousie University Health Law Institute, n.d.).

In Canada, (1972) the act of suicide itself is legal, but section 241 of the Criminal Code states: "Everyone who (a) counsels a person to commit suicide, or (b) aids or abets a person to commit suicide, whether suicide ensues or not, is guilty of an indictable offence and is liable to imprisonment for a term not exceeding fourteen years" (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3, s. 241.(1)(a)). On February 6, 2015, the Supreme Court of Canada released its unanimous ruling that prohibiting assisted suicide for persons suffering from grievous and irremediable medical conditions goes against the

Charter of Rights and Freedoms (*Carter v. Canada (Attorney General)*, 2015, SCC 5). Amendments to legislation followed, both on federal and provincial levels, to allow physicians and nurse practitioners to provide MAiD. The legislation legalizing the provision of MAiD has significant implications for nurses and particularly nurses working in palliative and end of life care settings.

Nurses' engagement with patients requiring palliative care entails a significant amount of time spent directly with patients relative to all other health care professionals (Canadian Nurses Association, 2017). However, discussion of the nursing role within MAiD has been absent in the current legislation. The Criminal Code was amended to allow legal provision of MAiD and affirms that "for greater certainty, no social worker, psychologist, psychiatrist, therapist, medical practitioner, nurse practitioner or other health care professional commits an offence if they provide information to a person on the lawful provision of medical assistance in dying" (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3, s. 241.(1)). However, nurses are not specifically named, and the term 'other health care provider' is not defined in Bill C-14. Nurses are also not specifically discussed in corresponding provincial legislation (*Medical Assistance in Dying Statute Law Amendment Act*, S.O. 2017 C.7).

Guidance for Nurses Regarding Assisted Death

Despite patients' inquiry about assisted death even when it was not legal (De Bal, Gastmans & Dierckx de Casterlè, 2008), professional nursing organizations and regulatory bodies did not support Canadian nurses to have the discussions about assisted death that their patients initiated. In 2008, the national nursing organization, the Canadian Nurses Association (CNA), posted a position statement on the provision of nursing care

at the end of life that did not address the role of the nurse when patients ask about assisted death and furthermore neglected to mention the topic at all (Canadian Nurses Association, 2008). The standard of care published by the College of Nurses of Ontario (CNO), the provincial nursing body that regulates nurses in the public interest, states “Nurses must keep in mind that euthanasia and assisted suicide are illegal; there is no role for nurses in facilitating these activities” (College of Nurses of Ontario, 2009, p.3). However, the standard also stated that the role of Ontario nurses in end-of-life care was to “support clients at the end of their lives and in making decisions about end-of-life care; support informed discussion about care goals and treatment options; contribute to client well-being by facilitating the implementation of the client’s wishes about end-of-life care and knowing and understanding current legislation” (College of Nurses of Ontario, 2009 p.3). Aspects of this professional standard contained contradicting statements, stating there is no role for nurses, but expecting nurses to support informed discussions about patients’ end of life care goals which may have included assisted death.

As expected, the legislative change to allow MAiD has created an impetus for organizations such as CNO and CNA to update their positions on the provision of nursing care within the context of MAiD to better support nurses. This is especially important considering the prominent role of nurses in patient care; patients often seek information from and first speak about assisted death with nurses (Canadian Nurses Association, 2015). The CNA (2015) outlined recommended options for the legislative response to the Supreme Court of Canada’s ruling on assisted death and submitted this to the Government of Canada’s expert panel who developed the federal legislation for MAiD (Canadian Nurses Association, 2015). Two years later in 2017, the CNA developed a

national framework to guide the Canadian nursing role in MAiD (Canadian Nurses Association, 2017). The CNO released an interim guide in 2016 for nursing practice in the context of MAiD to offer guidance to practicing nurses while the federal legislation regarding assistance in dying was developed (College of Nurses of Ontario, 2016). The provincial nursing association in Ontario, the Registered Nurses Association of Ontario (RNAO), has taken a lead in encouraging public dialogue and engaging its membership to participate in opinion polls on MAiD. However, as of July 2017, RNAO had no policy statement or position statement regarding MAiD and an online website search using the term 'MAiD' yielded no results. (Registered Nurses Association of Ontario, 2015).

The American Nurses Association (ANA) (2013) Code for Nurses specifies that nurses should not deliberately terminate the life of any person (American Nurses Association, 2013) but the document offers no additional guidance regarding the role of the nurse in assisted death of a terminally ill patient. Similarly, the International Council of Nurses (ICN) (2012) lacks clarity regarding the nursing role in assisted death, stating simply that the nurse's role in palliative care is to reduce suffering and improve the quality of life for dying patients and their families (International Council of Nurses, 2012).

In Oregon, where assisted death was legalized in 1998, the Oregon Nurses Association developed a position statement that neither supported nor opposed assisted death; the position statement provides guidance to nurses involved in caring for an individual at the end of life (Oregon Nurses Association, 1997). The position statement emphasizes the role of the nurse in terms of patient advocacy, improved patient comfort,

patient education on health care choices and support of the patient and their family; and provides direction for nurses who choose to support assisted death and for those who do not. Guidelines direct nursing care in assisted death and support nurses and patients by providing direction to assist patients (Denier, Gastmans, De Bal, & Dierckx De Casterlé, 2010).

Nurses are confronted with patient requests for assisted death regardless of the (il)legal status of the act (De Bal et al, 2008). This demonstrates a nursing role, recognized or not, that begins as soon as the topic is raised within the nursing therapeutic relationship (Denier, De Casterlé, De Bal, & Gastmans, 2009). End of life discussions between patients, the family caregivers, and nurses provide the patient and family with the opportunity to prepare for dying and death, and also ensure that care provided at the end-of-life is consistent with patients' values (Walczak et al., 2014).

Supporting conversations about assisted death with patients and families opens the dialogue to the discussion of many important end of life issues (Dobscha, Heintz, Press, & Ganzini, 2004; Norwood et al., 2009; Voorhees et al., 2014; White et al., 2009). Answering questions about assisted death provides an opportunity for discussion of current treatment options and end of life issues with patients and their family members, and supports a better understanding of a patient's beliefs about these issues (White et al., 2009). A good death, or "a death that has positive psychological benefits for the dying person, their family and their professional caregivers" (Smith & Maher, 1993. p. 22) depends primarily on self-determination, or what dying people consider good or bad (Goldsteen et al., 2006), making nurses' understanding of these beliefs an important part of quality end of life care. Nurses can make a significant contribution to patients' quality

of care by supporting these discussions with patients, families, physicians and other nurses in a professional manner, even in countries where assisted death is not legal (Del Bal et al., 2008). However, there is little guidance for nurses on how to manage these conversations. The Supreme Court has ruled that it is unconstitutional to deny a terminally ill person with intolerable suffering with death in the foreseeable future, the right to assisted death. Counselling individuals to commit suicide, or encouraging suicide is rightfully illegal, and different from a nurse responding to a patient requesting help to die, and different from a nurse – patient discussion about end of life options (including MAiD). Historically, nurses had to balance the need to address patient request for - or inquiry into - assisted dying with possible legal prosecution when fielding requests from terminally ill patients for help to die; thus highlighting the need for clarity of the nursing role with MAiD. Without clear and consistent guidelines for nurses, there is a risk that patients may not have access to information and services for all end of life options; despite the federal government of Canada's recognition of the importance of understanding end of life care options and support of programs to encourage all Canadians to engage in dialogue about advanced directives and end-of-life care planning (Canadian Hospice Palliative Care Association, n.d.).

Declaration of Self

I have spent 12 years in a clinical role as a Nurse Practitioner (NP) in community care, delivering home-based palliative care to terminally ill people and their family, friends and caregivers. I have experienced and observed situations where there is limited guidance as to how to respond or react when a patient expresses desire to die statements. I recognize that my experiences within my NP role have sensitized me to factors that I

have encountered in the context of providing end of life care to patients within the home care setting. Patton (2002) notes that an entirely objective voice is impossible, but a completely subjective voice will undermine credibility of the findings. Thus it was important to be self-analytical, aware and reflexive of my own beliefs about the provision of quality end of life nursing care and my position on the provision of MAiD that resulted from my experience in order to understand and authentically depict the findings of this study (Patton, 2002). I acknowledge my position on the provision of nursing care in the context of MAiD and used consultation with expert faculty advisors, and processes such as journaling to enhance transparency.

The purpose of this research was to explore the experiences of palliative care nurses providing end of life care in order to inform best practices regarding the role of nurses in care related to MAiD. This research may contribute to policy changes for palliative nursing practice, and enhance the care provided to patients.

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Chapter 2

Introduction / Background

Canada's demographic composition is changing; for the first time, Canadian adults aged 65 years and older outnumber children aged 14 years and under (Statistics Canada, 2016). Health care services are needed to meet the demands of an aging population and an increased prevalence of cancers and progressive diseases of the heart, lung and neurological systems that make up the leading causes of death in Canada (Statistics Canada, 2015). More than half of Canadians will experience a decline in their health, accompanied by distressful symptoms and will lose the capacity to care for themselves (Canadian Hospice Palliative Care Association, 2013; Statistics Canada, 2015). Increasingly, quality palliative care will be necessary for those facing these life threatening illnesses. With this aging population, increasing incidence of chronic illness with associated symptoms that impact quality of life along with the new legislation legalizing assisted death, there is increasing focus on these issues in Canada.

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organization, n.d. para. 1). End of life care is a component of palliative care and refers to the care of people who are in decline, who are deemed to be terminal, or dying in the foreseeable future (Canadian Institutes of Health Research, 2011). Regardless of the quality of palliative care, at end of life, some individuals may find their physical or psychological suffering intolerable and may choose to hasten their own death (Steck et al., 2013). The choice to hasten death became an option in Canada

for competent, adult, terminally ill patients in 2016 so long as they have been provided with information for all available treatment options to relieve their suffering (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3.). Even though Canadians may now consider MAiD an option for end-of-life care, there is little known about the role of the multidisciplinary team involved in the care of these patients, including nurses.

Increased public awareness regarding medical assistance to die (MAiD) began in 1993 when Sue Rodriguez, a woman with a life expectancy of less than one year due to her diagnosis of amyotrophic lateral sclerosis (ALS), was not successful in her quest to have a death assisted by a qualified physician (Beaudoin & Marshall, 2016). The Canadian judicial system debated the issue of assisted death again in 2015 largely in response to requests for assistance to die from Kay Carter and Gloria Taylor (Butler & Tiedemann, 2015). The outcome of the judicial proceedings for Carter and Taylor contributed to the legalization of assisted death in Canada, termed Medical Assistance in Dying (MAiD). Canadian legislation defines MAiD as “**(a)** the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or **(b)** the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death” (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3, s. 241.(1)). A person qualifies for MAiD when “(a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada; (b) they are at least 18

years of age and capable of making decisions with respect to their health; (c) they have a grievous and irremediable medical condition; (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care” (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3, s. 241.2(1)).

The legislation legalizing the provision of MAiD has significant implications for all nurses and particularly nurses working in palliative and end of life care settings. Nurses engagement with patients who require palliative care entails a significant amount of time spent directly with patients relative to all other health care professionals (Canadian Nurses Association, 2017). However, the role of the nurse within the context of MAiD is seemingly absent in the current legislation. The Criminal Code was amended to allow legal provision of MAiD and affirms that “for greater certainty, no social worker, psychologist, psychiatrist, therapist, medical practitioner, nurse practitioner or other health care professional commits an offence if they provide information to a person on the lawful provision of medical assistance in dying” (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3, s. 241. (1)(a)). This study focuses on the role of Registered Nurses (RNs); a protected title that requires licensing from the College of Nurses of Ontario (CNO). The protected title Nurse Practitioner (NP), mentioned in MAiD legislation, differs from that of the RN. The NP is an extended class of registration that gives NPs authorization of additional controlled acts in addition to the scope of practice of an RN; including

communication of a diagnosis, prescribing or dispensing of medication among others (*Regulated Health Professions Act*, 1991, SO 1991, c. 18). While Nurse Practitioners are included in the legislation for MAiD as being authorized to determine patient eligibility for, and provision of MAiD, nurses are not specifically named, and the term ‘other health care provider’ is not defined in Bill C-14. Nurses are also not specifically discussed in corresponding provincial legislation ON-Bill 84 (*Medical Assistance in Dying Statute Law Amendment Act*, S.O. 2017 C.7).

Despite the fact that patients have asked nurses about assisted death even when it was not legal (Del Bal, Gastmans, & Dierckx de Casterlè, 2008), Canadian nurses had not been given direction from their professional organizations and regulatory bodies or educational preparation as to how to deal with patient initiated conversations on assisted death. The act of assisted death was illegal, as was the act of counselling suicide and so nurses were left to deal with these questions blindly. In 2008, the national nursing organization, the Canadian Nurses Association (CNA), offered a position statement on the provision of nursing care at the end of life that did not address the nursing role when patients ask about assisted death (Canadian Nurses Association, 2008). The standard of care published by the College of Nurses of Ontario (CNO), the provincial nursing regulatory body that regulates nurses in the public interest, stated “Nurses must keep in mind that euthanasia and assisted suicide are illegal; there is no role for nurses in facilitating these activities” (College of Nurses of Ontario, 2009, p. 3). However, the standard also states that the role of Ontario nurses in end-of-life care is to “support clients at the end of their lives and in making decisions about end-of-life care; support informed discussion about care goals and treatment options; contribute to client well-being by

facilitating the implementation of the client's wishes about end-of-life care and knowing and understanding current legislation" (College of Nurses of Ontario, 2009, p. 3).

Seemingly, the professional standard contained contradicting statements; on one hand stating there is no role for nurses, while on the other hand expecting nurses to negotiate discussions about patients' end of life care goals, which may have included assisted death, while being mindful of existing legislation.

The legislation to allow MAiD provided the impetus for organizations such as CNO and CNA to reflect upon and update their policy positions to better support nurses. This is especially important considering the prominent role nurses play in palliative and end of life patient care (Canadian Nurses Association, 2015). The CNA (2015) outlined recommended options for the legislative response to the Supreme Court of Canada's ruling on assisted death and submitted this to the Government of Canada's expert panel for consideration when developing legislation for MAiD (Canadian Nurses Association, 2015). Two years later in 2017, the CNA developed a national framework to guide the Canadian nursing role in MAiD (Canadian Nurses Association, 2017). The CNO released an interim guide regarding assisted dying to offer direction to practicing nurses during the time the MAiD legislation was being developed (College of Nurses of Ontario, 2016). The provincial nursing organization in Ontario, the Registered Nurses Association of Ontario (RNAO), has taken a lead role in encouraging public dialogue on MAiD, but as of July 2017, RNAO had no publicly available policy statement or position statement regarding MAiD (Registered Nurses Association of Ontario, 2015).

Nurses have been confronted with patient requests for assisted death regardless of the (il)legal status of the act (De Bal et al., 2008). The role for nurses in MAiD, begins as

soon as the topic is raised by the patient with the nurse (Denier, De Casterié, De Bal, & Gastmans, 2009). End of life discussions between patients, family caregivers, and nurses provide the opportunity to prepare for dying and death, and ensure that the provision of care is consistent with patient values (Walczak et al., 2014). Allowing conversations about assisted death opens the dialogue to the discussion of many important end of life issues (Dobscha, Heintz, Press, & Ganzini, 2004; Norwood et al., 2009; Voorhees et al., 2014; White et al., 2009). Similarly, answering patients' questions about assisted death provides an opportunity for discussion of current treatment options and end of life issues with patients and their family members, and allows a better understanding of a patient's beliefs about these issues (White et al., 2009). Since a good death, or "a death that has positive psychological benefits for the dying person, their family and their professional caregivers" (Smith & Maher, 1993. p. 22) depends primarily on what dying people consider good or bad, or self-determination (Goldsteen et al., 2006), understanding these beliefs is an important part of quality end of life care. Nurses can and do make a significant contribution to the quality of patients' care by supporting these discussions with patients, families, physicians and other nurses in a professional manner, even in countries where assisted dying is not legal (Del Bal et al., 2008). However, there is little guidance for nurses on how to negotiate and conduct these conversations.

The Supreme Court has ruled that it is unconstitutional to deny a terminally ill person with intolerable suffering and facing death in the foreseeable future, the right to assisted death (*Carter v. Canada*, 2015, S.C.C. 5.). In essence counselling for suicide, or encouraging suicide is rightfully illegal, but different from a nurse responding to a patient requesting help to die, and different from a nurse – patient discussion about end of life

options (including MAiD). Historically, Canadian nurses had to balance the need to address patients' request or inquiry into assisted dying with the reality of possible legal prosecution; highlighting the need for clarity of the nursing role with MAiD. Without clear and consistent guidelines supporting nurses to have these end-of-life discussions, there is a risk that patients may not have access to information and services for all end of life options available to them.

Nurses have a significant involvement in the provision of end of life care to terminally ill patients (Canadian Nurses Association, 2017). However, there is little discussion in the current legislation and existing policy about the role of nurses with assisted death (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3.). With the legalization of MAiD in Canada (2016), it is imperative to better understand the nursing role in MAiD and how to support nurses who have legislative permission to discuss assisted dying options with their patients and the patients' families.

Review of the Literature

A review of research literature on the nursing role in assisted death was conducted to inform this research. Scopus, CINAHL and ProQuest Nursing databases were searched using the terms euthanasia OR assisted dying OR assisted suicide OR medical assistance in dying; AND nursing AND role. No restriction in time frame was made as many studies took place when legislation was being developed in different countries and a time restriction may have unnecessarily excluded important research. Five hundred and sixty-six articles were identified using the following inclusion criteria for this literature review: (a) English language (b) focus of the article was the role of nurses in assisted death.

Articles were excluded if there was a (a) focus on role of physicians in assisted death, (b)

focus on attitude of nurses in regards to assisted death, as this study is concerned with the role rather than attitude of nurses regarding assisted death. The abstract of each article was reviewed for relevance to inform this study; specifically discussing the role of nurses with assistance in dying. Twelve papers fit the criteria for eligibility for review.

The analysis of the research literature indicated that investigations on assistance in dying were conducted in the countries that first legalized assisted death: Belgium (Bilsen, Vander Stichele, Mortier, & Deliens, 2004; De Bal, Dierckx de Casterle, de Beer, & Gastmans, 2006; Denier et al., 2009; Dierckx de Casterlé, Denier, De Bal, & Gastmans, 2010; Gastmans, Lemiengre, & Dierckx De Casterlé, 2006; Inghelbrecht et al., 2009; Inghelbrecht, Bilsen, Mortier, & Deliens, 2010) and the Netherlands (de Veer et al., 2008; Muller, Pijnenborg, Onwuteaka-Philipsen, van der Wal, & van Eijk, 1997; van Bruchem-van de Scheur, van der Arend, Abu-Saad, et al., 2008; van de Scheur & van der Arend, 1998). There were no North American studies. A lack of studies on the Canadian nursing perspective was an expected result considering the recent timing of new legislation allowing access to MAiD. However, assisted death has been legal in some US states for 20 years.

The twelve articles reviewed included mostly quantitative, cross sectional survey studies (Bilsen et al., 2004; de Veer et al., 2008; Gastmans et al., 2006; Inghelbrecht et al., 2009, 2010; Muller et al., 1997; van Bruchem-van de Scheur, van der Arend, Abu-Saad, et al., 2008); two of which surveyed physicians regarding the role of nurses (Bilsen et al., 2004; Muller et al., 1997). One literature review was included in this review (De Bal et al., 2008). The analysis of the published research was thematically categorized as

(a) patient centred care and assisted death; (b) the nursing role when patients request help to die; and (c) policy supporting the nursing role with assisted death.

Patient Centred Care and Assisted Death

Nurses developed important and close relationships with patients who considered an assisted death, regardless of the country or care setting they practiced in (De Bal et al., 2006, 2008; Denier et al., 2010; Dierckx de Casterle et al., 2006). However, nurses felt powerless to provide quality end of life care when they did not feel able to help their patients who asked about assisted death, even where assisted death was illegal (De Bal et al., 2006). Nurses stated that their anxiety increased because they did not know how to respond or react to the patients' request for help to die (De Bal et al., 2006). In many cases nurses have advocated for legalization of assisted death in order to develop clear guidelines and facilitate open discussion for handling requests for assisted death in order to facilitate a positive patient death (De Bal et al., 2006). Being entrusted with a request for assisted death was seen as a positive experience for nurses who perceived this as a confirmation of patients' trust of the attending nurse (De Bal et al., 2006). Nurses were focused on respect for the patient's request and maintaining a strict division between their professional role and personal views when caring for patients who asked for help to die (Denier et al., 2009). It was important to nurses to show respect for the patient as a person in the broad sense of their unique life story, wishes, fears, and sources of suffering (Denier et al., 2009). These findings emphasize the importance of patient-centred care to nursing.

The Nursing Role when Patients Request Assisted Death

The role of nurses within assisted patient death included the role of (a) assessment (De Bal et al., 2006; Dierckx de Casterlé et al., 2010; van de Scheur & van der Arend, 1998); (b) consultation/decision making (Bilsen et al., 2004; De Bal et al., 2006; de Veer et al., 2008; Dierckx de Casterlé et al., 2010; Inghelbrecht et al., 2009; Muller et al., 1997; van de Scheur & van der Arend, 1998); (c) care during the procedure of assisted death (Bilsen et al., 2004; Dierckx de Casterlé et al., 2010; Inghelbrecht et al., 2009; van Bruchem-van de Scheur, van der Arend, Abu-Saad, et al., 2008; van de Scheur & van der Arend, 1998) and (d) bereavement or aftercare (Dierckx de Casterlé et al., 2010).

Assessment

The nursing assessment of a patient's request for assisted death began with their request to hasten death (van de Scheur & van der Arend, 1998). When confronted with a patient request for assisted death, nurses felt their role was to refrain from judgement, to clarify and confirm their understanding of the request, and report the request for assisted death to other members of the palliative care team (De Bal et al., 2006; Dierckx de Casterlé et al., 2010). Nurses felt they needed to give patients the opportunity to talk about the reasons for their request for assistance to die and to inform their patients about palliative care principles, end of life care alternatives and dying, and provide patients and their families with reassurance that resources will be available for them when needed (De Bal et al., 2006).

Decision Making and Consultation

Nurses participated in the decision making within the health care team as to whether to meet a patient's request for assisted death; specifically nurses would often be

the team member that reported the patient's request for assistance in dying to the rest of the palliative care team and supply information about the patient's needs and feelings (De Bal et al., 2006; Dierckx de Casterlé et al., 2010; van de Scheur & van der Arend, 1998). In Belgium, consultation of nurses, was a legal requirement of physicians providing assisted death, but did not always occur (Inghelbrecht et al., 2010). Surveys completed by Belgian physicians who had provided assisted death to patients demonstrated that the setting of care influenced the frequency of consultation with nurses when considering a patient's eligibility for assistance in death; where physician-nurse consultation occurred more often in hospital rather than the community setting (Bilsen et al., 2004). One study suggested that institutional policies that clarify the nursing role within assisted death interventions help to ensure that end-of-life decision making is consistent and not dependent on influencing factors (e.g., acute vs community settings) (de Veer et al., 2008). It is important to note that the research on assisted death and the role of nursing included in this review tends to position decision making about assisted death as a task within the healthcare team with little discussion of patient and family involvement, limiting the usefulness of these results in a patient-centred context.

The Intervention of Assisted Death

Research identified the nursing role in supporting patients and their families during the act of assisted death (van de Scheur & van der Arend, 1998). Preparation for assisted death included arrangements for the medication (e.g., starting intravenous access, preparing medication infusion pumps); and the setting (e.g., requested rituals like music, and people present and to support and monitor the people involved) (Dierckx de Casterlé et al., 2010). Although the administration of the life ending medication was exclusively

the role of the physician, there is evidence that nurses on occasion administered the medication; putting nurses at risk of prosecution and professional disciplinary measures (Bilsen et al., 2004; Denier et al., 2010; Dierckx de Casterlé et al., 2010). It is possible that the hierarchal relationship among doctors and nurses assigned nurses to a subordinate role and with limited power to refuse administration of life ending medications (Bilsen et al., 2004; Dierckx de Casterlé et al., 2010).

Bereavement Support

Only one study, a grounded theory study of nurses in Belgium, discussed the role of nurses in supporting bereavement of family members of patients who were assisted to die (Dierckx de Casterlé et al., 2010). Bereavement care provided immediately following an assisted death was consistent with bereavement care provided following natural death, and involved not only supporting the needs of the family, but also the health care team (Dierckx de Casterlé et al., 2010). Bereavement care involved nurses making contact with family members following a death, and participating in a formal debriefing with the health care team was important (Dierckx de Casterlé et al., 2010). In regards to caring for themselves, nurses felt the debriefing with colleagues was an important coping strategy; to talk about their experience and share the emotional burden served to relieve their tension and allowed them to continue to function in their personal and professional lives (De Bal et al., 2006).

Nursing Policies Related to Assisted Death

The nursing role in regards to assisted death was poorly articulated in institutional policies and professional guidelines in Flanders during the time of legalization, despite the fact that nurses are intimately involved in the care process for terminally ill patients

(Denier et al., 2009). Legal regulations can provide guidance to nurses about how to handle discussions about assisted death with patients and families (van Bruchem-van de Scheur et al., 2008; Voorhees et al., 2014). A Belgian study by Gastmans (2006) investigated assisted death policies in nursing homes and Catholic hospitals. Hospitals were more likely to have policies in place for nurses who were conscientious objectors to assisted death (nurses whose personal values conflict with assisted death), than nursing homes (Gastmans et al., 2006). Some hospitals allowed nurses who were conscientious objectors to excuse themselves from participating in assisting death, others allowed nurses who were conscientious objectors to remove themselves from the decision making process, and some institutions allowed nurses who were conscientious objectors to cease caring for patients who requested assisted death (Gastmans et al., 2006). The policies of each hospital offered one option to nurses who were conscientious objectors, not a choice of options that best accommodated their level of comfort with providing care.

In summary, previous research demonstrates the importance to nurses of patient centred care for those who ask about or choose an assisted death. A nursing role is present in all aspects of care regarding assisted death, from receiving and assessing the request, to liaising this information to the larger health care team, through to bereavement care of both the family and nurses. Professional guidelines and institutional policies exist to guide nurses to provide this care and are needed to support consistency in care for patients considering and assisted death. The lack of Canadian and North American research is a gap in the current literature. Considering the significant role of nurses in palliative and end of life care, the role of the nurse in assisted death is not predominant in the published research.

Research Purpose and Significance

Given the legalization of MAiD within Canada and the important role of nursing within palliative care, this study explored the experiences of palliative care nurses providing end of life care in order to inform best practices regarding the role of nurses in care related to MAiD. Examination of the experiences of nurses providing end of life care can inform best practices related to the role of nurses in supporting patients' self-determination and autonomy in death. The public focus and media attention on MAiD in relation to physicians, patients, and families largely ignores the experience of nurses. This information may contribute to a more conscious, personal, and professional dialogue with patients and contribute to best practices for end of life care and specifically MAiD.

Research Questions

The research questions guiding this research included:

1. What is the role of palliative care nursing related to MAiD?
2. What changes in nursing practice regarding MAiD are proposed by practicing palliative care nurses?

Methodology

The aim of this study was to understand and describe a phenomenon. Interpretive description, an approach to qualitative research (Thorne, 2008; Thorne, Kirkham, & MacDonald-Emes, 1997) derived from more traditional methodologies of ethnography, phenomenology and grounded theory was used to guide this study (Hunt, 2009; Thorne et al., 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). This methodology aims to generate knowledge that is of clinical relevance to applied health sciences (Hunt, 2009), specifically nursing (Thorne et al., 2004) making this an ideal methodology to apply to this research of palliative care nurses who provide end of life care.

Assumptions underpinning interpretive descriptive research include an understanding that knowledge is co-created during the interaction between the researcher and participants. (Thorne et al., 1997). Complex, constructed and contextual human experience allows for multiple realities that will have both shared and unique experiences (Thorne et al., 2004). The knowledge required for nursing practice is composed of both this shared knowledge of persons in similar experiences and personal knowledge that is particular to their own lived experience and context. This consideration of both similarities and differences between experiences of research participants and the researcher gives a fuller depth to the knowledge developed (Thorne et al., 1997). The research plan was reviewed by the office of research ethics at Western University and received approval.

Methods

Participant Recruitment

The researcher attended team meetings with nursing agencies that provide palliative homecare, and in residential hospices to explain the research study and provide contact information for interested volunteers. Recruitment flyers with information about the study were left with attendees to post and inform other nurses unable to attend the meetings. Potential participant volunteers contacted the researcher by email to express their interest in participating in the study. Participants were given a \$10 Tim Horton gift card to thank them for their participation in this research.

Selecting a diverse participant sample allowed the data collection and analysis to yield two kinds of findings: high quality, detailed descriptions of each case which are useful for documenting uniqueness, and shared patterns across the heterogeneous sample (Patton, 2002). The number of participants was not predetermined as the objective in this

exploratory study was not to produce generalizable findings, but to gain insight into the perceived role and palliative care practice of nurses caring for patients at the end of life and within the context of MAiD. Sample size was continually re-evaluated until commonalities revealed in the data indicated the data as saturated (Thorne et al., 1997).

Purposeful sampling was used to identify participants who could provide rich information relevant to understanding to role of nurses with MAiD (Patton, 2002). Purposeful sampling seeks to ensure different experiences are studied, aiming for maximum variation that helps establish a broader range of context and enhanced understanding for this study (Polit & Beck, 2012; Thorne et al., 1997). In addition, the snowball technique allowed participants to invite other nurses with relevant experiences to participate in order to provide a sample that captured participant variation (Patton, 2002). Purposeful sample selection ensured many contextual variations were captured (such as demographics of participants, setting of practice), to enhance the diversity of experiences and perspectives among participants (Thorne et al., 1997).

Volunteer participants were included in the study if they met the following criteria: (a) they were Registered Nurses (RNs); (b) they had been employed for at least one year in a palliative care setting such as residential hospice, hospital based palliative care unit, or community nursing agency with specialized palliative care clinical teams. These settings were selected because they are representative of the diverse settings where terminally ill individuals are cared for by nurses, including institutional, residential, rural and urban contexts; (c) they were currently employed as a palliative care nurse; and (d) they practiced in southwestern Ontario. RNs who did not provide direct clinical care (such as administrators or educators) were excluded from the study as the focus is on

clinical nursing practice in palliative care. Efforts were made to include RNs from the varied geographical, social and cultural contexts that are present across the region.

Data Collection

Data collection occurred during the time when legislation that legalized MAiD was being introduced across Canada. Participant interviews were conducted in a mutually agreed upon location. The locations were private in order to maintain confidentiality of the participants. Efforts were made to allow for uninterrupted flow of conversation and thinking by choosing locations that were not designated as public space such as a break room, but as a dedicated meeting space. Individual interviews with each participant were scheduled to collect data regarding participant perception of nurses' role in MAiD and inquiry into the changes in nursing practice consequential to the MAiD legislation. Each interview was approximately one hour in duration and allowed time for discussion of the nursing role within the context of MAiD without imposing unnecessarily on the time commitment of the participants. A semi-structured interview approach was used, with an interview guide comprised of open-ended questions to facilitate discussion and ensure all areas of interest were considered in each interview (see Appendix A). The guide was revised as data was collected to ensure questions captured new themes or patterns that emerged from participant input.

Data Analysis

The interviews were digitally recorded and transcribed verbatim for analysis. Data analysis was conducted concurrently with data collection (Thorne et al., 2004). Thorne (1997) recommends an inductive analytic approach that involves repeated immersion in the data prior to coding, classifying, or creating linkages. Complete transcripts of each

interview were repeatedly reviewed in their entirety. The goal of repeated immersion is to know each case intimately, to identify key words and phrases in the data, code these key words and phrases and place these codes into broader categories as patterns or themes are identified (Thorne et al., 1997). Detailed field notes were generated immediately following each interview, and were reviewed regularly. Analytical insights that occurred were recorded and tracked, maintaining openness to understanding the meaning of the experiences of the participants in their work, without rushing to premature conclusions. (Thorne et al., 1997). Lincoln and Guba (1985) use three criteria to evaluate trustworthiness of a study: relevance, rigor, and feasibility. Strategies that aimed to ensure trustworthiness of this study addressed these three criteria.

The research questions for this study are relevant to end of life care provision and the well-being of nurses, with potential for significant findings that may improve end of life care leading to improved patient and provider outcomes. Timing of the study aligned well with the current cultural context in Canada: specifically the 2015 Supreme Court ruling that denying assisted suicide to those that are suffering is contrary to the Charter of Rights (*Carter v. Canada (Attorney General)*, 2015 S.C.C. 5) and resulting legislation legalizing MAiD.

This methodology assumes individual experience and bias as an inherent quality of the researcher and the potential influence of this bias on the findings of the study must be explicitly accounted for (Thorne et al., 1997). This rigor was ensured through strategies to report the process and account for potential biases; including a reflective journal (Lincoln & Guba, 1985), and field notes that documented the context of the data collection episodes and link the context to the phenomena of end of life nursing

experiences (Thorne et al., 1997). These notes enabled analysis development to be retraced and defended, and were sufficiently described in the research report so that readers are able to judge the degree in which the findings are grounded within the data.

Experienced researchers with interest in end of life care constituted the research advisory committee and were consulted throughout the research process to ensure quality of the study being undertaken. During data analysis, emerging themes were judged to ensure the data in each category held together in a meaningful way (internal homogeneity) and that there is minimal overlap between categories (external heterogeneity) (Lincoln & Guba, 1985).

The scope of this research study and its goals of inquiry were feasible. The research questions guiding the inquiry were appropriate in that the methods provided adequate data to add to existing knowledge on nursing perspective of practice regarding MAiD. Participants described in the study were accessible, as were the settings in which to complete interviews. The time frame of one year allowed for data collection to saturation as well as thorough analysis including preparation of final report.

Findings

In total, nine registered nurses were interviewed. Their palliative nursing experience ranged from 2.5 years to 41 years. All of the participants were employed and provided direct palliative clinical care. There were three male participants and six female participants. Three participants worked in residential hospices where MAiD was not supported as an end of life option, six participants worked in the community providing home care where MAiD is an option in end of life planning. Two participants had previous inpatient hospital experience in emergency care and in intensive care specialties. All participants worked in the Southwestern Ontario region. Participants were

interviewed during the time in which Bill C-14 legalized MAiD in Canada (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*), S.C. 2016, C.3) which included the province of Ontario where the participants worked.

The thematic analysis of the data produced three broad themes of: (a) **Business as Usual** which reflects participants' perspective that MAiD will create little impact on the nurse's palliative and end-of-life patient practices; (b) **The Nursing Role and Patient Directed Dying** discusses the importance of patient centred care to nurses and includes the subthemes of (i) assessment, (ii) 'having the hard conversations', (iii) MAiD as a patient centred procedure, and bereavement; and (c) **Support for Nurses** reflects what is needed to support palliative nursing practice that now includes the option of MAiD. This theme includes the subthemes of (i) enhanced palliative education, (ii) conscientious objection, and (iii) give and take of the final intervention.

Business as Usual

Participants had not yet experienced or anticipated any significant changes in the nursing care they provide at end of life as a consequence of the legalization of assisted dying within Canada. Specifically, participants reported that the principles of quality palliative nursing care do not differ from patients who *do* or *do not* ask about or request MAiD. Generally, when asked if legislation legalizing assistance in death had, or would impact their practice, nurses reported that they would continue to provide patient centred care, respecting the needs and wishes of their patients. In fact, participants described their end of life caregiving as patient directed dying (PDD). Participants discussed their work with end of life patients as a patient centred approach to end of life care that places

the focus on patient needs and preferences as they considered all options available to them including but not exclusively focused on MAiD. This study has termed this approach to care as patient directed death (PDD). Participants stated that a patient centred approach to end of life caregiving is part of the care that nurses have provided and will continue to provide to patients and their families at the end of life with the addition of MAiD as an option for care. This perspective was indicated in the following quote:

Minimal impact [on client care]. I still intend to practice in a way that my clients' wishes are respected, regardless of what my background is, or what my ethical values are. I still intend to provide the same pain management and symptom relief that I provided prior to MAiD, so really and truly I'm still going to be practicing in the same client centred way. (Participant 716)

For nurse participants this included being open to patient directed discussion regarding all end of life options as indicated by participant 092 below:

I don't think it's really changed how I feel about my role I've always maintained a very open practice with my patients. ...I've always been very open to have frank discussions with people, without judgement, and it's not my job to talk them into one way or the other, it's just to give them whatever information that I can, and refer them to the appropriate physicians to have more in-depth discussions that are beyond my scope. (Participant 092)

The Nursing Role and Patient Directed Dying

Palliative nursing at end-of-life entails enhancing a person's quality of life and supporting the patient, their family, and significant others (Stajduhar, 2011). This theme describes the participants' perspective on the role of nurses in PDD, more specifically MAiD, and is organized into subthemes of assessment, planning, patient-centred intervention and bereavement.

Assessment

Participants in this study confirmed that they had been approached by terminally ill patients with questions about and requests for assisted death prior to legalization of

MAiD. Exploring the request for assisted death was described as part of the work involved in conducting a comprehensive palliative assessment with patients. Inquiry about end of life wishes and requests for assistance in ending life is needed in order to understand the meaning behind the patient's request; the intent is to assess whether or not patient and / or family needs are fully met. Participants described this experience in the following manner:

The kinds of conversations I end up entering into are when patients say, and they've said it for years, "You know, they put a dog down, why do they make me suffer? When I'm suffering, why don't they just put me down?" I always take those [statements] as let's have a discussion. What is it that's making you come to this statement; feeling this way that is despair? Is there spiritual distress? What's at the root of the...statement? And maybe it is their roundabout way of asking [about assistance to die], although there was never any means to go down that road before, but regardless whether it's a question then or now, it's still, to me, is more of what's at the root of this, what can we do differently to make your suffering lessen and explore what would make life worthwhile at this point (Participant 014).

Lots of our palliatives [patients at end of life] say "Oh I wish I could just die. Could you not just give me a shot and put me to sleep?" Lots of people say that and maybe don't mean it, sometimes they really do mean it. Usually to me that is a signal that there's more going on; that they're not in a good place and I will often call the doctor and see what else we can do to make them more comfortable (Participant 307).

Palliative patient assessments opened up the opportunity for patients to inquire about assistance in ending their life. However, nurses were previously not legally allowed to follow up with this line of inquiry. The legal restraints that prohibited nurses' conversations with patients regarding assistance to die did not align with the principles of patient centred care and PDD, in which, all options for treatment should be presented and explored with patients (Canadian Nurses Association, Canadian Hospice Palliative Care Association, & Canadian Hospice Palliative Care Nurses Group, 2012). Nurses in this study were engaged in PDD but stated that they did not initiate conversations regarding

assisted death or MAiD during end of life discussions as described in the following quotes:

I won't offer, I don't offer information on MAiD, I only talk about it if the patient brings it up because that is not within my role to bring that up as a treatment option (Participant 092).

We wait to hear from the client. No one is offering it [assisted death] as an option, it's not like it's something that we offer (Participant 934).

The study participants who identified themselves as conscientious objectors to MAiD, a person who believes the practice of actively ending life contradicts their personal values and beliefs, felt that they could assess the request, and find appropriate resources for their patients.

Personally speaking I think that [being a conscientious objector] would be all the more reason to give the patient opportunity to explore more, to understand whether that's truly what they want or not (Participant 221).

Participants supported the discussion of MAiD as an important aspect of PDD and an appropriate topic for patient assessment as part of the nursing role. Moreover, participants stated that they felt honoured when their patients trusted them, or felt comfortable within their therapeutic relationship to have the conversation about or make a request for MAiD. However nurses were also concerned about their ability to address the expressed needs of patients in a timely and effective manner, either because the question needed to be deferred to another member of the healthcare team due to conscientious objection issues or because nurses did not have permission to discuss assisted death with patients.

Medical Assistance in Dying, I would imagine for a client would not be a simple thing that's typically easy to bring up, really it would be sort of awkward potentially, for the client, knowing all of the, ... background or all the controversy surrounding this protocol ... So for somebody to approach you is almost an honour that they trust you enough to have this conversation, and to have to sort of shut them down, or acknowledge how they're feeling, but not to be able to really

explore those feelings is kind of limiting... Typically when somebody is discussing something with you that is very personal, they're discussing it at that point because that's when they want to discuss it. So moving it to another time, to a discussion with another person may not be most appropriate for your client. I mean it's really respect, it's respectful and it's honoring that they've chosen to have that conversation with you at that point and they're feeling safe. So you're sort of breaking that safety that you've established with them in a sense by referring that conversation elsewhere (Participant 716).

I worry that people who do shut the conversation down or redirect them to somebody who would assist them in that way, takes away from the therapeutic relationship, that the patient is trusting you with that information and that conversation. (Participant 014).

“Having the Hard Conversations”

Participants in the study indicated that nurses may act as a liaison between physicians and nurse practitioners who have the authority to assess patient eligibility and provide the intervention of MAiD and the patient; notifying them of an inquiry about or a request for MAiD. Nurses also consult with others on the palliative care team with the findings of the palliative assessment including patient request for assistance in dying, and the contextual information that gives a greater understanding of the patient's request. Of all health care providers, participants felt that nurses spend greater amounts of time in patient engagement as expressed below:

I think sometimes the nurses, the one the patient sees most frequently, develops a trust relationship with [the patient], so I often feel like a nurse is a liaison between the patient and the doctor and you know making sure that all the health team are involved that need to be involved (Participant 221).

This sharing of the nurses' assessment of patient needs within the larger health care team can facilitate understanding regarding patients' palliative care needs, and specifically regarding patients' requests for an assisted death. This is best reflected in the following quote by a nurse participant who perceived the nursing role to include “*having the hard conversations*” with patients.

I think we're going to have the harder conversations [about end of life decisions - MAiD]. I think that we are the mitigaters, we're the advocates, we are the ones who are there at 3 am when that distress is very imminent and the conversations happen. So I think that we're the ones that are going to be bringing those [requests for MAiD to the rest of the palliative care team]; ... if they are truly pursuing it [MAiD], then we're bringing it to the physicians to say we need to work through this and we probably even facilitate [the conversations]. I know in many ways I've facilitated conversations for physicians that they're going to have with the patients and mediate the family discussions. So then the physician comes in for their half hour conversation with a lot of work having already been done and so then they are able to...hone in on some of the very specific identifiers that have come up and then of course they're the ones that work with the patient deciding how and when and what and if it's really going to happen and go through the process they go through (Participant 014).

MAiD: Patient Centred Procedure

Participants were asked what they felt the nursing role should be during the intervention of MAiD. Participants indicated that the nurses' role in MAiD is guided by a patient centred, PDD approach. They stated that the ability to negotiate the nursing role within the larger health care team is required to best meet individual patient's needs. This is reflected by the following statement:

We will eventually have a [organizational and/or regulatory] policy that outlines step by step what we're [nurses] doing or how this process [of MAiD] is going to look. So we would really need some sort of guideline or policy; not necessarily a standard protocol because every situation is slightly different, every client is slightly different so we would need to have a little bit of fluidity in terms of the actual med administration process and the pronouncement [of death] process... But we would need at least a policy or a guideline to refer to in terms of the decision making process [within MAiD] and who is going to take ownership of what component of it (Participant 716).

Participants reiterated the principles of patient centred care within PDD as foundational in guiding nursing practice within the context of MAiD. This is expressed by the following quotes:

I think that this is a discussion [what the nursing role should be] that maybe should happen with the patient. What are their needs for support [at the time of assisted death]? ...Are they fine with a small, immediate family and physician [present at the time of the intervention] because they want to keep it small? Or do

they feel that they need another medical person there as a broader support (Participant 221).

The person that's going to die should direct who's going to be there, what the situation's gonna be...I could want to be in the room all by myself, and I could want my dog and my cat there and not my kids, I don't know (Participant 443).

Bereavement Care

Nurse participants felt bereavement needs (such as peer support groups, counselling, spiritual care) for patients and their families are very unique and individually determined. Therefore, most participants did not see bereavement needs being different in the context of MAiD from existing best practices in palliative care and PDD at end of life. However, participants also speculated that MAiD, as a new and somewhat controversial intervention, may create unique bereavement needs.

I don't know that [bereavement for families] would be a lot different [in the context of MAiD], I mean there would definitely be the component of the patient having made the choice, as opposed to just letting natural disease take its course. So I think a lot of families might have a hard time dealing with the fact that they're choosing to leave as opposed to just waiting until their time has come. ...But on the other hand there are other families that are one hundred percent on board and they don't want to see their loved one suffer just as much as their loved one doesn't want to suffer... (Participant 092).

Participants questioned whether the stigma attached to death as a choice through MAiD constituted an additional burden to families and friends at the time of bereavement; that families may require additional supports if divisiveness exists among family members and traditional bereavement services with respect to MAiD.

Well actually I feel like when we do bereavement care, we could probably do better... [An assisted death] might be harder on the family because of stigma of MAiD ..., the person was going to die anyway, but they decided to die sooner, and how hard that might be on the family or might not be, they might be relieved (Participant 934).

Supporting Nurses to Provide PDD

Legalization of MAiD means that patients receiving end of life nursing care may now consider or plan for an assisted death and while nurses felt this care was no different in principle than the care they are currently providing, there are supports needed for the nurses providing this care. Participants were asked what nurses will need to effectively practice within the context of MAiD. This theme is described in the sub-themes of: (a) enhanced palliative education, (b) conscientious objection, and (c) give and take of the final intervention.

Enhanced palliative education

Specialized palliative nursing education was not a mandatory pre-requisite of employment for six of the nine participants. However, all participants had successfully completed one or more of the specialized palliative care courses and felt these were important to their practice. While nurses were often approached by a patients with their request for assisted death - even when it was not a legal option (De Bal et al., 2008), the topic of assisted dying was never part of the curriculum in any of the specialized palliative courses. This is in despite of the fact that counselling on end of life options was a topic.

Participants in the current study agreed that palliative education that addresses how to best approach all end of life needs with patients, including discussions about assisted dying, should be part of the palliative education curriculum. Participants suggested there is a need for knowledge or best practices regarding how to handle patients' requests for assistance in dying regardless of the legal status. Historically nurses

were having to work ‘blind’ or without educational support in addressing patient requests for assisted death.

I think there's still a great deal of deficits in palliative care, I mean there's no national framework, the education and stuff is still very limited, undergraduates, graduates, still get very limited palliative care education although it ends up being something that people [nurses] are experiencing in any kind of setting, or sector. So I think there's still a long way to come, even without the context of [MAiD] (Participant 665).

When we know more, we're more comfortable, we're not as anxious about making a mistake or screwing up a medication or saying the wrong thing. It gives us those building tools that we need to listen more effectively to be able to encourage that therapeutic communication that the families need, and if we're not nervous, the family is more responsive...[The Comprehensive Advanced Palliative Care Education program, or] CAPCE [should be] a prerequisite [for nurses working with patients who may request information about end of life /MAiD] because really you can't be doing assisted death if you haven't got a sweet clue about palliative care in the first place... CAPCE gives you not just the medication and the symptom management but it gives you the counseling aspect, the therapeutic communication, the dealing with the families and the doctors and being confident when you turn to a doctor and say I think they need this and the doctor says “oh you're CAPCE nurse, okay you know what you're talking about” (Participant 307).

Conscientious Objection

Participants discussed the concept of conscientious objection not as black or white, but as a spectrum of comfort about assisted death; ranging from discomfort with any part of a discussion with patients on the subject of assistance in dying, to being comfortable with everything except the administration of medication as part of the MAiD intervention, to comfort with the entire process of patient directed death (MAiD as part of this) as part of the nursing role. Two of the nurses interviewed self-identified as conscientious objectors who did not agree with the provision of MAiD, seven were supportive of MAiD. Overall all participants were conflicted, trying to reconcile their own personal moral stance with facilitating the end of someone’s life.

So [administering the medication] that's where I think a lot of nurses would struggle, I probably would even struggle. I'm all for the conversation and knowing it's going to happen, but do I want to be the nurse who actually gives the medication I don't know. There might even be a spectrum right? You know, some people may be closer to [being a conscientious objector] but when they work it all through they aren't willing to give up the relationship with the patient and they can put their values aside (Participant 014).

I could see some [nurses] doing it [administering the medication for MAiD] and some not being able to, you know, "there's no way on earth I can do this". I think I could. I don't want to be cold or anything but I work with cattle and I've seen people pass [away naturally] and I've seen the pain and I've seen the suffering and I think I could do it [administer the medication for MAiD], but when push comes to shove, I don't know until I'm actually there (Participant 443).

When participants were asked to discuss how to support nurses in regards to their feelings about palliative care practice and MAiD, they approached the topic in terms of patient centred care; giving priority to the protection of patients over the feelings of nurses, regardless of their personal views and beliefs (i.e., conscientious objection) regarding MAiD.

...I can understand why it could be a little bit challenging for someone to be able to be totally on board with MAiD but at the end of the day I feel like my client choices come first, regardless, and I have clients that do all kinds of crazy things that I necessarily don't agree with or that I wouldn't do with my own life but I think that everyone has the right to make their own choices and to be respected and treated as a human really, and be provided with the best possible care that I can give regardless of what they've chosen to do (Participant 716).

I think it is an individual thing, so if the practitioner, be it the nurse, doctor, felt strongly they cannot participate in that [MAiD], then they should know that there is somebody who can honor the request of the patient because I don't think that patient should be left without an option. But, if an individual practitioner says "I can't do that [MAiD] for you, it's against my ethics", then they need to know that somebody else can pick that up for the patient. The patient shouldn't have to be abandoned (Participant 221).

Give and take: the final procedure

Participants who expressed support for the intervention of MAiD struggled to understand if they were 'killing' someone or 'caring for' someone in their most

meaningful time of life; a similar confusion was expressed regarding withdrawal of life support. Notable was the finding that participants likened the experience of patient death by MAiD to the experience of patient death by withdrawal of life support.

...I suppose in a way, there'd be a parallel between removing someone from life support and administering MAiD. My hope with MAiD would be that it is before somebody gets to a point where they are on life support in a vegetative state because really and truly that is watching somebody entirely deteriorate until the point where they're almost unrecognizable so hopefully MAiD would prevent those kind of instances (Participant 716).

It wouldn't be any different than a family that was asked to remove resuscitation equipment from a comatose patient. "Could they have woke up? Could they have been better?" [In regards to if there is a similarity between MAiD and removal of life support] To a degree, yes the family are agreeing that there is no hope left and we are speeding up the process by removing life-support. I personally have had to do that with two family members and for months afterwards you still question yourself "Did we do the right thing? Should we have left it on just a little longer? Should we have sped it up?" When you remove life-support now the body is functioning on its own and it's not going to sustain itself as well as if you had left life-support on, so by doing an assisted death we are speeding up the process as well...? (Participant 307).

Bereavement support: caring for the carers

Nurses are impacted in caring for patients at the end of life. The nurses in this study discussed the hard work (i.e., the emotional, physical, cognitive work) in providing effective palliative care to another person and their family.

...it's the hardest nursing. I've worked [in the emergency department], I've worked medicine floor, this is the hardest nursing there is, having somebody pass away, you actually feel something pulled out of you when that person passes. There's something missing. ... If you take care of somebody for an extended time and they pass away, you just feel, I just feel coldness, or whatever. You just feel drained (Participant 443)

Nurses wondered if the experience of losing a patient would be different in the context of MAiD.

I would find it more satisfying knowing that I helped that person reach their comfort level sooner, that's just my personal view,...but then again we had a 16 year old dog who had stroked in the backyard, and I took her to the vet, and I can

remember as the doctor injected her I thought “What, how do I have the right taking a dog to the vet and killing her?” Like, I don’t know. If a person was dying in front of you because you know, I gave them an injection or whatever, would that impact me in the same way? I have no idea until it happens (Participant 443).

I think it [the experience of losing a patient who chooses MAiD] definitely would be [different]. ... I guess it would be hard to know and it would really be person specific and it would depend on how you feel about the issue. I think even if you’re participating, there might be some niggling feeling of guilt because you are playing an active role in ending that person’s life, and even if you can justify it...I think it’s a big step to be able to perform that particular role. To not just be supporting someone as the disease and nature of time takes its course but to jump ahead of that and to pull the plug or to kind of have that role to be the one to kind of stop that person’s life, I think that’s that has a lot of implications to it ... (Participant 665).

Participants were asked what could be done to support palliative nurses who are now being asked to care for patients and their families who may choose MAiD as a component of their end of life care. Participants felt that bereavement support was important for nurses, not only for those providing care related to MAiD, but for palliative nurses in general; that current bereavement support for nurses could be improved:

...in terms of bereavement for staff, there’s always room for improvement there. Even just the debriefing after the fact, unless you take it upon yourself to sort of orchestrate your own bereavement at the time of passing, unless you choose to reach out to a co-worker to debrief, or you choose to say “You know what, I can’t continue to provide care today, I need to go home”, it’s not sort of approached for you. So I’d like to see sort of a more compassionate approach from an employer; support for the people who are front-line [and] who are providing this care... you really do bond and you want to make sure that these people are doing ok, and that they’re managing well post passing. Essentially, I feel that there are improvements for bereavement that can definitely be made for both client and direct service providers; a support group, education around taking care of yourselves, knowing your limits. (Participant 716).

Well, we need education, we need support, mentally, like I say, I don’t know how I’m gonna react if I, you know, if I’m pushing the button that makes somebody pass away, if I’m organizing somebody else to push the button, is that going to bother me? What right do I have to do that? (Participant 443)

Discussion

In Canada, MAiD is a sanctioned intervention for individuals that meet established criteria. Given the aging population, the need for palliative and end of life care will increase. Nurses have a significant role in providing end of life care and understanding their role specific to MAiD will support PDD. The purpose of the study was to explore the experiences of palliative care nurses providing end of life care in order to inform best practices regarding the role of nurses in care related to MAiD. Nine RNs with palliative nursing expertise participated in this study about the role of the RN with respect to MAiD. The major findings are discussed as follows: (a) patient centred end of life care: patient directed dying; (b) MAiD as a patient centred procedure; (c) liaison; and (d) supporting nurses.

Patient Centred End of Life Care: Patient Directed Dying

Palliative care nurses participating in this study claimed that patients asking about assistance to die is not a new phenomenon. Exploring patients' request for assistance in dying was described by participants as part of the palliative patient assessment conducted in part to understand the patient's end of life wishes and to help identify unmet needs. This finding is consistent with other researchers who identified a similar role for nurses working with palliative care patients (De Bal et al., 2006; Dierckx de Casterlé et al., 2010; van de Scheur & van der Arend, 1998). That some patients asked for help to die even when assisted death was not legal demonstrates the importance of this end-of-life issue and the need for nurses to respond to patients' request in a compassionate and informed manner.

Participants agreed that nurses working in palliative care and specifically end of life care would benefit from enhanced education and training regarding the management

of patients' request for assistance in dying in a way that is supportive of patient directed dying. Nurses in this study and empirical evidence suggests that patient requests to end their life were not uncommon occurrences (De Bal et al., 2008; Denier et al., 2009). The findings from this work and other research (Bilsen et al., 2004; De Bal et al., 2006, 2008) makes a compelling argument for nursing education on how to manage these challenging 'ending life' discussions with patients in a way that supports patient decision making while also maintaining the legal boundaries set out by the MAiD legislation. This education would be of value not only to nurses practicing in Canada with MAiD legislation, but also those nurses practicing where assisted death is not legal. Ignoring this in palliative nursing education leaves nurses to conjecture about best practices in this regard. Considering that nurses working in all health care settings are approached by patients with the request for help to die and not just those who focus on the care of terminally ill (De Bal et al., 2008), it is important to provide education regarding PDD and MAiD as part of all undergraduate nursing education in Canada. Education is needed to support nurses to effectively address patients' questions about all end of life options, policies to support these discussions, and guidelines for nurses as to how to support patients who want help to die, without stepping outside of their scope of practice.

The nurses interviewed for this study were clear that they did not initiate end of life conversations with patients about MAiD. However, patients' request for assistance to die, an experience familiar to the participants in this study, compelled participants to reflect on their professional (e.g., patient centred care including patient directed dying), moral or religious (e.g., sanctity of life), and legislative (e.g., legality) stance. Participants expressed decision-making challenges related to patient care resulting, in

part, when their value for patient-centred care competed against opposing religious beliefs and the need to be law-abiding. This omission of information about all possible end of life options (i.e., MAiD) represents a direct contradiction to PDD and patient-centred care, whereby all possible options should be presented and explored with patients and their families (Canadian Nurses Association, 2008).

The CNA position statement on the provision of quality palliative care and the position statement guiding nursing care within the context of MAiD appear contradictory (Canadian Nurses Association, 2008, 2017). The CNA position statement on the topic of MAiD advises that the intervention should be brought up by the patient only even though the revised legislation allows for nurses to provide information on MAiD but not encourage it (Canadian Nurses Association, 2017; *Medical Assistance in Dying Statute Law Amendment Act*, S.O. 2017 C.7). The position statement on provision of quality palliative nursing care acknowledges a person's right to making informed decisions about end of life care which would require a discussion of all available options through open and honest communication (Canadian Nurses Association, 2008; Canadian Nurses Association et al., 2012). This contradiction of not discussing the option of MAiD in the same manner as other end of life options is not clarified or even discussed by the College of Nurses of Ontario (CNO), the regulatory body for Ontario Nurses, contributing to the ambiguity of the RN role within the context of MAiD (College of Nurses of Ontario, 2016). There is no specific mention of nurses in the legislation that allows for the provision of information on MAiD which may have contributed to this lack of clarity by professional nursing organizations. This may be due to the fact that the definition of 'health care provider' may have been broadly defined in Bill C-14 because the Criminal

Code is the domain of the Federal government (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3, s. 241.(1)), whereas the definition of Regulated Health Professionals is the domain of the provincial governments (*Regulated Health Professionals Act*, 1991). The resulting lack of clarity between the law and health care professional policies may could impede the provision of quality palliative nursing care.

Nurses play an important role in PDD and in assisted death or MAiD, regardless of the lack of clarity within the new legislation. Defining the nursing role in MAiD with legislation and professional guidance, improves patient care, can prevent nurses from acting outside their scope of practice and may help to standardize the provision of care (Bilsen et al., 2004; de Veer et al., 2008; Inghelbrecht et al., 2010; Muller et al., 1997) and ensuring access to the care patients have a right to receive. To not formally recognize the role of nursing in MAiD ignores their skill and expertise in quality palliative care, and negates their significant contribution to ensuring patient directed care, or more specifically, patient directed death at the end of life.

MAiD as a Patient Centred Procedure

Nurses in the current study indicated that roles or skills that overlap between different professionals on the palliative care team should be negotiated with the patient, the family, and within the broader health care team on a case to case basis, as opposed to a strict predetermined process for MAiD, including the act of administrating the medication for the purpose of MAiD. The scope of nursing practice in Ontario gives nurses authority to administer a prescribed medication (*Regulated Health Professionals Act*, 1991). However, current legislation does not allow this controlled act to be

completed by nurses for the purpose of MAiD (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3) and while all participants were aware of this restriction, some thought there could be instances where a nurse would appropriately be the professional to administer the medication if it was within their scope of practice.

Patient centred care includes care of the patient's family (however the patient defines family) making bereavement care for these family members an important consideration of PDD. Nurse participants stated that bereavement care for families is lacking. The availability of bereavement supports for families and caregivers is inconsistent or lacking in Ontario (Ministry of Health and Long-Term Care, 2015). Participants also highlighted the gap in knowledge regarding best practices for the support of family bereavement; questioning if bereavement needs would differ if a death occurred in the context of MAiD. Participants felt there was a possible role for nurses, especially those with established therapeutic relationships, to provide bereavement care to families, but this important nursing role is limited by organizational policies that limit the nursing role past the time when a patient dies. The unanimous nursing support for improved bereavement care for families within the context of MAiD creates an opportunity for continued research regarding nursing practice and organizational policies on bereavement care within palliative care.

The importance of PDD as a component of patient centred care is an important finding of this study. Nurses feel end of life care must focus on the needs and preferences of the patient and family and allow patients at end of life, and their families, to consider all options available to them; including but not exclusively focused on MAiD. This study

introduces the concept of patient directed death (PDD) as a guiding framework for working with patients regarding decisions about their end of life care (Jannette et al., 2013). The phrase PDD is used in this study as it reflects the necessary patient-centered context of end of life care planning and ideally encompasses the multidisciplinary approach required.

Since MAiD is an end of life option, it is possible that the same benefits of early discussion of other end of life options and participation in advance care planning could also be achieved with the early discussion of MAiD. Factual information regarding end of life options can be provided and considered by patients earlier in their end of life journey, providing opportunity for patients and their families to reconcile their feelings regarding end of life choices that may include MAiD. This may facilitate self-determination in death, a 'good death' as defined by the patient, and more effective grieving for their families (Wright et al., 2008).

Findings of this study support the role of RNs in providing patient centred care at end of life; participants focused on the needs of patients with respect to assessing a request for help to die, acting as a liaison with the health care team, struggling with their own beliefs on assisting the death of patients and understanding the needs of bereaved families. When discussing the nursing role within MAiD, these nurses conveyed the necessity of patient centred care. This emphasis highlights the need for protecting a patient's self-autonomy as they prepare for end of life and reinforces the importance of PDD.

Liaison

The findings of this study support the role of nurses as liaison for patients who are considering MAiD as an option in their end of life care; nurses have the greatest contact with patients and often ‘have the hard conversations’ with patients (Canadian Nurses Association, 2015). Participants in the current study described this role as being a communication link or liaison between the patient / family and the larger health care team which is consistent with existing literature that describes consultation of nurses during the decision making within the healthcare team as important for providing information to the larger health care team (Dierckx de Casterlé et al., 2010; Inghelbrecht et al., 2009, 2010; van de Scheur & van der Arend, 1998). Participants in this study highlighted the liaison role as an important component of PDD; communicating patient needs related to all aspects of end of life care and specifically with respect to the option of MAiD within the interprofessional team.

Supporting Nurses

An important concept associated with assisted death is conscientious objection (White et al., 2009). While nurses feel legalization of assisted death may have a positive impact for patients, families and the healthcare system they also expressed concerns regarding possible conflict between their own personal and professional values (White et al., 2009). Participants in the current study were conflicted; trying to reconcile their own moral stance with the act of facilitating the end of someone’s life via MAiD. When participants were asked to discuss their perspective on the nursing experience with losing patients to MAiD, they likened it to the experience of a patient death when life supporting technology was withdrawn. These two fundamentally different clinical scenarios should

not be confused as being the same; the withdrawal of life support occurs when life is prolonged beyond when natural death would have occurred, while MAiD hastens death that would have naturally occurred in the foreseeable future. Each intervention interrupts the timeline of natural death. It may be that the *purposeful* participation in an act that contributes to ending another person's life - either in giving a medication or taking away life support - may be similarly discomfoting for nurses. Previous research exploring the nursing experience with withdrawal of life support found, as did this study, that nurses' were morally conflicted about their participation in an intervention that facilitated a patient's death (van Rooyen, Elfick, & Strümpher, 2005; Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman, & Gagnon, 2011). Further study into the experiences of nurses losing patients, both through the process of MAiD, and withdrawal of life support is important in order to glean insight into the effects of the experiences on the mental health and well-being of providers and how to best support them.

Nurses in this study described conscientious objection to MAiD as a spectrum of comfort that could fluctuate depending on the circumstances of each individual patient as opposed to simply being 'for' or 'against' MAiD. This is consistent with research reported by de Bal (2006) where nurses seldom expressed complete support or opposition to assisted death due to the complexity and contextual nature inherent to assisted death. While policies can support quality nursing care in the context of assisted death (Gastmans et al, 2006), it may be advisable to consider organizational policies for nurses that allow for a spectrum of participation in providing MAiD care that allows flexibility and responsiveness to specific circumstances of each patient and family situation. A consideration of policies that acknowledge a range of nurse-patient relationships may

include options that range from removing themselves from any discussion of MAiD with patients, allowing nurses to refuse participation of any manner during the actual intervention of MAiD, or removing themselves from caring for a patient considering MAiD entirely.

Nurses participating in this study associated the experience of losing patients through MAiD to losing patients following removal of life support which was an unexpected finding. Dealing with death of patients is a potent psychosocial stressor for nurses (Mark & Smith, 2012). Mental health issues of nurses who provide MAiD, care for the terminally ill, and experience patient deaths across health care settings and circumstances of death, must be further investigated to better understand how repeated exposure to patient death impacts nurses providing the care. This improved understanding will help determine appropriate supports that can be utilized support nurses in these roles. Further understanding of the concept of conscientious objection and how to protect nurses that face practices which are in conflict with their personal values could also improve the ways in which we support this profession.

Study Limitations

With all studies, there are limitations. This study represents exploratory research within the Canadian context regarding the palliative nursing role with the intervention of MAiD. Access to health care resources may influence experiences of palliative care nurses. Participants in this study practice palliative care in south western Ontario, Canada where there are several academic based health care services (e.g., teaching hospitals). Nurses recruited from other regions that do not have close alignment with academic health research centres may have reported different experiences. The participants all spoke English as a first language. Participants interviewed in person were white, and it is

not known if the three participants interviewed by phone were also white. Participants of different ethnic or cultural backgrounds may have different understanding of the RN role. This would be important to explore in follow up research. These factors limit the usefulness of applying the findings across other provinces and cultures. The study was conducted during the introduction of legalized assisted death; with the recent timing of this, many nurses provided input based on their palliative care experience and it would be of value to explore their perspectives again once they have experienced provision of care for patients who choose MAiD.

Conclusions and Implications

In Canada assisted death for terminally ill individuals is a federally legislated intervention. This research focused on palliative care nurses and their perceived role within the context of MAiD. There are significant advancements left to be made in order for Canadian nurses to truly have the legal and professional support they require to provide the best possible patient centred palliative care to Canadians. This work has implications for nursing practice, policy, education and research.

Research into the evolving framework of palliative care that includes PDD is an emerging area of research within Canada. Further development of the concept of patient directed death would be useful to improve the quality of palliative care now that Canadians can legally seek access to MAiD as part of end of life care. Placing PDD as a focus of end of life care, which is in turn a component of patient-centred palliative care, can facilitate patient understanding when faced with a terminal illness.

Policy that formally acknowledges and defines the nursing role in MAiD supports quality palliative nursing care (Bilsen et al., 2004; de Veer et al., 2008; Inghelbrecht et al., 2010; Muller et al., 1997). Provincial legislation that provides a formal definition of the

nursing role in MAiD provides an opportunity for nursing regulatory bodies to develop clear guidelines that facilitate open discussion on handling requests for assisted death that can contribute to positive death for patients (De Bal et al., 2006).

Nurses need to be acknowledged of their role, and additional educational support is required for the “hard discussions”; how to best respond to patients who ask for help to die. Supporting nurses through education that includes MAiD as a topic in the formal curriculum could better prepare nurses to fulfill their duty to patients that ask about help to die, diminishing the powerlessness they experience when they do not know how to respond (De Bal et al., 2006).

Defining the role of nurses with MAiD is important to support nurses in providing quality palliative care, including MAiD. There has been limited attention to the role of the RN in MAiD; what exists is positive but not adequate. This research highlights the need for additional investigation regarding nursing and MAiD.

The findings of this study relate specifically to nurses, however it is possible that other members of the multidisciplinary health care team have similar experiences and challenges with end of life discussions, conscientious objection, and need for bereavement support. Research on care provision in the context of MAiD is needed from an interdisciplinary perspective given the team approach to palliative and end of life care. It would be of value to nursing palliative care practice to understand if the findings of this study would be similar in different areas of Canada, or in other countries or with different cultures. Since nurses across healthcare settings care for patients at end of life, similar research with nurses who are not focused on palliative care could gain better understanding of the nursing experience in the context of MAiD.

Follow up research is needed to explore the use of interventions (MAiD or use of life support) within patient care. Participants described similarities among these seemingly discordant interventions. Further research is needed to understand the impact on patient and family care and support for nurses. As well the concept of nurses' willingness to engage in end of life care that included assisted death (conscientious objection) described their willingness to engage in this intervention as unique to each patient rather than a yes or no decision.

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Chapter 3

Implications for Practice, Education, Research and Policy

Canadians older than 64 years now outnumber persons under 14 years and are increasingly living with chronic illness heightening the importance of palliative and end of life care (Statistics Canada, 2016). Nurses have significant involvement in end of life care which in Canada may now include assisted death (Canadian Nurses Association, 2017). Within Canada's legislation on the legalization of Medical Assistance in Dying (MAiD), the role of physicians and nurse practitioners are clearly articulated yet the role of the nurse is largely unacknowledged (*An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, S.C. 2016, C.3, s. 241.2 (1)). Given the importance of the patient-nurse relationship, particularly with end of life care, it is important to understand the role of nurses within the context of MAiD (Canadian Nurses Association, 2017). This study used interpretive description, methodology, to explore the experiences of palliative care nurses and their perspectives of best practices in care related to MAiD (Thorne et al., 1997).

In Canada assisted death for terminally ill individuals is a federally legislated intervention. This research focused on palliative care nurses and their perceived role within the context of MAiD. There are significant advancements left to be made in order for Canadian nurses to truly have the legal and professional support they require to provide the best possible patient centred palliative care to Canadians. This work has implications for nursing practice, policy, education and research.

Implications for Practice

This study adds to the understanding of the work palliative nurses do with patients who request MAiD and can help to more fully define and develop their role. There has

been limited attention to the role of the RN in MAiD; what exists is positive but not adequate. Nurses clearly feel that care for patients asking about or considering MAiD as an end of life option is not different from care they are providing otherwise. The care of patients in the context of MAiD needs not be an exception to current practices, but instead needs to be aligned with current standards of care. This alignment includes discussing MAiD in the same manner as other end of life options are discussed, as opposed to being the sole option whose discussion must be initiated by patients, an approach supported with the concept of PDD. Additionally, the highly contextual nature of end of life care necessitates some degree of flexibility in regards to the roles of nurses in order to be responsive to individual patient needs while maintaining legal boundaries of nursing scope of practice.

Implications for Policy

Policy that formally acknowledges and defines the nursing role in MAiD supports quality palliative nursing care (Bilsen et al., 2004; de Veer et al., 2008; Inghelbrecht et al., 2010; Muller et al., 1997). This should be considered as organizations develop their institutional policies and professional organizations develop best practices with legalization of MAiD. A formal definition of the nursing role in MAiD and clear guidelines that facilitate open discussion on handling requests for assisted death that can contribute to positive death for patients (De Bal et al., 2006). Professional regulatory bodies, such as the College of Nurses of Ontario (CNO) need to clearly define the role of nurses and set standards of practice, while institutional policies need to align MAiD care with existing best practices for end of life care. The clear definition and best practices guide nursing care and support them to have the open conversations essential to quality

palliative care. These guidelines need to maintain the flexibility that is necessary to be responsive and patient centred for each individual situation.

Nurses in this study have identified conscientious objection in regards to MAiD as a fluid concept, changing in response to many factors related to both patient and personal beliefs. Organizational policies put in place to support conscientious objection of nurses must accommodate this fluctuation on the spectrum of comfort with providing care with MAiD by providing several options for nurses who have patients considering or choosing an assisted death. Additionally, these implications for policy need to apply across care settings and not be focused solely on palliative care as people face end of life care in many health care settings.

Implications for Education

The legalization of MAiD has created an impetus for important changes in nursing education. Nurses need additional educational support for the “hard discussions”; how to best respond to patients who ask for help to die. Participants reported that the palliative education they completed did not include information on how to discuss assisted death with patients. While assisted death is not part of formal palliative care curriculum, participants reported that students would ask questions about assisted death, prompting a discussion about desire to die statements from patients, what the statements mean, and role play with a standardized patient to respond to these questions. Supporting nurses through education that includes MAiD as a topic in the formal curriculum could better prepare nurses to fulfill their duty to patients that ask about help to die, diminishing the powerlessness they experience when they do not know how to respond (De Bal et al., 2006). Nurses in this study also indicated that patients’ asking for information about or

requests for assistance to die is not unique to palliative care nurses and education is needed to assist nurses to have the “hard conversations” with patients even in jurisdictions where assisted death is not legalized. Considering that nurses work with patients facing end of life issues across health care settings, palliative education that focuses on PDD and includes the topic of MAiD should ideally be part of undergraduate nursing curriculum.

Implications for Research

This study adds to the knowledge of the nursing role in assisted death, more specifically MAiD, but considering the lack of literature in the Canadian context further research is necessary. It would be of value to nursing palliative care practice to understand if the findings of this study would be similar in different areas of Canada, or in other countries or with different cultures. The United States of America has individual states legalizing or contemplating legalization of assisted death and best practices for nursing care could be informed with similar research. The impact of culture and ethnicity on the experience of nurses who work with MAiD is another opportunity for further investigation.

The findings of this study relate specifically to nurses, however it is possible that other members of the interprofessional health care team have similar experiences and challenges with end of life discussions, conscientious objection, and need for bereavement support. Research on care provision in the context of MAiD is needed from an interdisciplinary perspective given the team approach to palliative and end of life care. Since nurses across healthcare settings care for patients at end of life, similar research

with nurses who are not focused on palliative care could gain better understanding of the nursing experience in the context of MAiD.

Follow up research is needed to explore the use of interventions (MAiD or use of life support) within patient care. Participants described similarities among these seemingly discordant interventions. Further research is needed to understand the impact on patient and family care, and support for nurses. As well the concept of nurses' willingness to engage in end of life care that included assisted death (conscientious objection) described their willingness to engage in this intervention as unique to each patient rather than a yes or no decision. A deeper understanding of conscientious objection of healthcare providers in the context of MAiD could improve the way in which providers are supported. Additional research is needed to explore the impact on nurses who practice within organizations that are conscientious objectors (e.g., hospice) or have policy against MAiD.

A gap in bereavement support for families was identified. It would be of value to families to better understand the bereavement needs in the context of assisted death, or MAiD, as well as further investigation into the bereavement needs of nurses and providers and the impact to them of exposure to repeated patient deaths.

Continued emphasis on patient centred care warrants further development of the concept of PDD. Placing PDD as a focus of end of life care, which is in turn a component of patient-centred palliative care, can facilitate patient understanding when faced with a terminal illness.

This research studied the perspective on experienced palliative care nurses at a time when legislation legalizing MAiD was being introduced. The role of nurses in MAiD

could be better understood if this research was repeated after nurses had the opportunity to work within the new legislation.

Conclusion

Palliative care and end of life care in Canada is increasingly a focus of health services, especially with the introduction of MAiD, or legalization of assisted death. The focus has largely been on the role of physicians and nurse practitioners as providers of MAiD, however nurses play a large and important role for patients considering MAiD and serve as important contributors to patient direct dying within an interdisciplinary team. However, much work remains in understanding and developing the role of nurses in order to ensure provision of high quality, patient centred care, or patient directed death in the context of MAiD.

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Appendices

Appendix A: Semi Structured Interview Guide

Begin interview session with a description of the purpose of the research study.

1. Tell me about your role as a palliative care nurse- how long have you practiced in this role?
2. Describe your educational background- nursing program preparation: special preparation regarding palliative care; nurse specialty.
3. What impact will (or already has) the recent Supreme Court decision regarding MAiD have on the care you provide for terminally ill patients? Conversational triggers include: counselling; patient education; family caregiver education.
4. Drawing on your expertise can you please share your thoughts around the best practices for nurses engaged in MAiD?
5. Will legalization of MAiD change your palliative nursing practice? How?
6. Are you prepared for this change in legislation? Why?
7. Tell me what you understand of conscientious objection (practice that contradicts your personal values) related to MAiD. Share your perspective on conscientious objection with nursing and MAiD.
8. What practice/ education/ policy changes could be made to improve palliative nursing care in the context of MAiD?
9. Do you have any other comments? Is there anything else I should know about this topic?

Appendix B: Recruitment Poster



PARTICIPANTS NEEDED FOR RESEARCH ON PALLIATIVE CARE NURSING PRACTICE AND PATIENT DIRECTED DEATH

We are looking for volunteers to take part in a study of palliative care nursing practice and patient directed death who meet the following criteria: Registered Nurses employed for at least one year in a setting that focuses on palliative care.

If you are interested and agree to participate you would be asked to participate in an interview.

Your participation would involve one session that will be about 60 minutes long.

In appreciation for your time, you will receive compensation for your time and effort

For more information about this study, or to volunteer for this study, please contact:
Laura Sheridan

University of Western Ontario Nursing Graduate Studies

Appendix C: Letter of Information and Consent



Letter of Information and Consent

Project Title: When Patients Ask to Die: Patient Directed Death and the Perceived Best Practices Among Palliative Care Nurses

Letter of Information and Consent- Participant

Principal Investigator

Dr. Lorie Donelle PhD

Student Investigator

Laura Sheridan RN(EC)

1. Invitation to Participate

You are being invited to participate in the research study named above. There is much recent discussion about the legislation regarding assisted death, or patient directed death (PDD). This study aims to explore the role of nurses and changes in palliative care practice from the perspective of nurses who care for patients and their families at end of life.

2. Why is this study being done?

Learning about the experiences of nurses providing end of life care can inform best practices related to the role of nurses in supporting patients who choose PDD and may contribute to policy changes for PDD nursing practice and enhance the care provided to patients.

3. How long will you be in this study?

You will be participating in one interview session that will last approximately one hour.

4. What are the study procedures?

We will be conducting interviews in person with 8-12 nurses in Ontario who have experience in providing care to the terminally ill (with at least one year of experience in this role). The focus of these interviews will be on learning about nurses' palliative care experiences. If you are not a nurse with at least one year of experience in direct provision of care to the terminally ill, then you should not participate in these interviews.

You will be asked to participate in an interview at a location agreed upon by you and the researcher. The interview will be recorded and transcribed for analysis. In the interview, we will be asking about your experience in palliative care practice and your perceived changes in palliative care for nursing education and practice within the context of the new PDD legislation. The interview will be approximately one hour in length

5. What are the risks and harms of participating in this study?

There are no anticipated burdens, harms or potential harms for participation in this study. You will not have to answer any questions if you chose not to.

6. What are the benefits of participating in this study?

Nurse participants in the study will not be guaranteed any direct benefits as a result of their participation in this study. However, this study may add to knowledge that will inform nursing practice on how to support nurses and patients regarding PDD.

7. Can participants choose to leave the study?

Before deciding to participate, you should know that you do not have to take part in the study. Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your employment status. If, during the course of this study, new information becomes available that may relate to your willingness to continue to participate, this information will be provided to you by the investigator. Participation in this research is completely voluntary. You may refuse to participate and remove your information from the study at any time during the interview. You may also refuse to answer any questions that you prefer not to answer. Whether you participate or decide not to participate will not have any effect on the aid you receive. You indicate your voluntary agreement to participate by responding to the questions.

8. How will participants' information be kept confidential?

Your responses will be kept confidential. For the interviews, no identifying information of participants will be linked to the data. If the results of the study are reported in a publication, this document will not contain any information that would identify you. If data are used for secondary analysis, they will contain no identifying information.

All data will be sent to the office of the Primary Investigator at the University of Western Ontario and will only be accessed by members of our research team. Consent forms will be stored in a locked cabinet in a secure office, electronic data including audiotapes will be stored electronically on a secure university information system. Data is maintained for a minimum of five years.

Representatives of the University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

9. Are participants compensated to be in this study?

To compensate you for your time spent in the interview, you will be reimbursed with a \$10 gift certificate.

10. What are the rights of participants?

Providing written consent to be audiotaped, or verbal consent to participate in an interview, demonstrates that you understood to your satisfaction the information about the research study and represents your consent to participate in the study. You do not waive any legal rights by signing the consent form. You will be given a copy of this letter of information and consent form once it has been signed. If you have any questions about your rights as a research participant or the conduct of the study, you may contact the Office of Research Ethics (519) 661-3036, email ethics@uwo.ca.

11. Whom do participants contact for questions?

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics (519) 661-3036, email: ethics@uwo.ca.

If you have any further questions about this study, please feel free to contact Laura Sheridan or Dr. Lorie Donelle. We would very much appreciate your participation in this research project.

This letter is yours to keep for future reference.

Consent Form

Project Title: When Patients Ask to Die: Patient Directed Death and the Perceived Best Practices Among Palliative Care Nurses

Study Investigators:

Principal Investigator: Dr. Lorie Donelle PhD

Student Investigator: Laura Sheridan RN(EC)

Participant Consent

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Sound Recording Consent

I hereby consent to be audio-taped during the interview for the research study. As in all parts of the study my identity will not be known to anyone outside of the group other than the research co-investigator conducting the interview. The person transcribing the tapes will possibly hear my first name only but this information will not be included in the transcriptions. The tapes will be erased at the completion of the transcription. I understand that I can chose not to be recorded and still participate in the study, and that I can chose to withdraw from the study at any time without affecting my employment.

- I consent to being audio-taped during the interview
 I do not consent to being audio-taped during this interview

Name of Participant: (Print)

Participant signature:

Date: _____

I have explained the nature of the consent process to the participant and judge that they understand that participation is voluntary and that they may withdraw at any time from participating.

Name: (Print)

Signature:

Date: _____

Curriculum Vitae

Laura Sheridan RN(EC)

Educational Background

- MScN candidate/ University of Western Ontario/currently enrolled full time/ expected graduation winter 2016
- Primary Health Care Nurse Practitioner Graduate Certificate/University of Western Ontario/ Sept 2004
- BScN/Windsor University/ June 1993

Honors and Awards

- Dr. Sheela Basrur- GE Oncology Nursing Education Scholarship: Registered Nurses Foundation of Ontario 2016
- Heroes in the Home Award recipient 2015- nominated by patient
- Helen Fasken Nursing Bursary recipient- 2014
- Client Driven Care Awards: South West Community Care Access Centre- Team nominee 2014
- Client Driven Care Awards: South West Community Care Access Centre- Individual Client Service nominee 2013

Professional Presentations

- 2017 Guest Speaker, Graduate Health Policy, School of Nursing, University of Western Ontario
- 2016 Guest Speaker, 2nd year CTE undergrad nursing, School of Nursing, University of Western Ontario
- 2016 Invited Speaker, Death and Dying, LIFT Women's Group (Ladies In Faith Together)
- 2009 Annual NPAO Conference, Poster Presentation: *Advanced Home Care Team, Helping Patients Stay Safe at Home.* Laura Sheridan RN(EC)
- 2008 Ontario College of Family Physicians, Successful Ageing at Home: Supporting & Linking Family Physicians, Case Managers, Home Care Providers, "Care of the Elderly" Family Physicians & Specialized Geriatrics to Provide a Continuum of Integrated Care: *Family Physicians & Case Managers: Front Line Provider Perspectives on Required System Supports to Care for Seniors and the Frail Elderly.* Dr. John Jordan, Byron Family Medical Centre, London & Peer Presenter OCFP Alzheimer & related Dementias Physician Training Strategy & Ms. Laura Sheridan, Nurse Practitioner South West CCAC
- 2008 International Nurse Practitioner Advanced Practice Nursing Network 5th International Council of Nurses International Nurse Practitioner/Advanced

Practice Nursing Network (INP/APNN) Conference, Poster Presentation:
Advanced Home Care Team: Helping patients Get the Care They Need at Home.
 Laura Sheridan RN(EC)

- 2007 Annual NPAO Conference, Oral Presentation: *Advanced Home Care Team: Helping Acutely Ill Patients Get the Care They Need At Home.* Laura Sheridan RN(EC) Sara Renouf RN(EC)

Professional Work and Clinical Activities

- 2005- Present
 - Nurse Practitioner-Primary Health Care, South West Community Care Access Centre. Actively involved in the initiation and development of Intensive Home Care Team
 - Hospice Palliative Care Nurse Practitioner Lead. Provision of direct clinical care including symptom management for end of life clients with terminal illness in their homes
 - Provision of in-home care to complex chronic clients
 - Direct clinical care to residents of Long Term Care Homes
 - Member of a working group with the Local Health Integration Network, focusing on System of Care for High Risk Seniors. This group worked with Health Systems Performance Research Network in creating a program to facilitate clients transitioning from hospital to home (2010).
- 2002-2004
 - Registered Nurse, Elgin St. Thomas Health Unit
 - Public Health Nurse, Sexual Health
- 2000-2002
 - Registered Nurse, London Health Sciences Centre
 - Pediatric Intensive Care Unit

Community Volunteer Activities

- 2012-2014
 - St. Thomas Panthers Girls Hockey Association, Trainer
- 2014
 - Monsignor Morrison Catholic School, hair and makeup for drama program
- 2011-2014
 - Monsignor Morrison Catholic School, lunch program volunteer

Professional Licenses, Certificates

- College of Nurses of Ontario, Registered Nurse Extended Class 9336132 expiry December 31 2016

- Learning Essential Approaches to Palliative and End of Life Care (LEAP) program completed 2010

Professional Memberships

- RNAO member since 2003
- NPAO member 2003-2015