

NURSES' EXPERIENCES WITH ASSISTED DEATH

by

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Abstract

Background: The 2016 legalization of Medical Assistance in Dying (MAID) was a landmark event in Canada. For the first time in our country's history, healthcare providers are legally permitted to play a role in assisting patient death. Existing legislation includes registered nurses (RNs) as core members of the interprofessional MAID team, and nurse practitioners (RN/NPs) as assessors and providers of MAID. This constitutes a significant change in practice. Therefore, the purpose of this study was to understand the reported experiences of nurses who have participated in an assisted death.

Research Design: A modified systematic review and narrative synthesis of international research and grey literature on RNs' reported experiences with assisted death.

Findings: From a literature sample of 20 international sources, six major themes were identified. These themes included: RNs' reported experiences with receiving and navigating a request for assisted death; their ways of being during the practice; the intensity of their experiences; how assisted death caused significant moral conflict and uncertainty; the relationship between teamwork and assisted death and how RNs experienced the practice; and their personal and professional development over and time.

Discussion: Findings indicated that RNs experienced assisted death as complex, nuanced and challenging. RNs served as advocates for patient autonomy, beneficence and truth telling, which assisted in the development of relative freedom and equality between providers and patients. However, RNs often existed "in between" their own values and patient suffering and were required to examine the relationship between their subjective moral agency, the moral ontology of nursing, and decision-making. Finally, assisted death influenced RNs' experiences with interprofessional teamwork, wherein the nuanced aspects of collaboration, interprofessional

relationships and team-based engagement were influenced by the challenging landscape of actualizing teamwork in the face of assisted death. Ultimately, these experiences highlighted the exceptionally challenging nature of assisted death-related care.

Lay Summary

The legalization of Medical Assistance in Dying (MAID) was a significant event in Canadian society, and has broad implications for healthcare provider teams. As nurses are important members of these teams, their experiences in these roles need to be examined. The purpose of this study was to understand the reported experiences of nurses who have participated, either legally or illegally, in an assisted death. The author explored existing literature, and our findings indicate that nurses' experiences are influenced by their discussions with patients, their ways of being, the intensity of assisted death and its moral conflict and uncertainty, interprofessional teamwork, and their ability to grow alongside and become more comfortable with assisted death over time. Nurses experienced assisted death as a challenging part of their practice and were impacted by its legal permissibility. This thesis suggests ways in which nursing practice, supports, education and research can continue to develop as MAID evolves in Canada.

Preface

This thesis is original work of the author, Adam R. Fulton.

Figure 1 from © 2009 Moher et al. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred reporting items for systematic reviews and metaanalyses: the PRISMA statement. PLoS Med 6(7):e1000097. doi: 10.1371/journal.pmed1000097.

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Table of Contents

Abstract.....	iii
Lay Summary	v
Preface.....	vi
Table of Contents	vii
List of Figures.....	xi
List of Tables	xii
List of Abbreviations	xiii
Acknowledgements	xiv
Dedication	xv
Chapter 1: Introduction	1
1.1 MAID Eligibility in Canada.....	2
1.2 Global Historical Perspectives	5
1.2.1 Switzerland	6
1.2.2 Belgium.....	6
1.2.3 Luxembourg.....	7
1.2.4 The Netherlands	7
1.2.5 Colombia.....	8
1.2.6 Oregon & Washington	8
1.2.7 Montana	9
1.2.8 Vermont	9
1.2.9 California	10
1.2.10 New Zealand	10

1.2.11	Summary	11
1.3	Canadian Historical Perspectives.....	11
1.4	Canadian Legislative Efforts.....	13
1.4.1	Council of Canadian Academies Review	14
1.4.2	Public Consultations	17
1.4.3	Bill C-7.....	18
1.5	Canadian MAID Socio-Dempgraphic Trends & Practices	20
1.5.1	MAID Death by Setting	20
1.5.2	Diagnoses, Nature of Suffering & Palliative Care Services	21
1.5.3	Canadian MAID Frequency	22
1.6	Physicians' Experiences with Assisted Death	23
1.7	Nurses' Experiences with Assisted Death	26
Chapter 2:	Methods	31
2.1	Modified Systematic Review Approach	31
2.2	Search Methods & Data Sources	32
2.3	Selection of Relevant Resources.....	33
2.3.1	Second Search.....	34
2.4	Appraisal & Data Extraction.....	35
2.5	Data Synthesis & Analysis.....	35
2.6	Declaration of Self	38
Chapter 3:	Findings	40
3.1	Scope & Implications of the Review Process	40
3.2	Findings Chapter Roadmap.....	41

3.3	The Influence of Legality.....	42
3.4	The Role of Nurses	43
3.4.1	Experiences Where Assisted Death was Legal.....	43
3.4.2	Experiences Where Assisted Death was Illegal.....	47
3.5	“Let’s Have a Discussion.....	50
3.5.1	Common Experiences	50
3.5.2	Experiences Where Assisted Death was Legal.....	52
3.5.3	Experiences Where Assisted Death was Illegal.....	54
3.6	Ways of Being with Patients & Families.....	55
3.7	“It’s Intense, You Know...”	58
3.8	What is the Right Thing to Do?	62
3.8.1	Experiences Where Assisted Death was Legal.....	63
3.8.2	Experiences Where Assisted Death was Illegal.....	65
3.9	Working as Part of a Team	67
3.9.1	Experiences Where Assisted Death was Legal.....	67
3.9.2	Experiences Where Assisted Death was Illegal.....	70
3.10	“From Every Case You Learn Something...”	72
Chapter 4:	Discussion	74
4.1	Summary of Findings.....	74
4.1.1	Receiving & Navigating Initial Requests	74
4.1.2	Nurses’ Ways of Being with Patients & Families	75
4.1.3	Intensity of Assisted Death	75
4.1.4	Moral Conflict & Uncertainty.....	75

4.1.5	Working as Part of a Team	76
4.1.6	Evolving Experiences over Time.....	76
4.2	Advocacy, Autonomy & Truth Telling.....	77
4.3	Suffering, Morality & Decision-Making	81
4.4	Collaboration, Interprofessional	84
4.5	Limitations	88
4.6	Implications.....	89
4.6.1	Nursing Practice.....	89
4.6.2	Nursing Research	90
4.6.3	Nursing Education	91
4.7	Conclusion	92
Appendices	94
	Figure 1 – PRISMA Diagram	94
	Figure 2 – Search Strategy for Search #1	95
	Table 1 – Patient Demographic Information	96
	Table 2 – Data Extraction Table	97
References	143

List of Figures

Figure 1 - PRISMA Diagram.....	94
Figure 2 - Search Strategy for Search #1	95

List of Tables

Table 1 - Patient Demographic Information 96

Table 2 - Data Extraction Table..... 97

List of Abbreviations

ALS: Amyotrophic Lateral Sclerosis

AID: Aid in Dying

AIDS: Acquired Immunodeficiency Syndrome

BCCLA: British Columbia Civil Liberties Association

CNA: Canadian Nurses' Association

EPPI: Evidence for Policy and Practice Information

IV: Intravenous

JB: Joanna Briggs Institute

KT: Knowledge Translation

MAID: Medical Assistance in Dying

NP(s): Nurse Practitioner(s)

PAS: Physician Assisted Suicide

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

RN(s): Registered Nurse(s)

USA: United States of America

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Dedication

“Society teaches us that having feelings and crying is bad and wrong. Well, that’s baloney, because grief isn’t wrong. There is such a thing as good grief. Just ask Charlie Brown”. M. Scott.

This thesis is dedicated to my parents, Tom & Donna, who are and will always remain my heroes.

Chapter 1: Introduction

The legalization of Medical Assistance in Dying (MAID) in 2016 was a landmark event in Canadian society. For the first time in our country's history healthcare providers play an active role in assisting death. Existing legislation includes registered nurses (RNs) and nurse practitioners (NPs) as core members of the interprofessional MAID team and grants legal immunity to nursing professionals who participate in the practice (Supreme Court of Canada, 2012). This decision has implications for both RNs and, as assessors and providers of MAID, NPs. As part of an evidence-informed approach to explore the evolving roles of nurses within MAID, the purpose of this thesis was to conduct a modified systematic review and narrative synthesis of research and grey literature on nurses' reported experiences relating to assisted death.

In this background section, I will first provide an overview of assisted death definitions. I will then present global historical developments of assisted death and detail the evolution of MAID in Canada. Third, I will discuss global characteristics and indicators of assisted death, including prevalence, socio-demographic information and common diagnoses which result in assisted death requests. Finally, I will provide an overview of healthcare provider experiences, from both physicians' and nurses' perspectives, relating to assisted death practices; as nurses' role within the practice has been less central than that of physicians, it is important to preface this work with what has been learned from physician experiences, although caution will be exercised in extrapolating these experiences for nursing.

1.1 MAID Eligibility in Canada

In addition to defining assisted death, it is important to describe eligibility criteria. Specific to the Canadian context, a person may receive MAID if they meet all of the following conditions:

- (1) Be 18 years of age or older and have decision-making capacity;
- (2) Be eligible for publicly funded health care services;
- (3) Make a voluntary request that is not the result of external pressure;
- (4) Give informed consent to receive MAID, meaning that the person has consented to receiving MAID after they have received all information needed to make this decision;
- (5) Have a serious and incurable illness, disease or disability (excluding a mental illness until March 17, 2023);
- (6) Be in an advanced state of irreversible decline in capability;
- (7) Have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable (Department of Justice, 2021, para. 5).

Beyond defining patient eligibility in Bill C14, the *Act to amend the Criminal Code (medical assistance in dying)*, also known as Bill C-7, specifies eligibility and safeguards using a two-track system for those whose deaths are reasonably foreseeable and for those whose deaths are not reasonably foreseeable. For patients whose natural death is reasonably foreseeable, the following safeguards are in place:

- (1) Requests for MAID must be made in writing: a written request must be signed by one independent witness, and it must be made after the person is informed that they have a “grievous and irremediable medical condition”;
- (2) Two independent doctors or nurse practitioners must provide an assessment and confirm that all of the eligibility requirements are met;
- (3) The person must be informed that they can withdraw their request at any time, in any manner;
- (4) And the person must be given an opportunity to withdraw consent and must expressly confirm their consent immediately before receiving MAID (however, this “final consent” requirement can be waived in certain circumstances) (Department of Justice, 2021, para 11).

Changes within Bill C-7 no longer require a minimum 10-day reflection period as was the case with original legislation; this means that individuals whose natural death is reasonably foreseeable no longer have to wait 10 days between the approval of their MAID request and receiving MAID (Department of Justice, 2021).

In contrast, for Canadians whose natural death is not reasonably foreseeable, the following procedure must occur:

- (1) A request for MAID must be made in writing: a written request must be signed by one independent witness, and it must be made after the person is informed that they have a “grievous and irremediable medical condition”;
- (2) Two independent doctors or nurse practitioners must provide an assessment and confirm that all of the eligibility requirements are met

- a. if neither of the two practitioners who assesses eligibility has expertise in the medical condition that is causing the person's suffering, they must consult with a practitioner who has such expertise;
- (3) The person must be informed that they can withdraw their request at any time, in any manner;
- (4) The person must be informed of available and appropriate means to relieve their suffering, including counselling services, mental health and disability support services, community services, and palliative care, and must be offered consultations with professionals who provide those services;
- (5) The person and the practitioners must have discussed reasonable and available means to relieve the person's suffering, and agree that the person has seriously considered those means;
- (6) The eligibility assessments must take at least 90 days, but this period can be shortened if the person is about to lose the capacity to make health care decisions, as long as both assessments have been completed;
- (7) Immediately before MAID is provided, the practitioner must give the person an opportunity to withdraw their request and ensure that they give express consent (Department of Justice, 2021, para. 12).

Bill C-7 also introduces processes by which providers must receive final consent before MAID. In cases where natural death is reasonably foreseeable, the requirement for patients to provide final consent immediately before MAID is no longer required. When a patient is at risk of "...losing decision-making capacity before their preferred date to receive MAID, and has been informed of that risk" (Department of Justice, 2021, para. 15), they may make written

arrangements with their provider to waive final consent. The same is true in cases of self-administered MAID, wherein if complications arise after ingestion of the substance, causing loss of decision-making but not death, a provider can then administer MAID without immediate consent (Department of Justice, 2021).

While eligibility criteria have been articulated, and subsequent processes have evolved over time, they remain legal criteria, and hence, ambiguous. Like the definitions of assisted death, these criteria and requirements are vague and confusing, in that Canadian healthcare providers are required to interpret the legal language within their clinical context and judgement. To better contextualize the definitions and eligibility for MAID in Canada, it is helpful to review how assisted death has evolved globally.

1.2 Global Historical Perspectives

Assisted death has been a component of various global health systems for nearly 75 years (Steck et al., 2013). Each country, state and province where assisted death is permitted or legalized regulates the practice by different means. These regulations can range from the absence of laws or guidelines, thorough to decriminalization or complete legalization of assisted death (Luzon, 2019). Legislation establishes distinct guidelines for practitioners, and may be considered a “hard” approach to assisted death given its legal obligations (Luzon, 2019). Alternatively, decriminalization without legislation eliminates criminal culpability during assisted death, but does not institute comprehensive professional obligations (Luzon, 2019). These differences illustrate the potential challenges in identifying the permissibility of certain actions during assisted death; exploring practices in other countries can inform ongoing application efforts and debates within the Canadian context. Given the rapidly evolving MAID

landscape in Canadian health systems, it is important to explore the international development of assisted death.

1.2.1 Switzerland

Switzerland has legislatively permitted PAS since 1942. It was the first international health jurisdiction to regulate the practice. According to the Swiss Penal Code, assisting in the death of an individual is only punishable when borne from motives of self-interest (The Federal Assembly of the Swiss Confederation, 2020). While physician assisted suicide (PAS) is permitted in Switzerland, a physician cannot physically administer the lethal medication; the patient must play an active role in the dying process. In order to facilitate this involvement, right-to-die organizations are consistently involved in supporting PAS. Swiss courts have allowed for broad PAS application requirements and do not prevent individuals suffering from psychological pain to request assisted-death (Steck et. al, 2013). Switzerland is the only country which allows PAS for both residents and foreigners. Individuals who cannot access PAS in their own countries have travelled to Switzerland to capitalize on this availability.

1.2.2 Belgium

In 2002, Belgium passed its *Act on Euthanasia*. Although PAS is not explicitly included in Belgium's definition of euthanasia, the Belgian euthanasia oversight body determined that legislation does include both practices. Accordingly, the law establishes guidelines which require that: a euthanasia request to be voluntary, the patient's physical and/or mental suffering is unbearable and caused by a serious and incurable disorder caused by illness or accident, that the patient is well-informed and that no other care alternatives are appropriate. Belgian euthanasia requests must be evaluated by two physicians, and if a nursing team is involved in patient care, they must also be consulted (Federal Government of Belgium, 2002). In Belgium, a physician

may administer the lethal medication, and all cases of euthanasia must be reported to an authoritative body. In 2014, the Belgian government passed legislation which allowed euthanasia for mature minors aged 12 to 17 years (Federal Government of Belgium, 2014).

1.2.3 Luxembourg

Euthanasia became a legal practice in Luxembourg in 2009. The *Law on Euthanasia and Assisted Suicide* closely mirrors legislation in Belgium; the law permits both acts of euthanasia and PAS, and outlines similar eligibility and screening criteria including the request be voluntary, the patient be well-informed and be suffering from “...constant and unbearable physical or mental suffering without hope of recovery” (The Government of the Grand Duchy of Luxembourg, 2009, p. 2). Unlike Belgium, Luxembourg does not allow euthanasia for mature minors.

1.2.4 The Netherlands

The Netherlands passed euthanasia legislation in 2002. The Dutch Act does not differentiate between euthanasia and PAS, but uses the term euthanasia to encompass both practices. Guidelines in the Netherlands are similar to those in Belgium’s law, and euthanasia may include patients who experience incurable mental and/or physical suffering. Each euthanasia request must be evaluated by two independent physicians, and the physician may either administer the lethal medication or provide it to the patient who then may self-administer. Under the Dutch Act, minors are not eligible for euthanasia; however, in 2020, the Dutch Supreme Court ruled that individuals with advanced dementia may qualify for euthanasia with a written advanced request (Supreme Court of the Netherlands, 2020).

1.2.5 Colombia

Colombia passed legislation allowing PAS in 2015 (Department of Health and Social Protection, 2015). This came after many years of contentious debate: in 1997, the Colombian Constitutional Court permitted PAS for terminal patients who requested to end their life, but did not introduce guidelines or legal parameters at that time. Physicians were reluctant to participate in the practice given the absence of oversights (Public Radio International, 2015). However, new regulations provided guidance for Colombian practitioners. Legislation states that a patient requesting PAS must be informed of all other treatment options, and may only qualify if suffering from terminal cancer, AIDS, and kidney or liver failure (Department of Health and Social Protection, 2015). Patients dying from degenerative diseases such as ALS or Parkinson's do not qualify for PAS under current legislation. Each request must be evaluated by an external, independent committee. Furthermore, Columbia passed legislation in 2018 which permitted assisted-death for children aged 7-14 alongside parental consent and agreement (Department of Health and Social Protection, 2018).

1.2.6 Oregon & Washington

In 1997, the state of Oregon introduced the *Dying with Dignity Act*. This allows PAS for state residents who are considered "terminally ill" with a life expectancy of less than six months (Oregon State Legislature, 1997). The patient must be informed of their medical diagnosis, prognosis and care alternatives such as pain control and palliative care. Oregon stipulates that a physician may prescribe the lethal medication, but may not administer it; the patient possesses exclusive responsibility to self-administer the medication (Oregon Health Authority, 1997). In order to proceed along PAS continuums, the patient must make two oral requests, followed by a written request to the prescribing physician. After completing PAS, the physician must report

each case to state authorities. In 2009, Washington State passed its own *Dying with Dignity Act*, which is nearly identical to Oregon's law (Washington State Department of Health, 2009).

1.2.7 Montana

Montana, in 2009, became the third state to allow PAS. However, no legal permission was granted to allow state-wide practices (Supreme Court of the State of Montana, 2009). Instead, a single court case was heard where an end-of-life patient requested PAS. The Montana Supreme Court subsequently ruled that, under the State Constitution, the individual patient had a right to dignified death while the physician had a right to protection from criminal prosecution. The fundamental right to PAS was not granted, but instead found to be free from conflict with public interests and, therefore, not illegal (Supreme Court of the State of Montana, 2009). As PAS is not legislated, criteria surrounding determination of eligibility and overall processes are not explicit. Each individual case is left to the discretion of the Montana Supreme Court.

1.2.8 Vermont

The *Patient Choice and Control at End-of-life Act* was passed by Vermont lawmakers in 2013. This law is based upon the Oregon PAS model, but contains fewer legislative restrictions. Patients must make two oral requests of a physician for PAS; after the second request, the physician must offer an opportunity for the patient to rescind their application. A written request must follow. Under Vermont law, patients must be suffering from a terminal illness with less than 6 months to live, and must be informed of other treatment options. Medication must be self-administered and may be provided by either the prescribing physician or a pharmacist to whom the patient is referred (General Assembly of the State of Vermont, 2013).

1.2.9 California

In 2015, the *End-of-life Option Act* was brought into effect in California. This law closely resembles those in Oregon, Washington and Vermont: it requires a patient to have less than six months life expectancy, necessitates both oral and written PAS request and stipulates that a physician may prescribe a lethal medication but may not administer the dose. California's law provides healthcare providers legal immunity if they refuse to participate in PAS and does not mandate the practice across the state: individual healthcare facilities may decline to offer PAS without reprisal (California Legislative Assembly, 2015). California's bill was passed during a special legislative session and, as such, experienced delays in introduction. On June 9, 2016, the law officially took effect.

1.2.10 New Zealand

During the 2020 general election, New Zealanders participated in a referendum on euthanasia. Voters were asked whether they supported the *End-of-life Choices Act 2019* becoming legislation. Within the act, individuals aged 18 and older, who are suffering from a terminal illness which will likely end their life within six months, and are in an advanced state of irreversible decline in physical capacity (Parliament of New Zealand, 2019), would qualify for euthanasia. Individuals suffering from a mental disorder would not qualify. Under the *Act*, physicians or nurse practitioners must consult with one other health provider, and with the patient's permission, discuss the request with the patient's family. Lethal medication may either be ingested by the patient, or delivered by the provider. As the law was passed within a referendum, it will officially come into force in November, 2021.

1.2.11 Summary

Assisted death legalization and regulation efforts vary across global health systems. While some similarities do exist, several jurisdictions which regulate the practice have included unique protocols and permissions for both patients and healthcare providers (Steck et al., 2013). It is imperative to reflect upon these international differences as MAID continues to evolve in Canada in order to provide both historical and pragmatic context. Domestic implementation efforts must consider Canadian health values and procedures when implementing MAID; public perception and enduring success for MAID care continuums rely upon a unique Canadian interpretation of the practice (Parliament of Canada, 2016). Therefore, I will next explore both historical and ongoing MAID developments in Canada.

1.3 Canadian Historical Perspectives

MAID has been a part of Canadian health discourse for over 20 years. In 1993, Sue Rodriguez first challenged the Canadian Criminal Code in an attempt to strike down legislation that prohibited MAID. Diagnosed with amyotrophic lateral sclerosis (ALS), and given less than one year to live, Rodriguez argued that existing regulations violated sections of the Canadian Charter of Rights and Freedoms. These included sections 7: the right to “life, liberty, and security of person”, section 12: protection against “cruel and unusual punishment”, and section 15(1), which states “every individual is equal before and under the law and has the right to equal protection and...benefit of the law without discrimination...based upon mental or physical disability” (Government of Canada, 1982, para. 15). Rodriguez was concerned that the disease pathway of ALS would ultimately rob her of personal autonomy, quality of life and the ability to end her life when and how she wished. Her appeal was narrowly defeated by a margin of 5:4

(Supreme Court of Canada, 1993), but stimulated renewed conversations regarding MAID in a Canadian context (Canadian Broadcasting Corporation, 2021).

MAID remained a criminal offense in the Canadian health system for nearly two decades following the Rodriguez case. Over this period, legislative recommendations were introduced, but ultimately failed. Some medical practitioners who participated in MAID were removed from practice and occasionally incarcerated (National Post, 2016), although it is likely many provided MAID without consequence. This landscape shifted in 2011, when the British Columbia Civil Liberties Association (BCCLA) challenged existing regulations prohibiting MAID for terminally ill patients (Supreme Court of Canada, 2012); this attempt was similar to Rodriguez' previous legal efforts. This case, known as *Carter v. Canada*, was introduced by several parties including Kay Carter, a British Columbia resident who suffered from degenerative spinal stenosis and wished to end her own life. The case was heard by the Supreme Court of British Columbia in 2012.

The Supreme Court ultimately ruled in favor of the BCCLA case. However, the Government of Canada appealed the ruling, which was subsequently overturned (Supreme Court of Canada, 2015). In response, the BCCLA filed an appeal to the Supreme Court of Canada. On February 6, 2015, the court unanimously struck down provision in the Canadian Criminal Code which prohibited MAID. This ruling gave competent Canadian adults who are suffering from grievous and irremediable illness the legal right to MAID. The Supreme Court of Canada suspended the ruling for 12 months to allow the Federal Government adequate time to amend laws and introduce practice guidelines; this suspension was further extended an additional four months. On June 6, 2016, Bill C14 was adopted, wherein MAID became a legally permissible health service across Canada (Parliament of Canada, 2016).

While national MAID efforts were evolving, the province of Quebec was working to establish its own guidelines. *Bill 52: An Act Respecting End-of-Life Care* established a framework for the regulation and organization of MAID in Quebec. These guidelines were enacted independent of Federal MAID efforts. In 2013, *Bill 52* became provincial law. The legislation outlined specific eligibility criteria, wherein an individual must suffer from an incurable, irreversible illness and experience unbearable physical or psychological pain (Quebec National Assembly, 2013). Physicians were identified as primary care providers, and *Bill 52* required every medical institution within the province to offer access to end-of-life care (Quebec National Assembly, 2013). Quebec's efforts to legislate MAID propelled the practice to the forefront of national healthcare dialogues and established a legislative benchmark as federal efforts continued to advance.

With the passage of Bill C14, MAID became a legal practice in Canada. The culmination of 20 years of discourse, legislation of assisted death has significant impacts for citizens, lawmakers and healthcare providers. However, its introduction was contentious, and resulted in continued national dialogue and legal challenges. As such, it is important to understand ongoing legislative efforts within Canada, and I will turn to that topic next.

1.4 Canadian Legislative Efforts

National MAID legislation was slow to develop. The Liberal Party of Canada, who at the time formed a majority government, originally introduced a draft of Bill C14 in April 2016. It was, however, heavily criticized. Many lawmakers recognized the narrow scope of this draft as compared to the previous Supreme Court of Canada ruling (Parliament of Canada, 2016). Proposed legislation did not include mature minors as eligible for MAID, limited opportunities to place an advanced request, and included language which would potentially limit MAID

accessibility for patients, especially those experiencing mental disease (Parliament of Canada, 2016).

Language in the proposed MAID legislation was particularly challenging. Bill C14 indicated that MAID required an individual to be experiencing “...an advanced state of decline that cannot be reversed” and must be in a condition where natural death “...has become reasonably foreseeable” (Parliament of Canada, 2016, p. 6). These requirements were identified as ambiguous and severely limiting (Parliament of Canada, 2016). Many parties involved in the development of MAID legislation, including healthcare providers, lawmakers and members of the public, argued against the inclusion of these eligibility criteria. They feared eligibility language would severely limit the availability of MAID for many dying Canadians and pointed to the fact that, under such criteria, Kay Carter would not have been eligible for assisted-death. Despite this opposition, Bill C14 was adopted on June 17, 2016.

1.4.1 Council of Canadian Academies Review

Following initial legislation in 2016, the then-Minister of Health and Attorney General of Canada requested independent reviews related to MAID. Specifically, the Council of Canadian Academies was asked to explore three potential changes to eligibility requirements: “...requests for mature minors, advance requests and requests where a mental disorder is the sole underlying medical condition” (The Council of Canadian Academies, 2018, p.ii). An expert panel comprised of 43 individuals with experiences in “...law, medicine, nursing, bioethics, social sciences, and health sciences” (The Council of Canadian Academies, 2018, p. x) was commissioned. This panel was then divided into three separate working groups, each focusing on one of the three MAID versions under question.

The first group focused on MAID for mature minors, which was defined as “...a person under the age of majority (18 or 19 [years old] depending on the province or territory” (The Council of Canadian Academies, 2018, p. 5). After an evidence review, they found a dearth of definitive answers and identified a significant knowledge gap regarding the topic. Specifically, the working group described the relative rarity of MAID for mature minors; as only four jurisdictions currently allow the practice, evidence on the process was minimal. The group did, however, highlight the need to determine consent capacity for mature minors “...on a case by case basis by considering their experiences, maturity, circumstances, and the gravity of the decision at hand” (The Council of Canadian Academies, 2018, p. 14). Additionally, the group noted that mature minors must be listened to, wherein they are “...protected not only from exploitation, but also from being ignored and excluded” (The Council of Canadian Academies, 2018, p.15).

Advanced MAID requests were also explored. These were defined as requests for MAID “...created in advance of a loss of decision-making capacity, intended to be acted upon under the circumstances outlined in the request after the person has lost decisional capacity” (The Council of Canadian Academies, 2018, p. 5). In general, the Council found that, while advanced requests may reduce anxiety at end-of-life, they might also result in cases of inappropriate MAID. The Council stated:

“A judgement about whether to continue to prohibit or permit some form of (advanced requests) for MAID would need to consider the inherent tensions among values of respecting autonomy, alleviating suffering, and protecting against vulnerabilities, in light of risks and benefits specific to each scenario” (The Council of Canadian Academies, 2018, p. 25).

In order to protect against vulnerabilities, safeguards would be essential. These suggested safeguards might include decision-making support in regards to advanced requests, while ensuring the process is consistently aligned with a patient's informed decisions (The Council of Canadian Academies, 2018). However, the report cautioned that the unique nature of how individuals interpret competing "inherent tensions" related to advanced requests may produce disagreement about the practice.

Finally, one working group investigated MAID where a mental disorder is the sole underlying medical condition. After an evidence review, the group described a range of implications that may result from this application of MAID, yet disagreed on their potential frequency and significance (The Council of Canadian Academies, 2018). Specifically, the report highlighted that patients with mental disorders may not be able to rationally reflect on the nature of their suffering. In addition, these patients would often not meet the reasonably and foreseeable criterion of MAID (The Council of Canadian Academies, 2018). The group also described that patients with mental disorders may be pressured to request MAID as a result of societal pressures, especially those pressures which stigmatize mental health. They identified potential safeguards to protect the practice, including multidisciplinary psychiatric consultations, the requirements of judicial approval for each MAID case, and an increased waiting period between request and administration of MAID to patients with mental disorders (The Council of Canadian Academies, 2018).

Ultimately, the three Council of Canadian Academies reports did not offer tangible recommendations about the extension of MAID in these instances. Instead, they served as a review on the current state of knowledge relating to the 3 topic areas (The Council of Canadian Academies, 2018). Given that a governmental review of MAID legislation was required in 2021

(Parliament of Canada, 2016), the evidence in the reports provided an important component of informing a better understanding of evolving MAID knowledge within Canada. To augment this evolution, the opinions of non-experts were also identified as an important contributor to MAID knowledge development, and I will next explore those opinions.

1.4.2 Public Consultations

In 2020, the Government of Canada commissioned public consultations on MAID. These were intended to gauge public perceptions and opinions regarding proposed changes to MAID law, particularly regarding additional safeguards if death was no longer reasonably foreseeable, and the inclusion of advanced directives (Department of Justice, 2020a). The consultations were available as an online survey; in total, 300,140 Canadians responded, an unprecedented number for a consultation of this nature (Department of Justice, 2020a). The vast majority responded from Ontario and British Columbia, lived in urban locations and identified as English-speaking (Department of Justice, 2020a).

According to the survey results, 73.1% of respondents felt existing safeguards were appropriate to prevent abuse or misuse if MAID eligibility was expanded to include patients whose death was not reasonably foreseeable (Department of Justice, 2020a). In addition, respondents identified additional safeguards as “very important” within potential new legislation. These safeguards included, but were not limited to:

- 1) Making sure the person requesting MAID is aware of all the means available to potentially relieve their suffering, including health and social support services (for example counseling, disability support, palliative care) (61.9% of respondents)

- 2) Special training and tools to assist physicians and nurse practitioners to assess areas of potential vulnerability (for example mental health issues, or potential outside pressures or influences) (55.9% of respondents)
- 3) An obligation for the physician and nurse practitioner to offer to discuss their patient's situation with their family members or loved ones with the patient's consent (40.1% of respondents) (Department of Justice, 2020a)

Regarding advanced requests for MAID, 79.4% of respondents agreed that advanced directives should be legal (Department of Justice, 2020a). In addition, 78.6% of participants agreed that a patient who loses the capacity to provide final consent immediately before the procedure should still receive MAID (Department of Justice, 2020a).

In addition to the survey, a series of hosted in-person roundtables were held. These allowed the Government of Canada to hear from 125 experts and stakeholders, including health practitioners, legal experts, civil organizations and Indigenous stakeholders (Department of Justice, 2020a). The participants in these roundtables provided perspectives on MAID's eligibility criteria, appropriate safeguards, waiver of final consent and advanced requests (Department of Justice, 2020a).

Consultations highlighted the diverse, and at times, divisive nature of MAID. This is an intrinsic reality associated with assisted death (The Council of Canadian Academies, 2018), which was further reinforced when, in 2019, the Quebec courts struck down the 'reasonably foreseeable' criteria.

1.4.3 Bill C-7

In 2019, the Superior Court of Quebec found that Bill C14's provision that a patient's death must be "reasonably foreseeable" was "contrary to the rights to life, liberty and the security

of the person” (Superior Court of Quebec, 2019). Additionally, the court also declared that Bill C14’s section which required a patient to be “at the end-of-life” in order to qualify for MAID did not align with the equality right provision in section 15 of the Charter of Rights and Freedoms (2019). As such, the Superior Court of Quebec declared these sections of the law as invalid, and ultimately suspended them, resulting in implications for both Federal and Provincial MAID laws, until July, 2020 (Superior Court of Quebec, 2019).

Accordingly, in 2020, Bill C-7 was introduced in an attempt to amend MAID legislation. Specifically, the new bill attempted to amend the following components of the Criminal Code of Canada:

- a) Repeal the provision that requires a person’s natural death to be reasonably foreseeable in order for them to be eligible for MAID;
- b) Specify that persons whose sole underlying medical condition is a mental illness are not eligible for MAID ;
- c) Create two sets of safeguards that must be respected before MAID may be provided to a person, the application of which depends on whether the person’s natural death is reasonably foreseeable;
- d) Permit MAID to be provided to a person who has been deemed eligible to receive it, whose natural death is reasonably foreseeable and who has lost the capacity to consent before MAID is provided, on the basis of a prior agreement they entered into with the medical practitioner or nurse practitioner;
- e) Permit MAID to be provided to a person who has lost the capacity to consent to it as the result of the self-administration of a substance that was provided to them under

the provisions governing MAID in order to cause their death (Department of Justice, 2020b, para. 1).

On March 17, 2021, the proposed amendments in Bill C-7 came into law. However, some changes, specifically those related to individuals seeking MAID as a result of mental illness, will remain excluded from Federal law until recommendations are proposed in 2022 and potentially accepted in 2023.

1.5 Canadian MAID Socio-Demographic Trends & Practices

Canada reports consistent socio-demographic trends among patients seeking MAID. For example, the gender of MAID patients is evenly distributed; neither male nor female groups request assisted-death at significantly higher frequencies than the other. Data indicates that, of total requests for MAID in 2019, 50.9% originate from men and 49.1% from women (Health Canada, 2020) which is consistent with previous reports. Across provincial jurisdictions, the average age of individuals who received MAID in 2019 is 75.2 years, with the majority of MAID requests originating with patients over the age of 56 years. In general, the highest proportion of requests for assisted-death came from patients aged 65 to 70 years. Of the 5,631 MAID cases in 2019, 103 occurred amongst patients aged 18 to 45 (Health Canada, 2020). Socio-economic factors were not analyzed, such as income and education level, which impact the generalizability of equitable MAID access for Canadians.

1.5.1 MAID Death by Setting

Once MAID is administered, practitioners are asked to report the setting where it occurred. Legislation supports this process to better understand existing access to home- and community-based end-of-life patient care (Parliament of Canada, 2016). Reports indicate that, in 2019, the primary settings for MAID administration were hospitals (36.3%) and patients' private

residences (35.2%) (Health Canada, 2020). This is consistent with other reports from previous years (Health Canada, 2018; Health Canada, 2019a). Further, reports indicate that 20.6% of MAID occurred in palliative care environments, and only 6.9% occurred in residential care settings. There was noted variation across provinces regarding MAID setting, wherein Quebec practitioners predominantly administered MAID within hospital settings, while British Columbia, Nova Scotia, Manitoba and Ontario saw a greater proportion of patients receive MAID at home (Health Canada, 2020).

1.5.2 Diagnoses, Nature of Suffering & Palliative Care Services

Cancer is the most common diagnosis among all Canadian MAID requests (Health Canada, 2020). Malignant disease comprises 67.2% of diagnoses experienced by patients accessing MAID, which is followed by respiratory (10.8%), neurological (10.4%) and cardiovascular (10.1%) conditions (Health Canada, 2020). Since data collection began in Canada, cancer has remained the most prevalent diagnosis which precipitated a request for assisted-death (Health Canada, 2020); this mirrors trends observed across global jurisdictions where the practice is legal (Oregon Health Authority, 2021; Washington State Department of Health, 2019; Regional Euthanasia Review Committees Netherlands, 2019).

When asked to describe the nature of suffering, independent of diagnosis, Canadian patients who request MAID reported “...a loss of ability to engage in meaningful life activities” and “...loss of ability to perform activities of daily living” as the most irremediable in nature (Health Canada, 2020, para. 6.0). This suffering was subjectively described by Canadian patients, thereby providing insight into the reason(s) which initiated a patient’s MAID request.

When a request for MAID is fulfilled, Canadian practitioners are required to document whether a patient had received palliative care services. According to a Federal MAID reporting

requirement document, palliative care is defined as “...an approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of pain and other physical symptoms, and psychological and spiritual suffering” (Health Canada, 2019b, p. 8). In 2019, 82.1% of Canadian patients who received MAID were reported to have accessed palliative care services; most of those individuals received services for one month or more, and for patients who did not receive palliative care services, the majority (89.6%) had opportunities to access them (Health Canada, 2020). Data availability is limited prior to 2019.

1.5.3 Canadian MAID Frequency

According to the *First Annual Report on Medical Assistance in Dying in Canada*, evidence indicates that MAID frequency has increased year over year since initial legislation was introduced (Health Canada, 2020). From 2016 to 2019, total reported MAID deaths per year grew from 1,015 to 5,631. According to this report, this is likely due to increased awareness of MAID as a legal option, improved data collection processes, and greater acceptance of MAID by both the public and care providers (Health Canada, 2020). Additionally, MAID deaths accounted for 2.0% of all deaths in Canada in 2019 as compared to 1.07% in 2017 (Health Canada, 2019a). Compared to global frequency of total deaths attributed to MAID, which range from 0.3% (United States of America) to 4.6% (Belgium), the evolution of assisted-death in Canada has experienced sustained relative growth over time. This is an important development as MAID continues to become a more common end-of-life care option for Canadian individuals.

Canadian MAID indicators, except MAID frequency, have remained relatively stable since legislation was first introduced. As indicated by reports, increased MAID frequency, common diagnoses and consistent location of administration were documented. These developments are important to consider given the ongoing evolution of MAID in Canada; as the

frequency, societal acceptance and accessibility of assisted-death continue to advance, healthcare providers will encounter aspects of the practice on a more regular basis. As such, the experiences of healthcare providers must be explored as assisted death continues to evolve given their intimate involvement in the MAID process, and it is to that topic I next turn. I will first explore physicians' experiences with assisted death and then briefly describe some of the literature from nurses' experiences.

1.6 Physicians' Experiences with Assisted Death

Physicians are central to assisted death care continuums. Often identified as the “gatekeepers” to assisted death, physicians are integral to the process (Chandhoke et al., 2020). Without their involvement, assisted death cannot proceed in the vast majority of healthcare jurisdictions, yet many physicians report complexities when participating in the practice (Beuthin et al., 2020; Evenblij et al., 2019; Khoshnood et al., 2018). These complex situations significantly impact the reported experiences of physicians providing assisted death, and are therefore imperative to explore as policies and practices continue to evolve.

Assisted death significantly impacts many physicians in practice. Throughout care pathways, physicians indicate the process challenges their professional identity and role (Beuthin et. al., 2020; Khoshnood et al., 2018). For example, assisted death has been identified as impacting physicians' relationships with colleagues (Khoshnood et al., 2018). Relationships have both improved, given the solidarity experienced among physicians as a result of emerging legislation and practice guidelines (Khoshnood et al., 2018), and have also become strained; physicians report fear of potential reprisal from both colleagues and oversight bodies as a result of providing assisted death to patients (Beuthin et. al., 2020; Khoshnood et al., 2018). At times,

this fear has led physicians to practice in isolation and subsequently experience limited professional support during assisted death (Beuthin et. al., 2020).

Physicians in rural settings are particularly impacted by limited assisted death supports (Beuthin et. al., 2020; Khoshnood et al., 2018). Geographic isolation results in significant burdens for rural physicians; they often have to employ “underground” methods to provide assisted death to patients, such as operating outside working hours or traveling long distances (Beuthin et. al., 2020; Khoshnood et al., 2018). These constraints ultimately produce concerns among physicians about assisted death’s accessibility and sustainability in remote settings (Beuthin et. al., 2020; Khoshnood et al., 2018).

Regardless of the setting, physicians experience added professional workload when providing assisted death (Khoshnood et al., 2018; Beuthin et. al., 2020). Given the complexities of the practice, physicians describe “burning the candle at both ends” to accommodate both regular practice and the nuances of assisted death-related care (Khoshnood et al., 2018, p. 226). As a result, physicians describe modifying their practices, through creating shared positions or delegating work to colleagues, in order to accommodate cases of assisted death (Beuthin et. al., 2020; Khoshnood et al., 2018).

Even when able to accommodate assisted death, physicians experience limited financial compensation for their efforts (Beuthin et. al., 2020; Khoshnood et al., 2018). Specifically, physicians have found that “...there was no adequate remuneration for the time spent on documentation, assessments, pre-briefing, and debriefing for each...case” (Khoshnood et al., 2018, p. 225). The administrative processes are perceived as “burdensome”, and the stringent nature of MAID documentation require physicians to invest significant time, attention and unrecompensed resources (Beuthin et. al., 2020; Khoshnood et al., 2018). Additionally,

physicians invest considerable effort in the process of screening, assessing and evaluating requests, and experience that process as challenging in its own right.

These challenges arise from the nuances of evaluating a patient's request for assisted death. Specifically, physicians occasionally experience pressure from patients and family members to grant a request (Evenblij et al., 2019), and subsequently describe difficulty in denying requests when assisted death is not appropriate (Beuthin et. al., 2020). This ultimately results in personal and professional uncertainty and "emotional burden" for providers (Evenblij et al., 2019, p. 3). Despite these burdens, many physicians experience assisted death as extraordinarily rewarding (Beuthin et. al., 2020, Chandhoke et al., 2020; Evenblij et al., 2019).

Assisted death produces a variety of positive experiences for practicing physicians. Most report a willingness to engage in the practice (Chandhoke et al., 2020), and state that it results in both a practical and emotional impact (Khoshnood et al., 2018). They acknowledge that assisted death offers an opportunity to holistically engage with patients outside the practical "hubbub of daily work" and experience assisted death as a return to the emotionally-rooted artful nuances of practicing medicine (Beuthin et. al., 2020, p. 4).

Moreover, physicians experience assisted death as a process entailing "deep empathy" and "love" (Beuthin et. al., 2020, p. 4). This was an unexpected experience for some providers; given the contentious societal perception of assisting death, physicians are often hesitant to describe the practice in such affirming ways (Beuthin et. al., 2020). Regardless, physicians describe their experiences as comfortable and satisfactory (Evenblij et al., 2019), and express a sense of privilege in their ability to provide compassionate end-of-life patient care (Beuthin et. al., 2020).

This positive privilege is often informed by personal beliefs and values. Physicians report that, when assisted death aligns with values such as patient autonomy, social justice and beneficence, their experiences are positive (Beuthin et. al., 2020; Evenblij et al., 2019). Alternatively, the extraordinary nature of the practice may conflict with physicians' beliefs, thereby resulting in experiences of burden and uncertainty (Beuthin et. al., 2020; Evenblij et al., 2019). However, after reflection and periods of “soul searching”, most physicians describe the development of emotional resilience regarding assisted death, and express capacity to participate in the practice despite potential burden (Beuthin et. al., 2020, p. 5). However, this phenomenon has not been studied in diverse practice settings, which may limit generalizability.

Physicians play a vital role throughout assisted death. As ultimate “gatekeepers” of the practice, they assume essential responsibility and, as a result, experience substantial challenges. However, physicians are not the only care providers who participate in the practice; other members of the interprofessional care team, such as RNs and NPs, have been identified as core members of the assisted death team (Parliament of Canada, 2016) and experience assisted death from their own unique lens. As such, it is essential to examine and explore the experiences of these practitioners as assisted death continues to evolve as a component of the Canadian healthcare system.

1.7 Nurses' Experiences with Assisted Death

The evolution of assisted death has significant implications for most nurses. While physicians have been designated as “gatekeepers” of the practice, the complex nature of assisted death requires the involvement and participation of an interprofessional care team (Parliament of Canada, 2016). Nurses represent an essential part of this team: as indicated in empirical literature, their ongoing involvement with patient and families, acute assessment abilities, and

supportive practical focus greatly contribute to the delivery of holistic care throughout the process. As such, it is important to explore nurses' experiences with assisted death as the scope of their involvement continues to evolve and expand.

Nurses play a unique role during assisted death. Given the intimate nature of nursing practice, meaningful and poignant interactions between nurses and their patients are common (Nelson, 2020). For example, nurses are often the first healthcare provider group to receive and subsequently explore a patient's request (Suva et al., 2019). As a result, nurses are provided with an opportunity to assess the legitimacy and intent of a patient's request for assisted death.

In assessing a patient's request, nurses seek to understand the reasons behind it (Buchbinder et al., 2019; 2019; Nelson, 2020). Specifically, nurses attempt to identify the motivating factors which precipitate a patient's desire for assisted death; these include efforts to uncover concerns regarding finances, untreated depression, and/or the patient's fear of being a burden upon family members (Buchbinder et al., 2019; Suva et al., 2019). Ultimately, nurses are in a unique position to engage in these conversations given their intimate and ongoing interactions with patients (Nelson, 2020) and subsequently share them with other members of the care team.

Given this intimacy, nurses attempt to actualize and often realize their roles as patient advocates during assisted death. Nurses develop therapeutic relationships with patients, and are therefore able to advocate for the wishes, desires, and holistic care needs of patients at end-of-life (Nelson, 2020; Suva et al., 2019). In particular, nurses describe patient autonomy as a focus of their advocacy efforts, and often express this autonomy as more important than their own personal beliefs regarding assisted death (McMechan et al., 2019). As one nurse states:

“...we take an oath to care for people no matter what our own beliefs and values are. So, if that is someone else’s belief and value, and that’s what they want to do, then it is our responsibility to support them” (McMechan et al., 2019, p. 5).

Nurses’ dedication to supporting patient autonomy, regardless of their personal values or beliefs, is a challenging component of assisted death; while described as an important nursing responsibility, the dichotomy between personal values and professional practice often results in uncertainty, tension and emotional hardship for nurses.

Nurses experience complex uncertainty during assisted death. Given the potential dichotomy between personal values and professional responsibility, nurses experience uncertainty when attempting to reconcile the moral realities of engaging in the process with their own beliefs and values (McMechan et al., 2019; Pesut et al., 2019). For example, when nurses experience a moral conflict between assisted death and their personal moral standing, they subsequently experience an “...instinctive desire to make sense of it in a way what is coherent with who (they) are as individuals” (Pesut et al., 2019, p. 5). These attempts to “make sense” of assisted death’s moral uncertainty require significant and focused personal reflection from nurses who engage in the practice (McMechan et al., 2019; Pesut et al., 2019).

Moreover, nurses experience uncertainty between intellect and emotions during assisted death (McMechan et al., 2019). Nurses describe that, while they may intellectually understand and support the practice, there exists a “...contradiction between...intellectual understanding of [assisted death], and the emotions that arose during the process of caring for a patient considering or receiving...” assisted death (McMechan et al., 2019, p. 6). This incongruity results in experiences of ambiguity, discomfort, unease and emotional hardship for nurses (Nelson, 2020).

To alleviate these hardships, nurses require support from colleagues, institutions, regulatory bodies and legislation. Nurses who participate in assisted death experience a desire for holistic support throughout the process (Nelson, 2020; Suva et al., 2019). However, this support is often absent: nurses experience a dearth of accessible supports especially from institutional, regulatory and legislative resources (McMechan et al., 2019; Pesut et al., 2018; Suva et al., 2019). The absence of resources beget situations wherein nurses experience a sense of inadequate preparedness for and/or knowledge about how to participate in assisted death (McMechan et al., 2019; Suva et al., 2019).

To better support nurses, accessible resources must improve. Providers consistently describe a desire for enhanced personal and professional supports and resources; for example, a cohort of nurse leaders determined that “...organization-wide education, policies, and procedures that promote ethics and teamwork in end-of-life situations are needed to support nurses in practice” (Suva et al., 2019, p. 51). Additionally, transparent communication and improved educational resources, such as workshops, lectures and applied training, are identified as essential to support nurses during assisted death (McMechan et al., 2019; Suva et al., 2019).

Nurses play an essential role throughout assisted death. Their potential for intimate involvement in aspects of end-of-life care, ranging from first receiving a request to advocating for and supporting patients until death, require a comprehensive exploration of nurses’ experiences given these unique roles and responsibilities. As Canadian MAID legislation includes nurses as core members of the interprofessional care team and grants legal immunity to nursing professionals participating in the practice (Parliament of Canada, 2016), implications for nurses must be considered. As part of an evidence-informed approach to examine the evolution of nurses’ role during assisted death, and to build upon material presented in the preceding

chapter(s), the purpose of this thesis is to conduct a modified systematic review and synthesis of research and grey qualitative literature on nurses' experiences relating to assisted death.

Chapter 2: Methods

In this chapter, I will first introduce the concept of a modified systematic review, as compared to a traditional systematic review, and my present rationale for its use as a methodology for this thesis. I will then discuss search methods and data sources, resource selection, appraisal and data extraction, and the finally data synthesis processes.

2.1 Modified Systematic Review Approach

The research objectives of this thesis regarding nurses' experiences with assisted death were addressed through a modified systematic review of empirical and grey literature. To better understand the purpose of a modified systematic review, it is important to define a traditional systematic review. The Joanna Briggs Institute (JBI) manual for systematic reviews, which provides comprehensive guidelines for authors conducting evidence-based health research, recognizes a traditional systematic review as a process that involves identifying, evaluating and interpreting all available literature relevant to a particular question, topic area or research phenomenon. (Joanna Briggs Institute, 2020). During a traditional systematic review, emphasis is placed upon “comprehensive and exhaustive searching”, which usually includes numerous individual reviewers and/or a research team. However, given the scope of a Master of Science in Nursing thesis, a modified review format was utilized.

This modified review included various components of a traditional systematic review, such as a two-staged search strategy (discussed below) and the use of structured assessment criteria (JBI, 2020). It did, however, also implement a limited search methodology in terms of the number of data bases searched and the potential search strategies used given the scope of this thesis and the capacity of one single researcher to conduct a fulsome systematic review.

This modified review synthesized knowledge from empirical literature identified through database and grey literature searches which provided substantive qualitative data on nurses' experiences with assisted death. For the purpose of this thesis, substantive qualitative data were defined as literature wherein registered nurses subjectively described, in the form of direct quotations, their experiences across the care continuum of assisted death. Quantitative findings were not synthesized given my use of a qualitative meta-summary analysis methodology, as described in sub-section 2.4. Qualitative meta-summary allows the researcher to summarize qualitative topical and/or thematic survey research findings, and produce empirical foundations upon which to construct interpretative analyses of the target phenomenon (Sandelowski et al., 2007). Accordingly, quantitative literature, which do not provide topical and/or thematic survey findings, were omitted from synthesis.

Following recommendations of the Evidence for Policy and Practice Information and Coordinating Center (EPPI), an EPPI-Reviewer software was used to combine documents into one database, apply selection criteria, critically appraise documents, and facilitate synthesis of findings.

2.2 Search Methods & Data Sources

In this thesis, I utilized a comprehensive, staged search strategy to identify documents related to the phenomenon of interest. In accordance with JBI, a two-phased search strategy was used (2020). First, an initial search of MEDLINE and CINAHL was performed, relevant articles were identified, and from those articles a list of key words from titles, abstracts and index terms were developed. Second, a database search was conducted in consultation with a library scientist using these identified keywords and index terms. This search included the following reference databases using both controlled/subject heading and keyword vocabulary: MEDLINE, CINAHL,

EMBASE, PSYCHINFO and AGELINE. GOOGLE SCHOLAR was used to conduct grey literature searches to identify additional qualitative studies, as detailed below.

The completed search was then downloaded into EPPI-Reviewer software, used to manage and organize literature sources, and duplicates were identified based upon a 95% agreement criterion; duplicates were reviewed manually before being removed. Additional search strategies included reference checking (scanning reference lists of identified studies for relevant publications) and forward citation searches (automated searches of citation indexes). Unlike JBI recommendations, I did not identify experts who could then identify missing studies, and only performed forward citation searches if the study topic directly pertained to the research objectives of this thesis.

A grey literature search strategy was also used, where I executed an advanced search using GOOGLE SCHOLAR to identify and review relevant grey materials: this entailed a language-controlled search for grey literature which used the same identified keywords and index terms as above. Sources identified through these additional search methods were also downloaded into EPPI-Reviewer software for management. A PRISMA flow chart was used to demonstrate the entire search process through until data synthesis (Figure 1), which effectively allows for an accurate audit trail of data source screening and selection.

2.3 Selection of Relevant Resources

Screening of identified data sources was conducted by the author of this thesis and an experienced colleague at the University of British Columbia Okanagan. Iterative inter-rater reliability checks were completed, wherein a small number of sources were reviewed, level of agreement was determined and inclusion/exclusion criteria were negotiated and refined. This promoted homogeneous data screening processes with the minimum acceptable inter-rater

agreement set at 90%, which is above the widely accepted agreement threshold for systematic reviews (Belur et al., 2018; McHugh, 2012). The following selection criteria were utilized to guide screening:

Domain and Population of Interest: Studies that provided information about assisted death and which specifically focused on nurses' reported substantive qualitative experiences with the practice.

Settings: Studies which provided information about assisted death and nursing from all international contexts were included. Literature which explored assisted death in countries where the practice was not legal were identified and so this evidence was also incorporated.

Types of sources: Empirical literature, including theses and dissertations.

Language: Search strategies included only English language studies.

Time Period: Searches were limited to studies from 1997 until 2017. This selected date range was based upon knowledge of parameters relevant to research objectives: given existing knowledge gaps relating to nurses' experiences, these dates were chosen to reflect the introduction of assisted death legislation in North America, one of the earliest countries to adopt some form of assisted death (Oregon's Death with Dignity act was introduced in 1997).

Exclusion: Studies which explored practices related to, but did not constitute assisted death, were excluded: this involved literature on palliative sedation and withholding treatment. Additionally, expert opinions were not solicited.

2.3.1 Second Search

As there was a significant time delay between the initial search and the writing up of the thesis findings, a second search was completed in November of 2020. This search utilized the same controlled/subject headings and keyword terms as the initial search, and was completed in

the research databases CINAHL, MEDLINE, EMBASE and PSYCHINFO. Additionally, an advanced search using GOOGLE SCHOLAR was performed to identify relevant studies from the grey literature. The same inclusion and exclusion criteria were utilized in this second search. However, the time period was altered to only include relevant resources published between 2017 and 2020.

2.4 Appraisal & Data Extraction

A standardized data extraction tool, which ensures a standardized approach to identifying and extracting data, was used to minimize data extraction errors and to ensure the same data were recorded for each study. Documents were coded to extract data related to the research objectives of this thesis, and to better inform the ongoing development of knowledge which informed the preceding chapters of this thesis. The data extracted included specific details regarding the methodology, phenomena of interest, setting, geographic and cultural context, definition(s) of assisted death, participants and populations, methods of data analysis, findings and the author's conclusions and review comments (Table 2). An initial trial of data extraction was conducted in order to ensure completeness of extraction efforts and to refine the process and related tools.

2.5 Data Synthesis & Analysis

Findings were concurrently synthesized and analyzed to answer the primary thesis objectives regarding nurses' experiences with assisted death. This process was completed using a qualitative meta-summary methodology, which is defined as "...the extraction, grouping, [and] abstraction ... of findings" wherein the "...presentation and interpretation of synthesis results" are achieved (Sandelowski et al., 2007, p. 103). Qualitative meta-summary promotes the summation of research findings, produces empirical foundations for interpretive research

(Sandelowski et al., 2007), and allows for the analysis and deconstruction of research ideas across multiple contexts (Thorne, 2017).

Meta-summary enables a researcher to “...tap the available knowledge as widely as feasible and study it as deep as is conceivable” (Thorne, 2017, pg. 10), while allowing researchers to “...assess the impact individual primary reports and their findings had on the results of a synthesis” (Sandelowski et al., 2007, p. 109). This ultimately promotes a genuine and distinctive contribution to nursing knowledge while enabling researchers to recognize the “...theoretical and methodological trends that have shaped the study of a target phenomenon” (Sandelowski et al., 2007, p. 109), in this case nurses’ experiences with assisted death.

The qualitative meta-summary approach requires distinct methodological sequences, which were followed in this thesis:

- (1) Extracting findings using language defined by the research objective, namely substantive qualitative experiences of nurses relating to assisted death as previously defined. *Experiences* was defined as “...the fact or state of having been affected by or gained knowledge through...observation or participation” (Merriam-Webster Dictionary, n.d., section 1(b)). In this thesis, experiences included the emotions, practices or sentiments of nurses who, in some capacity (either directly or indirectly), were exposed to any aspect of the assisted death care continuum. Adhering to meta-summary recommendations, extracted findings were separated from data which did not pertain to the research objectives, such as author descriptions of analytic procedures and/or discussions of the significance of their findings. This improved the descriptive and interpretative validity of extracted findings (Sandelowski & Borosso, 2003).
- (2) Grouping findings according to their topical similarity. By grouping findings together, their complexity and validity were both preserved (Sandelowski et al., 2007), and the relationship

between themes became increasingly evident. The author created grouped categories and secondary sub-categories through a reflexive and iterative process. Categories were developed under *experiences*, and included such sub-themes as “intensity”, “ways of being” and/or “teamwork” that were identified as the process evolved. Further, these secondary subcategories inspired tertiary subcategories to emerge: for example, the “intensity” category led to the development of a tertiary subcategory for “fear” and/or “guilt”. Again, these processes developed as the extraction progressed. Analysis of these categories occurred concurrent to their grouping.

(3) Abstracting findings by further refining grouped statements into more comprehensive statements. This process produced a concise abstraction of grouped findings, eliminated redundancies and preserved contradictions and ambiguities (Sandelowski et al., 2007). The thesis author worked with his grouped findings and, while moving back and forth between those and his statement of abstracted findings, built a more complete summary of the evidence while preserving the original author(s) context and intentions. In doing so, the author considered these groups and subsequent statements in relation to study characteristics which included (but were not limited to) the year of study/findings; regional assisted death practices; sampling procedures between qualitative studies; the described facilitators/barriers to assisted death; nurses’ experiences regarding participation; and/or the described advantages/disadvantages of assisted death practices.

Abstraction promoted the development of clarity and consensus regarding core themes and concepts as they related to the research objectives of this thesis. Additionally, abstraction eliminated findings that may have been logically expected by the researcher, but did not appear: while logically-possible findings may be identified in empirical findings, they do not represent actual, informed findings in a qualitative meta-summary (Sandelowski et al., 2007).

Iterative analyses compared, contrasted and ultimately deconstructed these findings. While thematic aggregations (resulting from data synthesis procedures) informed this process, my efforts moved beyond a mere thematic analysis: comparisons between study design, underlying assumptions and critical reflections regarding questions asked and/or not asked occurred. This analysis produced a deconstruction of implicit ideas and/or beliefs regarding the phenomena of interest while allowing for the development of a richer, deeper understanding of nurses' experiences with assisted death. The results of this deconstruction informed the following findings section, by allowing me to explore nurses' experiences beyond those articulated in the literature, and the discussion and recommendations segments of this thesis.

2.6 Declaration of Self

Prior to and during the process of completing this thesis, I worked as an RN in multiple clinical practice environments. In those environments, I provided palliative care to terminally ill patients and families. While MAID was not a legally permissible healthcare practice at that time, I observed and experienced situations where terminally ill patients expressed, either directly or indirectly, a desire to die. Accordingly, these experiences sensitized me to components of assisted death care continuums as explored in this thesis.

In recognizing this sensitization, it was important for me to be self-analytical, reflective and reflexive of my own beliefs regarding assisted death as I conducted my research. This allowed me to holistically engage with, understand and authentically explore the findings of my literature search(s) while limiting my a priori assumptions. Furthermore, the process of abstraction, intrinsic to the qualitative meta-summary mythology, enabled me to limit my own logical expectations (Sandelowski et al., 2007) during the research analysis process. These efforts to bracket my assumptions were further facilitated through iterative consultation with my

supervisor, personal journaling, and self-guided reflection sessions in an effort to enhance transparency.

Chapter 3: Findings

In this next section, I will report the findings from my modified systematic review regarding nurses' reported experiences with assisted death. To provide some context to this chapter, I will first reiterate the scope and implications of the review process. Next, I will describe the overall goals and direction of this findings chapter, thereby providing a roadmap that will assist the reader to navigate the complexities of nurses' experiences. I will then define and contextualize key ideas, such as how I found that assisted death differs when it is either legal or illegal, and articulate how these concepts have impacted my interpretation of the evidence. Finally, I will present findings as they relate to the research objectives of this thesis.

3.1 Scope & Implications of the Review Process

The results of my review were detailed in the preceding chapter. To summarize, a total of 20 substantive qualitative evidence sources were used which related to nurses' reported experiences with assisted death. Demographics for the nurse participants included in this literature review are detailed in Table 1. The studies ranged in publication date from 1993 to 2020, over which significant evolutions in assisted death have occurred, and reported on nurses' experiences from jurisdictions where assisted death was either legal (13 studies) or illegal (7 studies) (Table 2).

I remind the reader of these sources to clearly locate the scope of the findings, and hence the limitations of the evidence. The evidence described within this chapter might appear controversial, and challenge traditional perspectives about nursing practices at end-of-life. However, I encourage the reader to remember that this thesis relies upon a nascent body of literature. The findings are not indicative of general nursing practices, but instead explore the *reported* experiences of a small sample of nurses from a limited body of available evidence.

However, while the frequency of reported experiences is limited, given the lack of quantitative evidence included in this thesis, the findings do have important implications for nursing practice at end-of-life.

Given this limited scope, findings will be both reported and interpreted. My goal is to both reflect upon the nature of available literature, and develop a cohesive narrative which “...critically reflects upon, and at times even deconstructs...ideas [from] research...over time and across multiple contexts” (Thorne, 2017, p.10). This reporting style will allow the subtle elements of nurses’ experiences with assisted death to be described and interpreted.

3.2 Findings Chapter Roadmap

My goal within this chapter is to describe identified evidence on nurses’ reported experiences with assisted death. Given the complexities of this topic, and the nuanced nature of crafting a narrative which accurately reflects nurses’ experiences, I will explain the overall structure and direction of my writing.

In this chapter, I will first discuss the influence of legality, then describe nurses’ roles during assisted death. This will focus on nurses’ pragmatic conduct, and better enable the reader to conceptualize the variable roles which informed nurses’ reported experiences. I will then discuss how nurses received initial patient requests for assisted death, and explore how they navigated those complex appeals for assistance in dying. Next, I will explore the ways in which nurses could be with patients and families during assisted death; given their potential for developing intimate relationships, most nurses described being relational, present, open and vulnerable with patients and family members as they progressed along assisted death care continuums.

Subsequently, I will describe how nurses experienced the outcomes and sequela resulting from their participation in assisted death. I will explore how nurses experienced the intense day and/or moment of assisted death, how those moments impacted their interpretations of the dying process, and how nurses qualified the nature of assisted deaths as either positive or negative. Additionally, I will describe how nurses experienced the personal and professional effects of engaging in assisted death, and how they navigated the moral uncertainty which often accompanied the process.

In the next subsection, I will explore the impact of interprofessional teamwork on nurses' experiences with assisted death, and how legality influenced their experiences. Given that the process often involved multiple healthcare providers, nurses were significantly impacted by the nature of their involvement as members of the interprofessional care team. Finally, I will explore how nurses' capacity to physically, emotionally and psychologically engage with elements of assisted death developed over time.

3.3 The Influence of Legality

Nurses experienced assisted death across two distinct practice landscapes: those which allowed them to legally participate in aspects of assisted death, or those which did not. The review process used in this thesis collected studies from both contexts. Nurses' capacity, or lack thereof, to legally participate significantly influenced the nature of their experiences. Therefore, I will briefly discuss these two contexts.

In some jurisdictions, assisted death was a legally permissible and accessible health service. As such, nurses were able to actively participate without threat of legal or professional reprisal; in legal settings such as Belgium, the Netherlands and Canada, nurses were given opportunities to participate as members of the care team. These opportunities subsequently

influenced both nurses' roles during assisted death and how they could be present with patients throughout the process.

Conversely, in contexts where assisted death was illegal, the practice violated both criminal law and professional nursing standards, and was not a permissible component of nursing practice. Professional organizations, regulatory bodies and jurisdictional courts prohibited nurses from participating in assisted death as it violated professional ethics and goals. According to the evidence, these nurses risked potential professional, legal and or/criminal reprisal if they were to participate in any aspect of care relating to assisted death. Despite these risks, some nurses did participate in illegal assisted death. As indicated by evidence later described in this thesis, nurses engaged in various aspects of assisted death even though it was not a permissible component of their practice.

In general, nurses' ability to participate in assisted death significantly influenced their experiences. My description of these findings will strive to reflect this variability, and I will begin by describing the role of nurses when assisted death was either legal or illegal.

3.4 The Role of Nurses

During assisted death, nurses' responsibilities were complex and comprehensive. As previously described, the legality of assisted dying led to significant differences among nurses' roles. This description of nursing roles will set the stage for the remainder of my findings chapter.

3.4.1 Experiences Where Assisted Death was Legal

When assisted death was legal, nurses performed distinctive roles. For example, nurses provided information, supported family members, advocated for patients, mediated conflict, organized assisted death-related care, and performed technical nursing interventions.

One such nursing role was that of providing information to patients. As one study reported:

“Nurses also make time for the patient...to provide answers to questions about their diagnosis and prognosis, to define concepts...to give information (about the legal procedure, about the hospital procedure, about possibilities in palliative care)” [Nurse Researcher] (Dierckx de Casterle et al., 2010, p. 2414).

Not only did nurses describe and define assisted death, they provided general information regarding various components of death and dying to their patients. These included options such as palliative care and pain management techniques. By sharing these options, nurses reported that they experienced a sense of comfort by serving as a source of information and knowing their patients were well-informed (Denier et al., 2009; Pesut et al., 2020a). Moreover, nurses explained that they engaged with and provided information to their patients’ families, who were often intimately involved in the process (Beuthin et al., 2018; Denier et al., 2010b; Pesut et al., 2020a).

Ongoing engagement with family members was an important component of the nursing role. Nurses described it as a responsibility which was not limited in time or space; the relationships between individual nurses and family members did not stop immediately following a patient’s death, and often extended beyond the care setting (Bruce & Beuthin, 2019; Dierckx de Casterle et al., 2010; Denier et al., 2009; Pesut et al., 2020a). For example:

“All nurses in our study reported that there is contact with the family afterwards.

Depending on the situation (policy, relationship with the patient and family, personal character of the nurse) this happens in either a formal way, by making a telephone call to the family [one] month afterwards [or] by organizing the annual memorial services in the

hospital, or in a more intimate, informal way by attending the funeral” [Nurse Researcher] (Dierckx de Casterle et al., 2010, p. 2415).

By remaining in contact with relatives, nurses attempted to support them and help them mourn. Additionally, nurses experienced ongoing contact with family members as an opportunity to evaluate the process of assisted death together (Denier et al., 2010b) and to begin an informal debriefing process.

Another role performed by nurses was advocating for their patients. They did this to ensure that the patient’s request for assisted death was being communicated and taken seriously (Beuthin et al., 2018; Dernier et al., 2010b; Sheridan, 2017) and to secure adequate pain relief and comfort (Beuthin et al., 2018; Dierckx de Casterle et al., 2010). Furthermore, nurses actively and transparently advocated for their patients’ written directives, end-of-life wishes and care requirements if advanced care planning was in place (Denier et al., 2010b). Nurses also functioned as mediators of conflict, disagreement(s) and anger during assisted death; they acted as agents between patients and both their relatives and members of the interprofessional care team, and described mediating as important given the challenging emotional elements of assisted death (Denier et al., 2010b).

As the assisted death process progressed, nurses described a shift in their role. If assisted death was decided upon as an appropriate course of action, nurses described a change in their focus from providing information, advocating and mediating to detecting, realizing and supporting patients to enact and implement their last wishes. This included efforts to understand the patient’s intent and desire for assisted death (detecting) and assisting them to engage in the process which facilitated that identified outcome (realizing). For example:

“Once the decision to carry out [assisted death] is taken, the atmosphere of the...care process changes. [Nurses] described how...they experienced that in this stage the care becomes much more focused on trying to provide exactly the care that patients and their relatives need to make it through their last days together...nurses try to detect and realize last wishes” [Nurse Researcher] (Dierckx de Casterle et al., 2010, p. 2414).

While this shift occurred, it did not mean nurses ignored their patient’s end-of-life desires prior to this point. Instead, nurses turned their attention to providing care which aligned, when possible, with their patients declared personal and care needs.

In addition to a shift in focus, nurses began acting as organizers of assisted death. They focused on achieving good practical and procedural organization and coordination. As care trajectories advanced towards the actual day of facilitating assisted death, this action became more meaningful. As one nurse described:

“I make sure everything is well arranged for everyone involved: for the family, for the patient, for the physicians, for everyone at the bedside. It’s a bit of...sort of coordinating everything. Making sure everything proceeds well” [Nurse Participant] (Denier et al., 2009, p. 267).

These organizational efforts focused on both the medical and contextual elements of providing assisted death. Nurses set up equipment, assigned staff tasks, explained medical procedures to patients and their families (Beuthin et al., 2018; Denier et al., 2010a), and reported that assisted death was considered successful when good organization was achieved (Denier et al., 2009; Pesut et al., 2020b).

Beyond organizing care, nurses actively participated in technical and/or medical preparations during assisted death. Where assisted death was legal, nurses reported that they

often prepared lethal medications (Beuthin et al., 2018; Dierckx de Casterle et al., 2010; Denier et al., 2010a; van de Scheur & van der Arend, 1998). These actions were usually limited to mixing medications and establishing aspects of the intravenous (IV) system, primarily due to nurses' expertise with IVs and physicians' lack of confidence regarding IV equipment (van de Scheur & van der Arend, 1998). In one study from the Netherlands, nurses did administer the lethal medication in the presence of a physician, due to hierarchical nurse-physician relationships and nurses' familiarity with IV medication administration (van de Scheur & van der Arend, 1998). However, nurses generally described lethal medication administration as beyond their competence and scope of practice (Dierckx de Casterle et al., 2010; Dierckx de Casterle et al., 2006) and as a role only for physicians. This was supported by transparent and accessible practice support policies and guidelines (Denier et al., 2010b; Pesut et al., 2020a), which clearly defined nurses' roles and supported the confident realization of their practical scope during assisted death.

Nursing roles included providing information, advocating for patients, mediating conflict, coordinating care and engaging in the technical aspects of assisted death. Interestingly, where assisted death was illegal, nurses experienced some similar roles, but the nature and scope of their involvement was considerably different. These related, but divergent, experiences will be explored in the following section.

3.4.2 Experiences Where Assisted Death was Illegal

The nature of nurses' roles was different where assisted death was illegal. For example, nurses still provided information to patients and their families, but its scope was limited due to the prohibited nature of assisted death. Instead of directly discussing assisted death, nurses initiated and subversively provided patients and family members with information that could

help patients to facilitate their own death. This included details regarding various lethal medications, their dosing parameters and how much might be too much (Volker, 1999). Nurses shared this information with patients and family members in an attempt to circumvent aspects of the challenging legal landscape (Wright et al., 2017), and to avoid adverse outcomes which could arise from patients using inappropriate medications or doses. While nurses did not know how patients would receive and utilize this information, most felt sharing information was the right thing to do (Volker, 1999).

Beyond providing information, nurses performed the role of dedicated patient advocate. When assisted death was illegal, nurses struggled to advocate for the practice as they were unable to explicitly encourage or endorse it as a patient care option (Wright et al., 2017). Instead, nurses considered themselves responsible to advocate when patient suffering became unbearable. They focused on ensuring the availability of adequate pain control and comfort measures, which nurses used to reduce patient suffering, respect dignity, and honor the vulnerable position of patients at end-of-life (De Bal et al., 2006; Schwarz, 2002; Wright et al., 2017).

Nurses, however, acknowledged that at times their efforts to provide pain control and reduce suffering could be a covert form of assisted death. These actions were, at times, beyond nurses' legal scope of practice. For example:

“She [nurse] wished that her dying patient’s suffering would end. She described her actions as a ‘form’ of assisted death. When a nurse determined to hasten the dying process in order to diminish suffering of an inevitable and imminently dying patient – Elizabeth wrote that ‘this intent...(although often disguised) is assisted death...’” [Nurse Researcher] (Schwarz, 2002, p. 144).

Though occasionally beyond scope, nurses did recognize the complex relationship between actions which reduced suffering and those which facilitated assisted death.

While some of these actions violated legal and practice standards, nurses experienced a moral responsibility to assist their patients in the face of unbearable suffering. When patients were suffering and wanted to voluntarily die, but were unable to deliberately and openly request assisted death given its illegal nature, nurses described a desire to act. Nurses would make attempts to alleviate patient suffering, but also acknowledged that these efforts may subsequently, and at times inadvertently, lead to death by assistance. For example, one nurse reported that: "...my intent is to end suffering, and if that leads to death – so be it!" (Schwarz, 2002, p. 137).

In addition, nurses described other specific and explicit actions they employed to reduce suffering which could lead to assisted death. For example, nurses increased and/or failed to decrease opioid infusions (Schwarz, 2002), provided medication doses which exceeded written orders (Volker, 1999) and/or physically "pushed the plunger" containing lethal drugs (Wosnick, 1999). While nurses recognized these acts as illegal, they legitimized them as necessary to reduce patient suffering (Kuhse & Singer, 1993; Matzo & Schwarz, 2001; Schwarz, 2002; Volker, 1999, Wosnick, 1999).

In summary, nurses' roles where assisted death was illegal were primarily focused on reducing patient suffering. They ranged from providing information that would enable patients to self-administer assisted death to actively manipulating lethal medications. While not a legal component of their practice, nurses experienced assisted death as an occasional aspect of end-of-life care. Given their self-described moral responsibility to reduce patient suffering, nurses

described an ability to engage in these roles in the face of potential personal, professional and/or legal risks.

Another important nursing role involved receiving and navigating initial patient requests for assisted death. In general, nurses experienced initial requests as a recurrent component of their role during the process, and I will turn to this topic next.

3.5 “Let’s Have a Discussion”

Whether or not assisted dying was legal, nurses described receiving and navigating initial requests as an essential role. Some similarities between nurses’ experiences were described across jurisdictions where assisted death was either permissible or not. As such, I will begin by introducing these common experiences and then describe how they were different between legal settings.

3.5.1 Common Experiences

The act of clarifying a request for assisted death was an important aspect of the nursing role. Specifically, this involved understanding the intent, rationale and meaning behind a request. For example, one study reported that nurses’ “...main focus was respecting the patient’s....request. The best way to do this, they reported, was to make absolutely certain that this was what the patient wanted” [Nurse Researcher] (Denier et al., 2009, p. 267). To achieve some measure of clarity, nurses described efforts to understand the intent and reasons which motivated their patients to request assisted death.

To better understand intent, nurses attempted to establish the authenticity of their patient’s requests. For example, one nurse shared: “I always take those statements [a request for assisted death] as ‘let’s have a discussion’. What is making you come to this statement...what’s at the root of this statement?” [Nurse Participant] (Sheridan, 2017, p. 41). However, nurses

reported that the root of a patient's request was not always influenced by a desire for assistance in dying, but by a variety of complex internal and external factors that were momentary, inconsistent, and at times difficult to understand (De Bal et al., 2006; Pesut et al., 2020a).

Nurses struggled to understand the complex root of patients' requests (Denier et al., 2010b; Pesut et al., 2020a; Wosnick, 1999; Wright et al., 2017). The process of identifying the impact of various influencing factors, such as fear and intense emotions, was difficult. For example:

“...nurses had difficulty in discovering the request's authenticity. It became worse if the patient was angry and distressed. Intense emotions, which could be a product of the time or situation, or the patient's personality may provoke someone to request [assisted death]. Such requests drifted off once the emotions tempered” [Nurse Researcher] (De Bal et al., 2006, p. 593).

Nurses described considerable and ongoing efforts to understand these influencing factors. They recognized the nuanced nature of a request for assisted death, and employed methods to successfully uncover, authenticate and understand the root of their patient's desire.

One such method nurses employed to uncover and authenticate a request was to engage in active and open listening. Nurses described that, following a request for assisted death, they attempted to erase personal judgements, facilitate open communication, and participate in a process of engagement with their patients. One study reported:

“The moment the patient utters a request, nurses analyze it with an open atmosphere, even though this may be very difficult. By refraining from judgement, by listening carefully and by asking specifically chosen questions, by being patient and going back several times, they try to understand the request, where it comes from and why it is a

reasonable thing for the patient to ask” [Nurse Researcher] (Dierckx de Casterle et al., 2010, p. 2413).

The demanding nature of this ongoing listening process was challenging for nurses; they made attempts, when appropriate, to refer patients to adjuvant care providers (Pesut et al., 2020a) and invested considerable amounts of personal and professional time, attention and effort.

The investment of significant efforts in navigating requests was a common experience for nurses. They described a deep desire to successfully receive and navigate a request for assisted death (Denier et al., 2010b; Pesut et al., 2020c; Wright et al., 2017). Therefore, nurses invested substantial moral, emotional and practical energy, as they considered it an intrinsic aspect of their professional duty to assist patients in actualizing their wishes at end-of-life. In general, nurses experienced the act of navigating an initial request, and the effort which was required to successfully achieve this, as an essential aspect of their role.

Nurses described these common experiences of navigating initial requests for assisted death whether it was legal or illegal. In general, they highlighted the significant and ongoing efforts nurses invested in interpreting, understanding and holistically conceptualizing patient requests. In this next section, I will specifically focus on nurses’ experiences where assisted death was permissible.

3.5.2 Experiences Where Assisted Death was Legal

In settings which legally permitted assisted death, nurses described unique experiences when navigating initial requests. These experiences illustrated that, while nurses reported common components of navigating requests for assisted death, legal permissibility inspired some variation of the phenomenon. For example, in a study from Belgium, nurses described that requests did not always come as a surprise:

“Interviewees unanimously reported that a request never happens unexpectedly. Having an open mind, being responsive to patient questions and worries and being alert and attentive, contribute to the fact that a request never comes as a total surprise” [Nurse Researcher] (Dierckx de Casterle et al., 2010, p. 2413).

The ability to anticipate a request was complex. Nurses reported that elements such as accessible practice guidelines, institutional policies and the transparent nature of assisted death impacted their level of engagement and communication with patients (Denier et al., 2010b; Pesut et al., 2020a). When such resources and realities were in place, nurses experienced increased comfort during discussions with their patients and, subsequently, an improved ability to interpret a request (Dierckx de Casterle et al., 2010).

Moreover, nurses described how patient language influenced their ability to anticipate a request. In other words, the way that patients openly engaged in conversations and delivered vocal cues allowed nurses to, at times, anticipate a desire for assisted death. For example, one nurse reported that:

“Patients...who wake up every morning and say, ‘Pfff, I am still here’. Who wake up gloomy and disillusioned. You give anodyne but it doesn’t have effect, it doesn’t help them. You increase the medication but they still say, ‘I am in pain’. These are the patients with whom you can expect a request. I must say that I always feel it coming [Nurse Participant] (Dierckx de Casterle et al., 2010, p. 2413).

Nurses experienced language cues as precipitating factors to a patient’s request. By “...listening carefully, taking signals and expressed concerns seriously, giving the patients the opportunity to express their feelings, concerns and fears...” (Denier et al., 2010b, p. 3374), nurses described an ability to predict a patient’s desire for assisted death.

However, nurses' perceptions of this desire were not always accurate. Despite the transparent communication intrinsic to jurisdictions where assisted death was legal, nurses' ability to correctly interpret a request was not guaranteed. Researchers reported that, based upon retroactive discussions with both nurses and patients, requests could be misinterpreted:

“There was not always a correct interpretation of a request during conversation with the patient. Because of their daily involvement and longer-lasting relationships with patients, nurses sometimes formed an impression only of the right interpretation of the request and therefore did not always check that interpretation” [Nurse Researcher] (van de Scheur & van der Arend, 1998, p. 501).

While nurses aspired to correctly interpret a request for assisted death, it was not always successful. Given the unique nature of communication, patient's subtle language cues and casual conversational tone could be misinterpreted; as one study stated: “This determination by nurses had pragmatic implications for patients...it could lead either to a referral to the [assisted death] coordination service or to a referral to a palliative care social worker” (Pesut et al., 2020a, p. 6)

When assisted death was legally permissible, nurses' experiences with initial requests were often transparent in nature. They were able to engage with their patients in conversations regarding assisted death, and experienced an ability to better interpret and predict a request. While these efforts were not always successful, legality influenced nurses' roles when navigating initial requests. In contrast, nurses in jurisdictions where assisted death was illegal did not experience a similar level of transparency, and therefore described different experiences.

3.5.3 Experiences Where Assisted Death was Illegal

Where assisted death was illegal, nurses experienced different roles when navigating initial requests. For example, nurses experienced requests as “...unusual and disturbing

experiences that rarely occur in their practice” (Schwarz, 2020, p. 103). Given this rare and disturbing nature, nurses often experienced a desire to examine their own personal and professional values. They struggled to achieve harmony between responding to a request for assisted death and the potential for significant professional and/or legal consequences (De Bal et al., 2006; Volker, 1999).

Patient language influenced and exacerbated this sense of conflict. Given the illegal nature of assisted death, nurses described that patients would use implied, obscure and indirect language to express a request (Wright et al., 2017). As a result, nurses were unsure of the true intent and/or root of their patients’ desire and experienced conflict. For example, one study reported that “The way in which patients formulated their requests...influenced the degree of conflict felt by the nurses. Many patients used veiled terms when requesting assisted death” [Nurse Researcher] (De Bal et al., 2006, p. 592). When such veiled and/or indirect terminology was used, or when patients would not explicitly utter the words “assisted death”, nurses struggled to adequately respond to and navigate a request. They were legally unable to actively explore the intent and/or desire(s) for assisted death, despite their aims to correctly navigate the process.

In general, nurses went to great effort to better understand a patient’s desire for assisted death. However, they experienced conflict in determining the nature of a request when they were constrained when the practice was illegal. As nurses struggled to navigate these requests, they made distinctive efforts to physically and emotionally be with their patients during the process. This phenomenon will be discussed in the following section.

3.6 Ways of Being with Patients & Families

During assisted death, nurses sought to provide comprehensive physical, emotional and psychological patient care. This enabled nurses to not only perform various roles during assisted

death, but also be with patients in distinctive ways. Whereas the former characterized what nurses did, their ability to be with patients defined the behaviors, manners and presence nurses demonstrated with patients during assisted death. Specifically, “Presence is enacted when nurses recognize and act on the opportunity...to enhance the level of their therapeutic connection to their patients” (Wright et al., 2017, p. 59). Nurses across jurisdictions where assisted death was either legal or illegal described similar experiences of this presence; this illustrated the fact that, regardless of nurses’ legal ability to engage in assisted death, their dedication to holistic ways of being transcended the restrictions of legal permissibly.

Nurses described that they entered into intimate relationships with individuals and family members receiving their care, and were able to be companions and sources of support (Dierckx de Casterle et al., 2010; Schwarz, 2002; Pesut et al., 2020a). This subsequently allowed nurses to engage and connect with these individuals in ways which were deeper than mere professional relationships. One study described these relationships as “...of a close and intimate nature” (Dierckx de Casterle et al., 2010, p. 2416), whereas another reported that “...nurses held to a common value of staying with patient and families...” (Pesut et al., 2020b, p. 3877) during assisted death. The deep and profound nature of these relationships allowed nurses to remain physically and emotionally engaged and present during assisted death.

Nurses described a strong desire to be present with patients during assisted death (Beuthin et al., 2018; Denier et al., 2010b; De Bal et al., 2006; Pesut et al., 2020a; Pesut et al., 2020b; Schwarz, 2002; Wosnick, 1999). This presence was both physical and emotional, and involved physically being with patients and their families while supporting the psychosocial needs of individuals within their care (De Bal et al., 2006; Pesut et al., 2020a). For example, nurses described that individuals could not be left alone during the process of assisted death

(Dierckxy de Casterle et al., 2006), and therefore they endeavored to be with patients by remaining present, expressing vulnerabilities and being emotionally open.

The ability to be emotionally open with patients was essential to nurses' ways of being. This openness entailed non-judgmental communication, compassionate listening, and the establishment of safe, trusting care environments between patients and providers (Sheridan, 2017; Dierckx de Casterle et al., 2006; Schwarz, 2002). As one nurse described, emotional vulnerability was important:

“When you are cool, clean and distant in your manner, you cannot expect the family or other people involved to talk about their emotions. But when you show your emotions, and show that you were touched...you will receive a lot in return” [Nurse Participant] (Denier et al., 2009, p. 268).

Nurses' ability to be emotionally vulnerable was influenced by the nature of their relationships with patients and family members. When nurses developed deep connections, they were better able to remain present, to express their emotions (Dierckyx de Casterle et al., 2010) and to experience “increased relational engagement” (Pesut et al., 2020a) with patients during assisted death.

Nurses' ability to be and engage with patients was further influenced by time. Specifically, nurses experienced a general lack of time to engage with patients, due to intense workloads and competing clinical priorities (De Bal et al., 2006; Wright et al., 2017). When this occurred, patients often stopped asking for care as they did not want to bother the nurses with complaints (De Bal et al., 2006). This negatively influenced nurses' ways of being during assisted death, as it impacted the nature and development of nurse-patient relationships. As a result, nurses felt as though they had let their patients down (Dierckyx de Casterle et al., 2006).

However, nurses also made significant efforts to overcome the contextual limitations of time through prioritizing emotional and physical presence during moments of care delivery.

Overall, nurses' ways of being demonstrated their willingness to be holistic care providers before, during and after assisted death. However willing, nurses nevertheless experienced assisted death as intense, an experience I will explore in the subsequent section.

3.7 “It’s Intense, You Know...”

Nurses described the process of assisted death, regardless of legal permissibility, as emotional, significant and intense (Bruce & Beuthin, 2019; Beuthin et al., 2018; Denier et al., 2009; Dierckx de Casterle et al., 2010a; Dierckx de Casterle et al., 2006; Pesut et al., 2020b; Pesut et al., 2020c). While the process of assisted death was emotionally demanding for nurses, they experienced the actual day and/or moment of death as especially intense. This intensity was characterized by several emotions such as disbelief, incredulity, and fear. For example, nurses experienced disbelief when they themselves actually facilitated assisted death. One nurse reported that:

“It was a very weird feeling to be the last person to push the morphine. They die right there...All of a sudden, they stop breathing, and you’re standing there, and you’ve got the syringe in your hand, and you go, ‘umfff? Well, umfff’” [Nurse Participant] (Wosnick, 1999, p. 134).

The incredulity of participating in the moment of death, was significant. It was related, in part, to the extent of control which nurses possessed over patients within their care. When they actively participated in assisting death, many nurses experienced this control as awesome (as in awe/fear inspiring) and/or strange (Beuthin et al., 2018; Schwarz, 2002). Given this position of power, these nurses experienced the day and/or moment of assisted death as nerve-wracking and

frightful (van de Scheur & van der Arend, 1998; Wosnick, 1999), due to the intense responsibility, potential power relationships and complex physical demands of participating in assisted death.

Part of this fear arose from nurses' perspectives that assisted death must be done with proficiency. Similar to nurses' desire to get it right when navigating initial requests, they aspired to capably facilitate the day and/or moment of death. For example, one nurse reported:

“It is intense, you know...at other moments you can sometimes allow yourself to make a mistake, but not at such moments. So, actually, you strive for perfection, and that always involves stress” [Nurse Participant] (Denier et al., 2010a, p. 43).

Nurses wanted to ensure that the day and/or moment of death was positive for patients and their families. As such, they exerted intense physical and emotional energy in their attempts to achieve perfection.

This desire for perfection naturally led to nurses judging the goodness or rightness of patient death. For example, when nurses were able to facilitate a death which fulfilled their patient's end-of-life wishes, and when that death was peaceful, dignified and well-coordinated, nurses often labelled the outcome as good. These experiences were not informed by empirical outcomes, but by nurses' ability to make peace with the process and ultimate outcome(s) of fulfilling their patients' desire for assisted death (Pesut et al., 2020b; Schwarz, 2002). As one nurse reported: “...to me, these are most peaceful deaths. I feel peaceful in those times...an extensive level of comfort and peace in these deaths” (Pesut et al., 2020b, p. 3879). When these outcomes were achieved, nurses were, generally, able to recognize assisted death as a peaceful process, express gratitude at the opportunity to participate, and become physically and psychologically prepared to experience subsequent cases of assisted death (Denier et al., 2010a).

Furthermore, nurses' experiences of intensity were influenced by the swiftness of assisted death and by the ability to predict when death would occur. Nurses reported that assisted death facilitated a reality wherein the natural process of dying became less evident (Denier et al., 2010a; Pesut et al., 2020a; Pesut et al., 2020b). This perspective was primarily influenced by the intensely rapid nature of deaths with assistance. For example, one study reported:

“...it is a very quick death, taking only minutes. Several nurses described it as a striking experience. [Investigator]: ‘How did you experience the moment of administering the medications?’ [Participant]: ‘I was surprised. Surprised by the swiftness of its effect. You see the person change from a rosy complexion to complete paleness. A man with whom you spoke to for so many hours, so deep and intense, is now gone. Just like that...’”

[Nurse Researcher] (Denier et al., 2010a, p. 43).

This sense of surprise at the swiftness contributed to the striking intensity of assisted death, as it dramatically altered nurses' perception of what the normal and widely-recognized dying process entailed.

In addition, when death occurred at a predetermined day and/or moment in time, it conflicted with nurses' usual experiences of having to wait days or weeks for someone to die naturally (Pesut et al., 2020a; Volker, 1999). As such, nurses viewed assisted death as a way to sidestep the natural dying process. However, they did not necessarily experience this change as negative; while it was intense and striking, nurses described that arranged death was “...much more conscious [and]...more peaceful than a natural deathbed” [Nurse Researcher] (Denier et al., 2010a, p. 43). Often, nurses experienced assisted death as different, but no more intrinsically challenging, than the natural and customary process of dying.

While assisted death was not always more challenging than the natural dying process, it did not leave nurses unaffected (Beuthin et al., 2018; Derirckx de Casterle et al., 2006; Pesut et al., 2020b). Nurses reported that assisted death affected their identities, world views and caused them to question life (De Bal et al., 2006; Denier et al., 2010a). While these effects were described as complex and powerful, nurses did experience them as fluid: they occurred within a broad emotional range and could be both positive and/or negative in nature. For example, one study reported that:

“In many cases, there was a range of emotional reactions that participants demonstrated...that varied from positive feelings of pride, to relative discomfort, to feelings of guilt and distress”. [Nurse Researcher] (Schwarz, 2002 p. 178).

From a positive perspective, nurses experienced assisted death as a vector which promoted trust between patients and care providers. This occurred when nurses were entrusted with a request for assisted death (De Bal et al., 2006). Furthermore, nurses described feeling proud to engage with patients during assisted death, as it promoted the development of intimate nurse-patient relationships.

Conversely, nurses also described negative effects. Especially where assisted death was illegal, nurses experienced guilt after facilitating death (De Bal et al., 2006; Matzo & Schwarz, 2002; Schwarz, 2002; Volker, 1999). This often occurred when nurses actively provided and/or manipulated lethal medications in an attempt to relieve suffering (Schwarz, 2002; Volker, 1999). Nurses' guilt resulted from the realization that they were directly and solely responsible for facilitating death. This subsequently affected nurses over time; for example, one nurse “...remembered and described the details of that day as though the experience had occurred last week and not five years ago. She said she would always remember it” [Nurse Researcher]

(Schwarz, 2002, p. 106). Additionally, nurses often experienced flashbacks when thinking of specific patients or events (Schwarz, 2002; Volker, 1999); this could be interpreted as an element of Post-Traumatic Stress Disorder resulting from the intense nature and subsequent effects of assisted death.

Accordingly, nurses exerted efforts to process the effects of assisted death. They personally engaged in self-reflection to process their experiences and achieve clarity. For example, one nurse described that "...at night, in bed, I think about it for a while; just go through the points once again" (van de Scheur & van der Arend, 1998, p. 503). However, these reflective attempts were challenging for nurses. Given the enduring effects of assisted death, nurses experienced reflection as an often-difficult and painful process (Schwarz, 2002; Volker, 1999). It forced them to revisit the nature and scope of their participation, and reawakened adverse emotional processes and recollections, such as guilt, fear and moral conflict.

The intense nature of engaging in assisted death was variable and broad. Nurses experienced a range of effects, which were both positive and/or negative. Regardless of their nature, the effects of assisted death were indelible and affected nurses across time. As a result, nurses often experienced conflict and uncertainty. Building upon this, I will next explore the complex nature of moral conflict, given its pervasive influence upon nurses' experiences during assisted death.

3.8 What is the Right Thing to Do?

The complex nature of assisted death confronted nurses' morals, values and ideals. This resulted in experiences of conflict and moral uncertainty. The Canadian Nurses Association (CNA) defines moral uncertainty as "...when a nurse feels indecision or a lack of clarity, or is unable to even know what the moral problem is, while at the same time feeling uneasy or

uncomfortable” (2008, p. 6). Given the diversity of nurses’ experiences with moral uncertainty across settings where assisted death was either legal or illegal, I will specifically delineate the nature of nurses’ moral uncertainty according to legal and illegal contexts.

3.8.1 Experiences Where Assisted Death was Legal

Within jurisdictions where assisted death was legally permissible, nurses’ moral uncertainty was complex and multidimensional. Often, nurses’ moral experiences were influenced by the dichotomy between their interpretation of the profession’s guiding ethical principles and their own personal morals (Beuthin et al., 2018; Clymin et al., 2012; Denier et al., 2010a; Pesut et al., 2020b; Pesut et al., 2020c). When these principles and morals were unable to harmonize during assisted death, nurses experienced uncertainty. For instance, one nurse reported that, given her self-identified lack of harmony between professional expectations to provide assisted death and personal morals, she would rather relinquish her nursing license than actively participate in the practice (Clymin et al., 2012).

Even though the practice was legal, nurses described experiencing uncertainty and hesitancy given the moral magnitude of assisted death (Beuthin et al., 2018; Pesut et al., 2020b). For example, one nurse reported that “...when you have been in the medical profession all your life and we do no harm, and then you are killing somebody, or participating in that, it’s a boundary that is hard to cross. Nobody wants to play God” (Pesut et al., 2020b, p. 3876). As a result of these experiences, and their subsequent moral impacts, some nurses described that assisted death had the potential to “...change nurses’ lives and careers” (Pesut et al., 2020b, p. 3876). This ultimately produced situations wherein nurses were forced to face moral uncertainty, and render a choice to either engage, or not, in providing assisted death to patients.

In the face of uncertainty, nurses were not forced to participate in assisted death. Instead, they could elect to become conscientious objectors. This occurred when a nurse's moral or religious beliefs and/or values prohibited them from participating in assisted death. While these individuals were not obliged to participate, they were required to maintain the quality and continuity of patient care. As such, conscientious objectors experienced significant challenges when attempting to uphold their moral values and beliefs in the face of assisted death. For example, they described difficulties when attempting to harmonize moral reservations against assisted death with their desires, both personal and professional, to provide holistic patient care (Beuthin et al., 2018; van de Scheur & van der Arend, 1998).

Specifically, conscientious objectors experienced moral conflict when providing care both before and during the actual day of assisted death. They reported significant uncertainty when attempting to holistically support the needs of their patients (Beuthin et al., 2018; Sheridan, 2017; van de Scheur & van der Arend, 1998). Objectors described that, while they should not abandon their patients, they were unable or unwilling to participate in patient care during an assisted death. As one nurse reports:

“...I think it's easy to feel that you could be forced to participate in something that you don't want...or don't feel comfortable doing. And the...”duty to provide care” has written that you have the right to be a conscientious objector, however...you could be charged with abandonment...there is a contradiction between my rights” (Beuthin et al., 2018, p. 516)

In an attempt to actualize personal rights, nurses would avoid engaging with colleagues and/or remain absent from ward duties on the actual day of assisted death (van de Scheur & van

der Arend, 1998). This was described as a type of protest against assisted death, wherein nurses actively advocated for their values, but nevertheless experienced moral conflict.

Where assisted death was legal, nurses experienced complex aspects of moral conflict and uncertainty. Many struggled to harmonize their personal values and beliefs with professional obligations in relation to assisted death, which produced challenging moral experiences. In the subsequent section, I will explore nurses' moral experiences where the practice was not legal.

3.8.2 Experiences Where Assisted Death was Illegal

In jurisdictions where assisted death was illegal, nurses experienced significant conflict between what they wanted to do and what they were legally and professionally allowed to do. As such, nurses reported intense moral conflict when faced with a request for an assisted death. One study from the United States of America (USA) stated that nurses: "...experienced intense conflict and ambivalence as they attempted to decide what, all things considered, was the right thing to do" (Schwarz, 2002, p. 162). Nurses were confronted with upholding their personal and professional values of alleviating patient suffering while explicitly violating professional guidelines and criminal laws. One study from the USA described:

"... [a] sense of conflict nurses experienced was between competing values. Many stories reflected an experience of tension in wanting to meet the patient or family's request versus upholding professional values. For some, the experience...was rife with conflict between competing values, principles and interests. On one hand, nurses wanted to uphold the professional ethic to do no harm and support life, yet on the other hand, they wanted to support patients" [Nurse Researcher] (Volker, 1999, p. 160).

Nurses had to grapple with the conflict between losing their nursing license and/or facing criminal culpability and upholding their beliefs and values. As a result, nurses described

significant efforts to evaluate and appraise the moral implications of participating in assisted death.

Nurses contemplated and critically evaluated the moral scope of their participation. They described a moral line in the sand which enabled reflections upon personal and professional values in the face of assisted death. As one study described:

“Almost every participant spoke about a line – explicitly or implicitly they identified a line that delineated morally acceptable (or at least tolerable) responses that caused them [when crossed] sufficient moral discomfort and/or professional uncertainty to render those responses unacceptable. They described a boundary that limited their responses, a place they would not go, a border they would not cross. The closer the prospective response was to their personal line, the more discomfort and conflict they experienced” [Nurse Researcher] (Schwarz, 2002, p. 164).

Nurses described that the position of their moral line depended on variables such as patient context, personal convictions, professional ethical principles and situational ethics (Schwarz, 2002). Ultimately, nurses experienced this conflict and uncertainty as not black and white, but as a gray area of nursing practice (Matzo & Schwarz, 2001; Schwarz, 2002; Wright et al., 2017).

This gray nature of nurses’ experiences was influenced by various elements. For instance, nurses recognized the principle of double effect, which sanctions medical treatments which benefit patients (such as pain management) while acknowledging that they may have secondary, potentially unintended outcomes (such as hastening death) (CNA, 2015). Nurses stated that, while they believed facilitating a patient’s death was emphatically wrong, they nevertheless would invoke the principle of double effect when providing potentially excessive amounts of pain medication to reduce suffering (Schwarz, 2002; Wosnik, 1999). Nurses used the principle to

reduce moral conflict during assisted death, wherein they would hide “...behind the principle of double effect to ease their conscience...their appeal to this principle sometimes functions as a sort of ‘rubber stamp’ that in effect short-circuited thoughtful reflection about this complex and often hidden area of practice” [Nurse Researcher] (Schwarz, 2002, p. 145).

Where assisted death was illegal, nurses experienced complex aspects of moral conflict and uncertainty during assisted death. When faced with these experiences, nurses often turned to their colleagues, when possible, in order to gain clarity and validation. Therefore, I will next explore nurses’ experiences as members of the interprofessional team.

3.9 Working as Part of a Team

Collaboration was an important aspect of care during assisted death. Its presence, or lack thereof, significantly impacted nurses, patients and the overall nature of care delivery. The scope and nature of collaboration often confirmed, clarified and validated nurses’ roles and overall experiences. However, these findings were different in contexts where assisted death was legal or illegal.

3.9.1 Experiences Where Assisted Death was Legal

Nurses’ experiences were often shaped by being part of an interprofessional team. Transparent communication was an essential aspect of interprofessional teamwork, particularly following an initial request for assisted death. Once a request had been vocalized, nurses shared it with members of the interprofessional care team. For example, one study reported that:

“In the interprofessional context, nurses reported that they communicate...with their nursing colleagues and with other care professionals (physicians, members of the palliative support team, psychologists, paramedics, pastoral/moral counsellors). The nurses perceived communication as an essential tool for dealing with the patient’s request

as a team, practically [and] organizationally...” [Nurse Researcher] (Denier et al., 2010b, p. 3376).

By engaging in this communication, nurses were able to provide important information to the interprofessional team, and subsequently participate in discussions regarding the nature of the request, the patient’s prognosis, and subsequent care processes (Dierckx de Casterle et al., 2006). Following a request for assisted death, nurses experienced a desire to not only contribute to interprofessional discussions, but to be included as informed and active decision makers. When nurses were involved, they felt validated.

When nurses were not involved, but excluded and merely informed of decisions, they experienced it as a lack of respect for their professional expertise. This often resulted from team-based hierarchies between physicians and nurses, wherein nurses and physicians struggled to develop cohesive team relationships (Pesut et al., 2020c; van de Scheur & van der Arend, 1998). However, as integral members of the care team, nurses wanted to contribute to decision-making efforts. They felt they brought unique insights to the interprofessional team (Denier et al., 2010b; Pesut et al., 2020c). For example:

“The participation of nurses in this [decision-making] process was deemed critical because of the nurses’ expertise in dealing with terminally ill patients and their unique, close relationships with...patients. ‘As a nurse you have a very special relationship with your patient. There is 24 hour follow up, constant interaction with team members, enabling me to get a broad picture of what my patient is thinking and of how he is functioning. I think the nurse plays an important role in the interdisciplinary team’ [Nurse Participant]...in addition, because of their holistic training, nurses can gain insight into

the physical, psychological, social and spiritual dimensions of the patient's suffering"

[Nurse Researcher] (Dierckx de Casterle et al., 2006, p. 189).

Given these contributions, nurses experienced their presence during decision-making as important and valuable (Denier et al., 2010b). They added value by representing and advocating for their patient's needs, and empowered the interprofessional care team to deliver assisted death which fulfilled the patient's end-of-life wishes.

Interprofessional relationships and subsequent debriefing were other important aspects of team collaboration. Given the challenging effects of assisted death, the process of evaluating and debriefing among interprofessional team members was essential. (Bruce & Beuthin, 2019; Denier et al., 2010a; Dierckx de Casterle et al., 2010b; Pesut et al., 2020a; Pesut et al., 2020c; Sheridan, 2017). Engaging and debriefing with colleagues allowed nurses to evaluate the outcomes of patient death, achieve clarity and peace, and was an important aspect of caring for the caregivers. As one study reported:

"...supportive relationships within the [assisted death] team were acknowledged as an integral part of the process...relationships facilitated the ability to know how each person would respond to such an impactful event...and the ability to effectively debrief after the process" (Pesut et al., 2020c, p. 6).

This interprofessional debriefing ultimately enabled all members of the team to move on if and/or when they were again exposed to the impact of assisted death.

In addition to team members, nurses described a desire for legislative and leadership support. As members of the assisted death care team, nurses experienced a need for comprehensive guidance from individuals in clinical, organizational and policy-centric leadership positions (Beuthin et al., 2018; Pesut et al., 2020a; Pesut et al., 2020c). Given the

often-evolving landscape of assisted death legislation, nurses described themselves as “pioneers” who were navigating “uncharted territory” (Beuthin et al., 2019, p. 514). Accordingly, when nurses experienced a “void” of procedural and leadership support, it subsequently impacted their ability to safely and competently engage as members of the interprofessional care team.

Interprofessional teamwork was an important aspect of nurses’ experiences. In jurisdictions where the practice was legal, collaboration influenced nurses: their experiences with communication and decision-making validated nurses’ role and abilities. Furthermore, nurses identified the importance of open reflection and debriefing with members of the care team. This process achieved both clarity and peace and enabled nurses to engage in a form of self-care, regardless of whether leadership and/or organizational supports were present. Conversely, collaborative practices where assisted death was illegal were reticent in nature, as nurses did not experience the same level of transparency among colleagues.

3.9.2 Experiences Where Assisted Death was Illegal

In jurisdictions where assisted death was illegal, interprofessional teamwork occurred, but was not always transparent. For example, nurses did discuss assisted death with selected members of the interprofessional care team, but they did not experience open communication. Nurses only consulted with colleagues whom they trusted and/or shared similar values and viewpoints. In one study from the USA, nurses reported that they:

“...only discussed...assisted dying with a ‘select’ group of colleagues – those who they knew shared their convictions and political beliefs about an individual’s right to be assisted in dying. These were clinicians they trusted” [Nurse Researcher] (Schwarz, 2002, p. 218).

Moreover, other members of the interprofessional care team would often only engage nurses about assisted death if a pre-existing relationship existed. Physicians would discuss the process of assisted death with nursing colleagues they knew well and trusted, but not with someone unfamiliar or where a relationship was not present (Wosnick, 1999).

Given the criminal nature of assisted death in illegal jurisdictions, nurses described that interprofessional communication was characterized by a shared and pervasive sense of fear and apprehension. One nurse reported that:

“I was talking to one of my colleagues [about assisted death]...and I think she was very ‘sympathetic’, but suddenly this paranoia came over me. I thought, she is not one of my good friends. What am I doing...suddenly I just got this terrible paranoia...it scared me”
[Nurse Participant] (Wosnick, 1999, p. 181).

Communicating not only promoted fear, but risked significant professional consequences such as regulatory sanctions and/or legal penalties. As such, nurses were decidedly taciturn: they did not engage in blatant discussion, but instead employed furtive, covert communication with interprofessional colleagues. This indicated that practitioners understood what was happening, but did not explicitly communicate the nuanced nature of their practices (Volker, 1999).

In summary, nurses in illegal contexts described interprofessional communication as characterized by vagueness, secrecy, and fear of reprisal. However, nurses developed abilities to navigate the challenging nuances of this practice landscape over time, and developed enhanced relationships with colleagues given the solidarity and trust inspired by their shared experiences with assisted death in illegal settings. As a result, and with subsequent and ongoing exposure, nurses reported that they were better able to engage with both their colleagues and patients during the process of assisted death.

3.10 “From Every Case You Learn Something...”

Nurses’ capacities to engage with assisted death positively developed over time. For example, nurses generally increased their knowledge regarding aspects of the process as they gained experience (Denier et al., 2009). While positive development was not a universal phenomenon among nurses, and some experienced poor experiences and outcomes, nurses’ ability to ask and answer appropriate questions evolved, wherein they better knew what to ask, when to ask it and how to appropriately respond to questions from patients and families. Additionally, nurses were more able to organize and attend to the various practical dimensions of assisted death as they experienced successive cases (De Bal et al., 2006). One nurse described that her first encounter with the process was “...very different, with regard to your view, way of dealing with people, with bystanders, than your last. From every [case] you learn something” [Nurse Participant] (Denier et al., 2009, p. 270). This development process generally enabled nurses to experience enhanced practical knowledge, increase the quality of care delivery and become more comfortable when participating in assisted death.

Nurses also developed emotionally in their ability to cope with assisted death. Successive exposure to assisted death caused less fear, apprehension and anxiety (Bruce & Beuthin, 2019; Denier et al., 2010a). Nurses became more comfortable with their roles, were more capable when navigating initial requests and, generally, experienced less intense shock and distress over time (De Bal et al., 2006). Whether practicing in a jurisdiction where assisted death was legal or where it was illegal, nurses characterized these developments as a process of personal growth (Bruce & Beuthin, 2019; Denier et al., 2009; De Bal et al., 2006; Wosnick, 1999). While growth did occur, it was gradual in nature, and only followed ongoing and recurrent participation in aspects of assisted death (Denier et al., 2010a; Pesut et al., 2020b).

Despite this personal growth and improvement, assisted death was rarely easy for nurses. When nurses were exposed to elements of the process, they often experienced it as challenging. For example, one study in a jurisdiction where assisted death was legal reported “nurses experienced it as something they never get used to. As such, the experience of the care process remains...difficult” [Nurse Researcher] (Denier et al., 2010a, p. 44). While nurses experienced improved knowledge and comfort, assisted death nevertheless continued to be a complex, intense, gray area of practice which did not leave nurses unaffected.

Nurses’ experiences with assisted death were complex, compelling and nuanced. They comprised various aspects of nurses’ attempts to navigate through and interpret a request for assisted death, their holistic ways of being and the complexities of interprofessional teamwork. In addition, the intense, indelible effects of assisted death, which illustrates the broad, expansive impact of the process, influenced nurses’ experiences. Accordingly, the relationship between nurses’ experiences and assisted death must be further explored, examined and discussed, which is where I will turn to next in the following section.

Chapter 4: Discussion

Nurses' experiences with assisted death were impacted by various physical, emotional and psychological phenomena. These experiences included navigating requests for assisted death, moral conflict and uncertainty, and growth in the pragmatic aspects of assisted death over time. Ultimately, nurses were influenced both personally and professionally by these experiences. In this discussion, I will first highlight and summarize emergent themes from the findings, then present concepts which further inform and explore nurses' experiences in the context of assisted death. I will then discuss limitations to this thesis, and describe potential implications for nursing support, education and research.

4.1 Summary of Findings

Assisted death significantly affected nurses' experiences in legal or illegal contexts. As discussed in the previous section, these experiences were broad ranging and complex. To remind the reader of important concepts that emerged from the literature review, I will briefly summarize these findings below.

4.1.1 Receiving & Navigating Initial Requests

Nurses invested significant efforts in attempting to receive and navigate initial requests for assisted death. Specifically, nurses experienced a desire to understand a patient's request, and to establish the authenticity of their patient's wishes (Denier et al., 2009; Pesut et al., 2020a; Sheridan et al., 2017; Wright et al., 2017). Additionally, nurses attempted to navigate their patients' use of veiled or indirect language when requesting assisted death (De Bal et al., 2006; van de Scheur & van der Arend, 1998; Wright et al., 2017). Regardless of legal context, nurses experienced this process as having pragmatic implications for both themselves and their patients (Pesut et al., 2020a).

4.1.2 Nurses' Ways of Being with Patients & Families

To navigate this uncertainty around requests, nurses described their ways of being as essential during assisted death. When nurses could enact caring behaviors focused on both physical and emotional presence, they experienced an enhanced level of therapeutic connection with patients and families (Wright et al., 2017). These ways of being transcended legal permissibility of assisted death and enabled nurses to experience their patient relationships during assisted death as intimate, profound, and engaging.

4.1.3 Intensity of Assisted Death

While nurses' ways of being enabled them to holistically engage with patients during assisted death, the impact of the process was intense. Regardless of the legal setting, nurses experienced assisted death as emotional, significant, and fear-inspiring (Bruce & Beuthin, 2019; Beuthin et al., 2018; Denier et al., 2009; Dierckx de Casterle et al., 2010a; Dierckx de Casterle et al., 2006; Pesut et al., 2020b; Pesut et al., 2020c). Nurses felt disbelief when they participated in the practice, and described a sense of incredulity at the extent of control they possessed over their patient's end-of-life care pathways (Beuthin et al., 2018; Schwarz, 2002); this experience was amplified when nurses personally facilitated aspects of assisted death. Ultimately, the process of assisted death resulted in indelible memories for nurses, and impacted their identities, worldview, and moral experiences at end-of-life.

4.1.4 Moral Conflict & Uncertainty

Nurses' experiences with their own morals, values and ideals were significantly impacted by assisted death. Many described a dichotomy between their own personal morals about assisted death and the guiding professional ethics of their nursing practice in the context of assisted. When participating in assisted death, nurses struggled to harmonize the principles of

beneficence and non-maleficence with their desire to support patient autonomy, dignity, and choice at end-of-life (Beuthin et al., 2018; Clymin et al., 2012; Denier et al., 2010a; Pesut et al., 2020b; Pesut et al., 2020c; Volker, 1999). As a result, many nurses experienced conflict and uncertainty in both their personal and professional lives. In legal settings, they struggled to balance their own morals with supporting the needs of their patients (Beuthin et al., 2018; Sheridan, 2017; van de Scheur & van der Arend, 1998). In illegal settings, nurses had to choose between participating in assisted death and facing potential criminal culpability and/or professional sanctions (Volker, 1999).

4.1.5 Working as Part of a Team

Nurses further attempted to address the impacts of assisted death through teamwork and collaboration. Their experiences with the practice were influenced by the scope of their role, their ability to vocalize observations, and their involvement with care teams. In legal settings, nurses were principal communicators between the care team and patients, and leveraged their close patient relationships into advocacy efforts at end-of-life (Denier et al., 2010b). In setting where assisted death was illegal, nurses experienced interprofessional communication as covert and absent. Regardless of legal context, nurses experienced team-based debriefing as essential in evaluating the outcomes of assisted death and achieving some sense of clarity and peace following the process (Bruce & Beuthin, 2019; Denier et al., 2010a; Dierckx de Casterle et al., 2010b; Pesut et al., 2020a; Pesut et al., 2020c; Sheridan, 2017; Volker, 1999).

4.1.6 Evolving Experiences over Time

Nurses' ability to achieve clarity and peace over their role in assisted death positively developed over time. This evolution allowed nurses to develop knowledge and comfort with assisted death as they gained experience (Denier et al., 2009). They were better able to navigate

and respond to requests and experienced an increased ability to organize the process (De Bal et al., 2006). In addition, nurses' emotional coping abilities developed over time; their fear, apprehension, and anxiety diminished with successive experiences (Bruce & Beuthin, 2019; Denier et al., 2010a). Regardless of legal context, nurses experienced their development as a process of personal growth; despite this growth and evolution, assisted death was never a comfortable experience and significantly affected nurses.

Given these challenges and the indelible effects they had on nurses, it is important to further analyze findings from the literature, explore their nuances and underscore their implications for nursing practice, research and education. As such, in this next section I will introduce three themes that expand upon existing research and demonstrate the complex relationship between assisted death and nurses' experiences with the practice. These themes focus on advocacy, autonomy and truth telling; suffering, morality and decision-making; and collaboration, interprofessional relationships and engagement in assisted death.

4.2 Advocacy, Autonomy & Truth Telling

The nature of assisted death demands effort and attention from participating providers. Nurses, as integral members of the provider team, are essential to the delivery of patient care in the context of assisted death. Throughout the process of assisted death, nurses serve as navigators (Beuthin et al., 2019; Denier et al., 2010b; Pesut et al., 2020c; Wright et al., 2017), which requires them to engage in practices that promote advocacy, autonomy and truth telling.

Nurses are in key positions to support patient advocacy during end-of-life care (McSteen & Peden-McAlpine, 2006; Hanks, 2008; Thacker, 2008). As evident in the research findings, nurses act as multifarious advocates during assisted death: they champion patients' subjective end-of-life wishes and care requirements, and ensure the availability of adequate comfort

measures and pain control options (Beuthin et al., 2018; Dernier et al., 2010b; Dierckx de Casterle et al., 2010; Sheridan, 2017). In actualizing advocacy, nurses uphold the principles of patient autonomy and beneficence, and attempt to “...protect and represent patient-perceived needs and values” (Schwartz, 2002, p. 38). In doing so, nurses contribute to the realization of their patients’ “...integrity as a person...” wherein “...the [advocate] makes his [patient’s] interests his own in so far as this is necessary to preserve and foster the [patient’s] autonomy...” (Schwartz, 2002, p. 8).

Nurses advocate for patient autonomy across care continuums at end-of-life (McSteen & Peden-McAlpine, 2006; Hanks, 2008; Thacker, 2008). As explored by Thacker, advocacy at end-of-life is essential to the delivery of high-quality patient care wherein nurses provide pain management, actualize ethically-informed practice, and support patients through the dying process (2008). However, the intrinsically challenging nature of death and dying significantly impacts nurses’ advocacy efforts (McSteen & Peden-McAlpine, 2006); the “...ethically and morally charged issues...” (2006, p. 259) surrounding end-of-life care, and the subsequent imperative to support patient advocacy and uphold autonomy during death, create challenging conditions for nurses. During assisted death, the challenging nature of this patient advocacy is magnified.

The challenges associated with patient advocacy are influenced by the legal permissibility of assisted death (Denier et al., 2010b; Dierckx de Casterle et al., 2010). In settings where assisted death is legal, nurses can transparently advocate for patient autonomy and clearly communicate these efforts to other members of the care team (Beuthin et al., 2018; Dernier et al., 2010b). In jurisdictions where assisted death is illegal, however, this transparency is not possible; nurses are unable to explicitly advocate for assisted death as a patient care option given the

potential professional consequences (Wright et al., 2017). Regardless of legality, advocacy provides nurses with opportunities to protect their patients' needs and values (McSteen & Peden-McAlpine, 2006), and subsequently preserve autonomy, during the dying process, including assisted death where appropriate.

In addition to autonomy, nurses advocate for truth telling within the context of assisted death (Denier et al., 2010b; Dierckx de Casterle et al., 2010; Schwarz, 2002). While the nature of truth telling is also influenced by the legality of assisted death and nurses' ability to be transparent about patients' wishes, truth telling allows nurses to promote care processes and outcomes based on subjective patient truth(s) (Tuckett, 2004; Tuckett, 2006). As described by Tuckett, truth telling enhances patient care outcomes by improving disclosure between nurses and patients; this subsequently promotes patient autonomy, self-determination and psychological well-being (2006). In the context of assisted death, this process of truth telling is essential whether the process of assisted death is legal or not. Accordingly, when nurses advocate for and uphold truth telling, they are better able to uncover the hidden meaning(s) and/or understand the root of a patient's desire for assisted death. This has been identified in research findings as an essential component of the nursing role at end-of-life (Denier et al., 2010b; Pesut et al., 2020a; Wosnick, 1999; Wright et al., 2017).

Furthermore, truth telling allows nurses to promote freedom and equality during assisted death. Specifically, truth telling between nurses and patients allows for honesty (freedom) and the development of reciprocal worth (equality) within the relationship (Tuckett, 2004). Truth telling promotes equality by maintaining the patient's status as a competent, autonomous individual within the healthcare context (Tuckett, 2004), thereby preserving equality between the nurse and the patient in decision-making and the identification of care goals at end-of-life. While

equality within the nurse-patient relationships often transcended legal permissibility (Beuthin et al., 2018; Denier et al., 2010b; De Bal et al., 2006; Pesut et al., 2020a; Pesut et al., 2020b; Schwarz, 2002; Wosnick, 1999), honesty can be negatively influenced by legality during assisted death. This was evident in the findings of this study when nurses struggled to honestly and transparently engage with patients given the criminal nature of the practice (Schwarz, 2002; Wright et al., 2017). However, this conflict did not restrict nurses' overall attempts to actualize honesty and freedom in the face of assisted death.

Nurses' attempts to promote honesty and equality are informed by their desire to be with patients during assisted death. Across general end-of-life care continuums, nurses remain with their patient and experience a desire to be present through emotional, physical and psychological engagement (McSteen & Peden-McAlpine, 2006; Pesut et al., 2012). This desire was confirmed by multiple study findings (Beuthin et al., 2018; Denier et al., 2010b; De Bal et al., 2006; Pesut et al., 2020a; Pesut et al., 2020b; Schwarz, 2002; Wosnick, 1999), wherein nurses' engagement and ways of being with patients promoted the free and vulnerable expression of both pragmatic and psychological emotions and vulnerabilities during assisted death (Denier et al., 2009). These honest ways of being allow nurses to practice some form of truth telling and to promote patient autonomy, self-determination and psychological well-being (Tuckett, 2006).

During assisted death, nurses promote advocacy, patient autonomy and truth telling. While efforts to advocate for a patient's "...integrity as a person..." (Schwartz, 2002, p. 39) are influenced by legal permissibility, nurses nevertheless attempt to uphold beneficence and autonomy throughout assisted death care continuums. These were, in part, achieved through actualizing freedom and equality within the nurse-patient relationship (Tuckett, 2004; Tuckett, 2006), and by being emotionally honest and vulnerable with patients during care. Ultimately,

these efforts contribute to the realization of positive care outcomes for both patients and nurses at end-of-life.

4.3 Suffering, Morality & Decision-Making

Nurses also experience significant moral challenges during assisted death. Their exposure to patient suffering, and the resulting imperative to alleviate that suffering, is a hallmark of nurses' experiences (De Bal et al., 2006; Schwarz, 2002; Wright et al., 2017). Accordingly, those participating in assisted death are required to directly confront suffering, exercise moral agency while grappling with the moral ontology of nursing, and implement morally informed decision-making when providing end-of-life care.

Suffering is an intrinsic component of assisted death, regardless of legal context (Beuthin et al., 2018; De Bal et al., 2006; Dierckx de Casterle et al., 2010; Kuhse & Singer, 1993; Schwarz, 2002; Wright et al., 2017). As evident in findings from the literature, patient suffering informs nurses' moral decision-making, interpretation of moral responsibilities, and actions in practice (De Bal et al., 2006; Schwarz, 2002; Volker, 1999, Wosnick, 1999; Wright et al., 2017). When faced with these experiences, nurses are required to engage with suffering and exercise moral agency in response to that suffering. Moral agency, defined as "...action[s] by the nurse based upon self-embodied principles and knowledge to facilitate a perceived positive outcome for the patient, family or society" (Raines, 1994, p. 7), informs nurses' response to patient suffering and encourage them to practice in ways that are consistent with what they understand as the right thing to do (LaSala, 2009). It assists nurses to establish a moral roadmap in the face of suffering and assisted death, and influences their moral judgement(s) and position(s) on participating, relieving suffering, and supporting the concept of assisting death.

Nurses' judgements and positions are further influenced by their interpretation(s) of, and engagement with, the moral ontology of nursing. Moral ontology is the examination of the influence of fundamental objective moral patterns of knowledge within nursing practice, such as alleviating suffering and restoring health, which informs how individuals choose to achieve and actualize morally-informed outcomes in the context of that knowledge (Carper, 1978). In other words, it focuses on exploring the relationship(s) between moral values and moral duties and/or actions in the context of nursing practice. However, these morally-informed actions are complex. In the context of this study nurses recognize their moral ontology to relieve suffering, but struggle to implement that ontology during legal or illegal assisted death (Beuthin et al., 2018; Clymin et al., 2012; Denier et al., 2010a; Pesut et al., 2020b; Pesut et al., 2020c; Volker, 1999; Schwarz, 2002). As stated by Carper:

“Knowledge of morality goes beyond simply knowing the norms or ethical codes of the discipline...nursing is deliberate action, or a series of actions, planned and implemented to accomplish defined goals. Both goals and actions involve choices made...on occasion, the principles and norms by which such choices are made may be in conflict” (1978, p. 29).

Such conflict produces situations wherein nurses struggle to harmonize the moral ontology of nursing practice with their own interpretation(s) of moral values, and this impacts their ability to implement coherent decision-making and/or actions within patient care environments during assisted death.

When faced with this challenging landscape, nurses inform their decision-making through the realization of nursing's moral ontology and subsequent application of their own moral agency as nurses. Within the context of assisted death, the moral ontology of nursing

practice often informs nurses' moral agency (Schwarz, 2002; Volker, 1999). Nurses are required to examine their own ontological interpretations of morality within nursing practice, and decide how to enact moral agency in response. It is here where nurses exist "in between" their own morality, their interpretation of the moral ontology of nursing, their ability to enact their own moral agency, and the moral agency of their patients. They are required to decide whose morality, either their own or their patients, are preeminent in the context of assisted death; in other words, nurses must choose how to implement moral actions and which set of values will inform their decision(s).

The values which inform nurses' decisions are based upon both personal and professional principles and experiences. The realization of personal beliefs and values is a subjective exercise for each nurse when faced with moral decision points; this was evident in research findings when nurses had to balance their own personal values, the guiding ethical principles of nursing practice and legal permissibility in the context of assisted death (Beuthin et al., 2018; Clymin et al., 2012; Denier et al., 2010a; Pesut et al., 2020b; Pesut et al., 2020c). With successive experiences with, and exposure to, assisted death, nurses are better able to balance these principles and actualize informed moral decision-making in the face of assisted death. As illustrated in research findings, nurses' moral and pragmatic decision-making evolved and became more contextualized with experiences over time (Bruce & Beuthin, 2019; De Bal et al., 2006; Denier et al., 2010a; Pesut et al., 2020b, 1999; Wosnick, 1999).

This evolution presents nurses with an opportunity to decide how, in a pragmatic sense, they might actualize their practice during assisted death (Beuthin et al., 2018; Denier et al., 2010a). Informed by their own ideas about what was the right thing to do, nurses grow in their abilities to enact subjective moral agency toward supporting patients. However, this shift is

difficult for nurses; this was evident in the findings when nurses experienced conflict and uncertainty during assisted death, and described the emotional, physical and emotional components of the practice as complex (Matzo & Schwarz, 2001; Schwarz, 2002; Wright et al., 2017).

The mechanisms through which nurses informed and actualized decision-making during assisted death are also decidedly ambiguous in nature due to the struggle between personal convictions and professional responsibilities. How nurses implement actions in practice, while accepting the potential for moral uncertainty, is a challenging component of their experiences of assisted death (Beuthin et al., 2018; Clymin et al., 2012; Denier et al., 2010a; Matzo & Schwarz, 2001; Pesut et al., 2020b; Pesut et al., 2020c; Schwarz, 2002; Volker, 1999; Wright et al., 2017). Nurses' interpretation of moral agency, and the ontological morality of nursing practice, further complicate these decisions, and produce situations wherein nurses found themselves in between patient suffering and their own perceptions of the right thing to do. As a result, the nature of assisted death became distinctly "gray" for nurses as individuals and as members of the interprofessional care team.

4.4 Collaboration, Interprofessional

Assisted death ideally requires the participation of an interprofessional care team. Comprised of individuals working together towards common goals and/or care outcomes, interprofessional teamwork enables providers to realize shared objectives in practice (Goebel et al., 2016). However, the complex pragmatic and legal nature of assisted death challenges this realization, wherein team-based collaboration, interprofessional relationships and engagement are impacted, as discussed below.

Interprofessional collaboration is essential to the realization of positive care outcomes (Donaghy & Devlin, 2002; Goebel et al., 2016; Goldsmith et al., 2010; Kalisch & Begeny, 2005). Across nursing practice contexts, collaborative practices enhance and improve the quality of care for both patients and providers (Kalisch & Begeny, 2005). For example, Goebel et al. (2016) state that, during end-of-life care delivery, "...perceptions of excellent palliative care quality were influenced the most by providers who identified high levels of collaboration and communication in their practice setting and by providers who reported the ability to collaborate with numerous disciplines" (p. 245). Similar to Goebel et al.'s findings, interdisciplinary collaboration during assisted death is identified as essential to the realization of high quality outcomes (Bruce & Beuthin, 2019; Denier et al., 2010a; Dierckx de Casterle et al., 2010b; Pesut et al., 2020a; Pesut et al., 2020c; Schwarz, 2002; Sheridan, 2017; Volker, 1999; Wosnick, 1999).

During assisted death, nurses' contributions to interdisciplinary collaboration and high quality care outcomes have been recognized as critical (Dierckx de Casterle et al., 2006). The nature of their relationships with patients, interprofessional communication and ability to share requests within the care team contribute to quality care continuums (Denier et al., 2010b; Dierckx de Casterle et al., 2006). Moreover, collaboration supports nurses to mentally, physically and emotionally evaluate the outcomes of assisted death (Bruce & Beuthin, 2019; Denier et al., 2010a; Dierckx de Casterle et al., 2010b; Pesut et al., 2020a; Pesut et al., 2020c; Sheridan, 2017). The process of collaboratively evaluating care outcomes, regardless of practice setting, is beneficial to care providers. As stated by Goldsmith et al. (2010), when "...hearing each other's stories, team members can identify and evaluate team processes. Practices and reflection can lead to positive team building and future successes in teamwork" (p. 103).

While collaborative evaluation supports care providers (Donaghy & Devlin, 2002; Goldsmith et al., 2010), its realization during assisted death can be impacted by legal context. The legal permissibility of the practice either promotes or prevents collaborative discussions among assisted death team members (Bruce & Beuthin, 2019; Pesut et al., 2020c, Schwarz, 2002; Wosnick, 1999). For example, as evident in the findings of this study, collaboration in legal settings is achieved through transparent communication and interprofessional debriefing efforts (Bruce & Beuthin, 2019; Pesut et al., 2020c). This transparency allows nurses to achieve clarity and peace in the face of assisted death, and promotes the development of supportive interprofessional relationships, which is described across the literature as integral to quality care outcomes (Donaghy & Devlin, 2002; Goebel et al., 2016; Goldsmith et al., 2010; Kalisch & Begeny, 2005).

However, in settings where assisted death was illegal, team-based collaboration is less evident and transparent in nature (Schwarz, 2002; Wosnick, 1999; Volker, 1999). This lack of transparency results from the intrinsic uncertainty, apprehension and fear associated with participating in illegal assisted death practices (Wosnick, 1999). These phenomena influence the scope of nurses' collaborative communication and interprofessional relationships when assisted death was illegal, and result in a reality wherein communication among team members is not capacious, but confined to select groups of colleagues or individuals who share the same value-based worldview in relation to assisted death (Schwarz, 2002).

This confined nature of communication threatens interprofessional relationships during illegal assisted death (Wosnick, 1999). As reported by Goebel et al. (2016), end-of-life care settings, "...by virtue of their intense emotional milieu, are fraught with opportunities for ineffective communication, which can lead to team conflict and influence quality of care" (p.

243). When communication is shrouded in secrecy and silence, both relationships between team members and the nuances of team-based care are impacted. This is important as nurses experience team-based relationships as “essential” in navigating assisted death “...as a team, both practically [and] organizationally” (Denier et al., 2010b, p. 3376). When these essential relationships are negatively influenced by legality, situations occur wherein teamwork is fragmented, uncertain and laced with apprehension (Schwarz, 2002; Volker, 1999). This enhances the intensity of nurses’ experiences with assisted death, and may lead nurses to disengage from aspects of the practice.

Nurses may actively decide to disengage from interprofessional relationships and team-based care in the face of apprehension and uncertainty. The scope and transparency of their detachment is influenced by legal context: nurses in settings where assisted death is legal could choose conscientious objection (Beuthin et al., 2018; van de Scheur & van der Arend, 1998), while those in setting where the practice is illegal were able to avoid assisted death given the intrinsic legal and/or criminal consequences associated with participation (Schwarz, 2002). While nurses’ decision to not participate in assisted death is an individual right (in settings where the practice is legal) and/or an obligation (in settings where the practice is illegal), it ultimately reduces engagement between conscientious objectors and other members of the care team, thereby negatively influencing collaboration and interprofessional relationships and engagement during assisted death (Beuthin et al., 2018; Schwarz, 2002; Volker, 1999; Wosnick, 1999)

Teamwork is an essential component of collaborative care at end-of-life (Donaghy & Devlin, 2002; Goebel et al., 2016; Goldsmith et al., 2010; Kalisch & Begeny, 2005). Given the complex nature of assisted death, collaboration is required to actualize outcomes for patients and providers (Bruce & Beuthin, 2019; Denier et al., 2010a; Dierckx de Casterle et al., 2010b; Pesut

et al., 2020a; Pesut et al., 2020c; Schwarz, 2002; Sheridan, 2017; Volker, 1999; Wosnick, 1999). However, implementation of teamwork is dependent on legal context, the scope and nature of interprofessional relationships, and nurses' decisions to participate or disengage from the practice of assisted death. Ultimately, these phenomena illustrate the complex impact of teamwork upon nurses' experiences with assisted death.

In conclusion, nurses' experiences with assisted death are influenced by the complex and nuanced nature of the practice. Given their essential role(s) as members of the provider care team, nurses serve as holistic advocates during assisted death, whereby they attempt to respect patient autonomy, uphold truth telling and promote freedom and advocacy. However, these efforts often result in moral challenges for nurses. Nurses are required to confront patient suffering during end-of-life, and must subsequently balance moral agency and patient autonomy when engaging in morally-informed decision-making. This often produces situations wherein nurses are "in between" patient suffering and their own moral decision-making. The consequent ambiguity effects the experiences of individual nurses and other members of the interprofessional care team. As such, the participation of the care team in achieving shared objectives during assisted death is an important aspect of navigation in this moral uncertainty. However, the contentious nature of assisted death challenges teamwork, which ultimately influences interprofessional relationships and engagement in end-of-life care practices. In summary, the challenging realities of assisted death produce a complex landscape for nurses, and has significant implications for ongoing nursing practice, research and education efforts.

4.5 Limitations

Limitations to this thesis include the relatively low number of available evidence sources related to thesis objectives. As previously discussed, a total of 20 substantive qualitative articles

were reviewed; this indicates a nascent body of literature, which subsequently limits the scope of the findings. A further limitation is the utilization of a modified systematic review format. This used a restricted literature search methodology, given the capacity of one single researcher to conduct a fulsome systematic review; as a result, evidence sources may have been inadvertently omitted from analysis. Finally, this study reports nurses' experiences as explained by other researchers rather than reporting nurses' first-hand accounts.

4.6 Implications

Findings from this research have several implications for nursing practice, education and research. Each will be discussed below.

4.6.1 Nursing Practice

Assisted death has significant implications for nursing practice. Given their identified roles and responsibilities during assisted death, nurses experience substantive shifts in how they provide care at end-of-life. Specifically, the shift in the natural dying process, which is no longer obvious during assisted death, impacts practice; nurses must prepare and educate patients, families and colleagues about the realities of this new dying process.

Additionally, technical nursing practices will shift to accommodate assisted death. As “good” end-of-life care is actualized through proficient coordination and delivery of assisted death, nursing practice must reflect the technical aspects of care. This includes knowledge of and proficiency with IV initiation(s), care coordination and clinical documentation; accordingly, nurses must be provided with and identify opportunities to develop and refine these skills and abilities as assisted death continues to emerge across nursing practice landscapes. This will require the involvement of individual nurses, nursing leaders, organization and regulatory bodies to ensure adequate and appropriate practice supports development.

The indelible impact of assisted death demands the availability of comprehensive supports for nurses. Given the intense emotional, moral and psychological influence assisted death has upon providers, as evident in the findings of this study, accessible psychological supports are essential to protecting the wellbeing of care providers. While the positive impact of debriefing was described in the literature (Bruce & Beuthin, 2019; Pesut et al., 2020c), its availability is not commonplace. However, supported debriefing, achieved through structured sessions following assisted death, counselling opportunities and/or policy which supports disability leave, are important to consider as assisted death continues to emerge as a care option at end-of-life.

Moreover, nurses require supportive guidelines to enhance their awareness, understanding and engagement during assisted death. Accordingly, nursing leaders, organizations, regulatory bodies and legislative efforts must focus on developing and articulating guidelines that accurately reflect the realities of the practice. These must support and guide both nurses who choose to participate, and those who engage in conscientious objection. As assisted death continues to emerge as a component of nursing care, iterative evidence-informed practice support development is essential.

4.6.2 Nursing Research

Evidence-informed practice is essential throughout assisted death. As such, research which further examines and articulates nurses' experiences and involvement in the process is important. Historically, research has primarily focused on physicians' involvement; given their role as "gatekeepers" to assisted death, research often prioritizes analysis of care providers' experiences through a physician-centric lens. However, nurses play an essential role during

assisted death; their involvement, and subsequent experiences, must be further explored to better inform emerging practices and policies specific to the nursing role.

In addition, research efforts that continue to explore nurses' moral experiences with assisted death are essential. Given nurses' intimate relationships with patients, and the indelible personal and professional effects of assisted death on nursing experiences, research must examine the longitudinal impact(s) of this phenomenon. This temporal relationship has significant implications for both nursing practice and individual well-being; while poorly understood at present, nurses' moral experiences with assisted death offers opportunity for ongoing research and exploration.

4.6.3 Nursing Education

Assisted death is a new treatment available within end-of-life care and thus requires focused education for nurses. Nurses who are required to be involved with assisted death must be educated on the scope, professional implications, and impact(s) of assisted death; through education, their knowledge of practice requirements, comfort with the pragmatic aspects, and awareness of emotional impacts will be enhanced. This will require dedicated education opportunities in both practical settings and for undergraduate nurses; current curricula should include aspects of assisted death education in an effort to prepare undergraduate nurses for the pragmatic reality of end-of-life care in nursing practice. Moreover, education will equip nurses with ways to develop their theoretical, moral and pragmatic foundations within the context of assisted death. Given its emergence across practice landscapes, nursing education, in both academic and clinical settings, must reflect the nuanced realities of assisted death while establishing a foundation upon which future practices are built.

4.7 Conclusion

The purpose of this thesis was to conduct a modified systematic review and narrative synthesis of research and grey qualitative literature on nurses' experiences with assisted death. In total, 20 articles were identified and subsequently analyzed; this analysis explored nurses' experiences with assisted death in settings where the practice was either legal or illegal. From the literature, 6 major themes were identified: nurses' experiences with receiving and navigating a request for assisted death, their ways of being during the practice, the intensity of their experiences, how assisted death caused significant moral conflict and uncertainty, the relationship between teamwork and assisted death, and how nurses experienced the practice, and their personal and professional development, over and across time.

Overall, nurses' experience assisted death as complex and challenging. As integral members of the care team, nurses experience unique roles and responsibilities throughout the practice. Across practice settings, nurses serve as advocates for patient autonomy, beneficence and truth telling. However, their efforts to engage with patients result in moral conflict and uncertainty. Often existing "in between" their own values and patient suffering, nurses experience significant conflict and uncertainty during assisted death. This requires nurses to examine the relationship between their own moral agency, the ontology of nursing and their consequent decision-making.

In light of this uncertainty, findings from this study suggest that assisted death exists as a complex and ambiguous component of nursing practice at end-of-life. Further, assisted death influences nurses' experiences with interprofessional teamwork. Across these care contexts, nurses experience aspects of collaboration, interprofessional relationships and team-based engagement, and are influenced by the challenging landscape of actualizing teamwork in the face

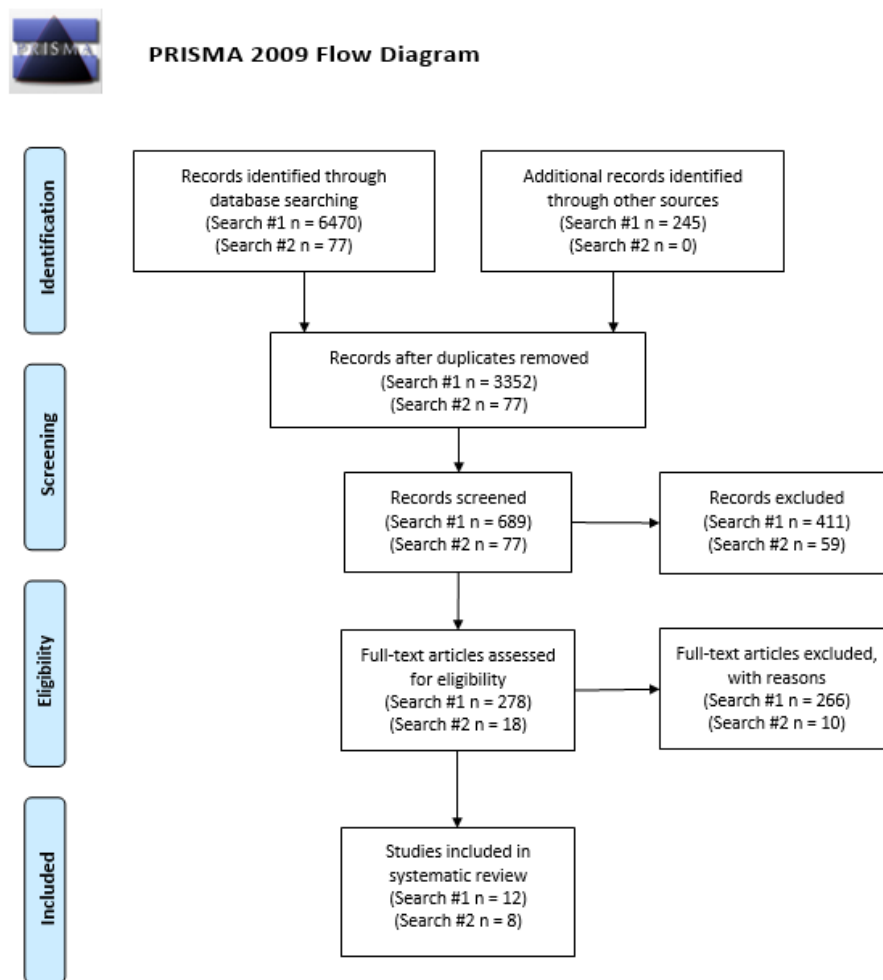
of assisted death. Ultimately, these experiences highlight the exceptionally challenging nature of assisted death-related care.

These challenges expose an ongoing need for practice, research and education development. Specifically, the landscape of nursing care at end-of-life is shifting; as such, nurses must be supported in practice, through the availability and accessibility of comprehensive guidelines, to engage in assisted death. In turn, research efforts must produce evidence that informs this development. An enhanced research focus on nurses' experiences with assisted death, as compared to historical physician-centric efforts, is essential; this will lead to the development of a unique body of nursing knowledge and subsequently inform nursing practice. Finally, nursing education in both academic and clinical settings is required. This will equip nurses with the theoretical, moral and pragmatic foundations upon which they can ground their complex experiences with assisted death.

Appendices

Figure 1 – PRISMA Diagram

Copyright: © 2009 Moher et al. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred reporting items for systematic reviews and metaanalyses: the PRISMA statement. PLoS Med 6(7):e1000097. doi: 10.1371/journal.pmed1000097.



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Figure 2 – Search Strategy for Search #1

1. ((assist\$ or hasten\$ or prescribe\$ or aid or aided or aiding or directed) adj2 (death or dying or suicide)).tw. (4 597)
2. (dign* adj2 (death or dying)).tw. (845)
3. (suicide adj2 (rights or rational)).tw. (108)
4. ((choosing or choice) adj2 (death* or dying or suicide)).tw. (163)
5. euthanasia.tw. (9 684)
6. right to die.tw. (922)
7. end of life decision\$.tw. (1 872)
8. MAID.tw. (223)
9. life terminating.tw. (29)
10. ending the life.tw. (160)
11. lethal medication.tw. (23)
12. killing.tw. (51 612)
13. Suicide, Assisted/ (5 374)
14. Euthanasia/ or Euthanasia, Active/ or Euthanasia, Active, Voluntary/ (9 423)
15. Right to die/ (4 955)
16. nurs\$.tw. (402 340)
17. (midwife* or midwives).tw. (20 695)
18. ((physician or doctor) adj2 assistant*).tw. (2 787)
19. exp Nursing/ (245 723)
20. exp Nurses/ (82 289)
21. Nurse's Role/ (38 779)
22. exp Nursing Care/ (129 743)
23. exp Nursing Process/ (83 803)
24. exp Physician Assistants/ (5 204)
25. or/16-24 (588 847)
26. or/1-15 (74 742)
27. 25 and 26 (1 987)

Table 1 – Patient Demographic Information

Total Number of Participants Across Literature Sample ¹	Gender of Participants ²	Participant's Country of Origin (participant sample size)
N = 223	Male = 16 Female = 151	Belgium (n = 45) Canada (n = 96) The Netherlands (n = 20) The United States of America (n = 62)

¹Only includes those who participated in qualitative interview studies

²Not all literature sources provided participant gender demographics

Table 2 – Data Extraction Table

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
Beuthin et al., 2018 <i>Medical assistance in dying (MAID): Canadian nurses' experiences</i> Nursing Forum	To understand Canadian nurses' experiences of participating or opting out of MAID	Urban and rural areas across Vancouver Island, British Columbia, Canada	17 nurses (NPs, RNs, LPNs)	Semi-structured interviews conducted in-person or by phone which asked about participants' decision to participate in MAID, the decision-making process, and the challenges and/or concerns which arose from participation	Medical Assistance in Dying (MAID)	Legal	3 main themes were identified: Profession of nursing: MAID positively reinforced nurses' views of their profession, their experiences of providing holistic care without judgment and of advocating for patient choice and supporting a good death as defined by the patient Personal impact: Many nurses identified themselves as being pioneers in MAID given various unanswered questions, experienced a sense of taking a stand amid limited

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>professional guidance and shared the emotional impact of MAID</p> <p>Nursing practice: Nurses emphasized the importance of communication and technical intravenous (IV) insertion skills. They drew on existing competencies related to end-of-life care and relational skills that fostered trust and engagement</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
Bruce & Beuthin, 2019 <i>Medically Assisted Dying in Canada: "Beautiful Death" is Transforming Nurses' Experience of Suffering</i> Canadian Journal of Nursing Research	To explore how nurses' overall experience of suffering as shaped by participating in MAID	Urban and rural areas across Vancouver Island, British Columbia, Canada	17 nurses (15 RNs, 1 NP, 1 LPN) Same sample as used in Beuthin et al., 2018	Semi-structured interviews conducted in-person or by phone which asked about participants' decision to participate in MAID, the decision-making process, and the challenges and/or concerns which arose from participation	MAID	Legal	3 key narratives were identified: Nurses' taken for granted suffering-feeling terrible: Nurses were often tasked with suffering as an intrinsic part of the RN role. They were asked to witness painful deaths, experienced helplessness when patients asked to end their suffering, and experienced ambiguity in the role of providing comfort care which may unintentionally cause patient death Transformational feelings of a beautiful death: Nurses experienced MAID as a change in their

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>experience of dying. It was different than natural dying. Many identified MAID as “quick” and “beautiful”, and described gratitude, in lieu of suffering, at the opportunity to participate in MAID</p> <p>Residual discomfort: Nurses experienced discomfort evoked by unresolved questions and concerns. They experienced a desire to “think more deeply” about the process of dying and to reflect on their experiences with MAID in order to better support themselves and their patients</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
Clymin et al., 2012 <i>Washington State Death with Dignity Act; A Survey of Nurses' Knowledge and Implication for Practice Part 2</i> Journal of Hospice & Palliative Nursing	To examine Washington State nurses' level of knowledge related to the DWDA	Washington State, USA. Various care settings	7500+ RNs licensed in Washington State and members of the Washing State Nurses Association Total survey response (n=582)	Open-ended survey questions asking about nurses' comments regarding personal views on DWDA; responses to actual or theoretical patient inquiries about the DWDA; comments or concerns about the DWDA related to their professional practice	Physician-assisted death (PAD)	Legal	2 main themes were identified: Knowledge: Nurses lacked knowledge of the DWDA and were unable to respond to patient questions regarding PAD. They didn't feel comfortable providing teaching/answering patient inquiries given the lack of training or information; as a result nurses felt frustrated Policy: Nurses were concerned about how much they could say within the confines of their care facility policy. Some nurses felt conflicted about policy regarding the

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							process of opting out of providing assisted suicide; this caused them to experience fear. However, most nurses would refer a patient to another care provider if more information was required
De Bal et al., 2006 <i>Involvement of Nurses in Caring for Patients Requesting Euthanasia in Flanders (Belgium): A Qualitative Study</i> International Journal of Nursing Studies	To provide an in-depth understanding of the experiences of nurses who are involved in the care of patients who request euthanasia	Two general hospitals in Flanders, Belgium	15 nurses	One-on-one interviews guided by open-ended questions	Euthanasia	Illegal	Nurses experience intense internal conflict and powerlessness when a patient requested euthanasia. They felt miserable and sad due to existing relationships with patients, but were in a good position to receive a request given these relationships. When a request was ignored or overlooked, they felt frustrated. However, past

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>experiences with receiving a request for euthanasia made the experience easier for nurses</p> <p>Nursing context and work pressures resulted in inadequate amounts of time to spend with patients. This resulted in poor opportunities to communicate, grieve with colleagues and a lack of time to discuss requests with patient</p> <p>Key roles which nurses experienced during euthanasia included: Confronting the request for euthanasia</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>Reporting the request to other caregivers</p> <p>Participating in decision-making</p> <p>Providing aftercare to families and colleagues</p>
<p>Denier et al., 2009</p> <p><i>Involvement of Nurses in the Euthanasia Care Process in Flanders (Belgium): An Exploration of Two Perspectives</i></p> <p>Journal of Palliative Care</p>	<p>To explore nurses' involvement in the care process for mentally competent, terminally ill patients requesting euthanasia</p>	<p>Nine general hospitals in Flanders, Belgium</p>	<p>18 nurses</p>	<p>Individual, one-on-one in-depth interviews, where participants were asked to recall their experiences of caring for a patient requesting euthanasia</p>	<p>Euthanasia</p>	<p>Legal</p>	<p>Two perspectives were identified:</p> <p>Procedural, action-focused perspective:</p> <p>Nurses who used this perspective reported practical organization of euthanasia to be important. Their main focus was on respecting and exploring a euthanasia request. Nurses here maintained a division between professional roles and personal views and</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>considered euthanasia successful when it was well organized</p> <p>Existential-interpretive perspective: Nurses who used this perspective reported that holistically understanding a request for euthanasia was important. Their main focus was on showing respect for the patient in a broad sense. They experienced the relationships between personal/emotional feelings and care provision as important, and considered euthanasia successful when all involved were able to make peace with the situation</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
Denier et al., 2010a <i>"It's Intense, You Know." Nurses' Experiences in Caring for Patients Requesting Euthanasia</i> Medicine, Health Care and Philosophy	To explore the experiences of registered nurses who have had experience in caring for patients requesting euthanasia	Nine general hospitals in Flanders, Belgium	18 nurses Same sample as used in Denier et al., 2009	Individual, one-on-one in-depth interviews, where participants were asked to recall their experiences of caring for a patient requesting euthanasia	Euthanasia	Legal	Nurses used the word "intense" to describe their experiences with euthanasia. It was a grave, ambivalent and difficult process on both emotional and practical levels, and caused fear over time. However, with subsequent experiences, this fear subsided to some degree; this was characterized by nurses experiencing a development over time, wherein they grew into the role and learned with each subsequent euthanasia case Nurses described euthanasia deaths as very quick and swift, opposite to a natural death, and experienced

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							<p>accessible practice policies as important when navigating through this landscape</p> <p>It was necessary for nurses to install a strict division between themselves as a person and as a professional, but they experienced a profound duty to provide euthanasia, even if personal values are not aligned with the practice</p> <p>Nurses described euthanasia as difficult, but positive, serene and peaceful; where experiences were confirmed when the patient/family express gratitude</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
Denier et al., 2010b <i>Communication in Nursing Care for Patients Requesting Euthanasia: A Qualitative Study</i> Journal of Clinical Nursing	To describe the communication during euthanasia care process	Nine general hospitals in Flanders, Belgium	18 nurses Same sample as used in Denier et al., 2009, Denier et al., 2010a	Individual, one-on-one in-depth interviews, where participants were asked to recall their experiences of caring for a patient requesting euthanasia	Euthanasia	Legal	Nurses experienced the most important form of communication as active listening, wherein they listened carefully, identified signals and expressed concerns seriously. This allowed patients the opportunity to express their feelings, concerns and fears, and helped nurses better understand what a request for euthanasia really meant Nurses also provided information to patients. They answered questions regarding diagnosis and prognosis, described and defined actions and concepts and provided information

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							<p>on care alternatives and legal procedures</p> <p>Nurses went through the steps of euthanasia with patient, made arrangements to prepare for the process and discussed last wishes. Non-euthanasia-related conversations were also experienced as important</p> <p>Interprofessional communication was essential, from nurse to nurse and nurse to physician. This ensured that all care providers involved in the euthanasia process are informed and that appropriate consultation was supported</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
Dierckx de Casterle et al., 2006 <i>Nurses' Views on their Involvement in Euthanasia: A Qualitative Study in Flanders (Belgium)</i> Journal of Medical Ethics	To interview palliative care nurses about their views on euthanasia and their role in the care process	Palliative care sites in Vlaams-Brabant, Belgium	12 nurses	One-on-one semi-structured interviews with open-ended questions	Euthanasia	Legal	<p>According to palliative care nurses (PCNs), improper euthanasia requests originated from suffering that could be alleviated by alternative care options. By offering palliative care alternatives, many improper requests were withdrawn</p> <p>PCNs experienced the participation of nurses in decision-making process as essential. They had unique and close relationships with patients and possessed expertise in dealing with terminally ill patients. This allowed PCNs to communicate the significance of the physical, psychological, social,</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>spiritual dimensions of patient suffering</p> <p>PCNs experienced their primary role as supporting their patient, family members and colleagues by being present, regardless of opinions on euthanasia. However, most nurses believed that the administration of lethal euthanasia medications was beyond their competence, and that the physician was most responsible</p> <p>Following euthanasia, it was an important role for PCNs to offer support to family members. By having good communication with family,</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							nurses experienced positive outcomes. Additionally, emotional support for care providers themselves was experienced as important
Dierckx de Casterle et al., 2010 <i>Nursing Care for Patients Requesting Euthanasia in General Hospitals in Flanders, Belgium</i> Journal of Advanced Nursing	To explore nurses' involvement in the euthanasia care process	Nine general hospitals in Flanders, Belgium	18 nurses Same sample as used in Denier et al., 2009, Denier et al., 2010a, Denier et al., 2010b	Individual, one-on-one in-depth interviews, where participants were asked to recall their experiences of caring for a patient requesting euthanasia	Euthanasia	Legal	Nurses experienced the euthanasia care process as complex and dynamic, consisting of seven interwoven stages: 1-Period preceding a request Euthanasia request never happened unexpectedly, and nurses often "felt it coming" 2-Confronting a request Nurses tried to understand the request through listening carefully and asking specific questions. Additionally,

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							<p>nurses often report the request to the care team as to make sure something was done about it, made time to answer questions, defined concepts and mediated conflict between patients and family members</p> <p>3-Decision-making stage</p> <p>Nurses experienced a difference in their role if decisions were made in multidisciplinary team settings or not: if not, the nurse was merely informed of the outcome. Team cooperation was beneficial in the care process, wherein nurses would provide specific information about the patient</p>

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							<p>4-Preceding the euthanasia moment</p> <p>Nurses tried to detect and realize their patient's last wishes, and to comply with requests and wishes with special and more focused care than usual.</p> <p>Additionally, nurses experienced the process of talking to colleagues as form of emotional/psychological preparation for the euthanasia moment</p> <p>5-Carrying out euthanasia</p> <p>Nurses were involved in the practical organization of euthanasia, such as in preparing medical aspects of euthanasia (infusions,</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>medications) and organizing contextual aspects of care. However, nurses explicitly stressed that the administration of euthanasia drugs was the exclusive responsibility of physicians</p> <p>6-Stage of immediate aftercare Nurses provided mourning care for the family, and experienced it as important to provide support to the care team. Additionally, nurses expressed a desire to pay their last respects to patient following euthanasia</p> <p>7-Period of later aftercare Nurses reported contact with family after euthanasia,</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							either formally or informally, and experienced it as important to have formal ongoing debriefing sessions with all staff involved in the process
Kuhse & Singer, 1993 <i>Voluntary Euthanasia and the Nurse: An Australian Survey</i> International Journal of Nursing Studies	To explore the practices of nurses in Victoria (Australia) with regard to requests for active or passive help in dying euthanasia	Victoria, Australia	943 nurses	Mailed questionnaire which asked participants to share their experiences with receiving a request for active euthanasia, and how participants navigated those requests	Active/voluntary euthanasia	Illegal	When asked for euthanasia, nurses discussed it with other nurses, medical staff, relatives or close friends, religious advisers, legal advisers, and/or patient's family members Nurses' were often directly asked by patients to end their life, and listening to a request resulted in positive experiences for both nurses and patients

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							Nurses said they felt like euthanasia was, when appropriate, the right thing to do; this was often without a direct physician's order to end life. With or without an order, most nurses stated they had done the right thing in ending a patient's life
Matzo & Schwarz, 2001 <i>In Their Own Words: Oncology Nurses Respond to Patient Requests for Assisted Suicide and Euthanasia</i> Applied Nursing Research	To further examine what is known about the views of oncology nurses regarding their role in EOL care and their participation in assisted suicide and euthanasia.	New England, USA	110 nurses	Cross-sectional mailed survey & questionnaire asking participants to share their practices and experiences with assisted suicide and euthanasia	Assisted suicide & euthanasia	Illegal	Nurses expressed feeling overwhelmed by the cumulative effects of witnessing patient's suffering, and wished they would support their patients to end life in the face of that suffering. When witnessing this suffering, nurses experienced it as gut-wrenching and were unable to forget the experience

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							<p>Many nurses hesitated to provide sufficient analgesia because they feared the possibility of hastening or causing a patient's death; this was a "gray and persistently uncomfortable" area of practice. However, nurses' primary goal was to relieve distress and provide comfort, and they experienced an awareness of a line separating comfort care and/or pain management that may secondarily hasten dying from the act of intentionally ending life. In turn, nurses described the practice of managing pain as accepting the possibly of potentially,</p>

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							<p>but not intentionally, hastening death</p> <p>Nurses stated that legalization of euthanasia would complicate nursing practice, and that economic pressures might lead to euthanasia as a “cheaper treatment option”</p>
<p>Pesut et al., 2020a</p> <p><i>Constructing Good Nursing Practice for Medical Assistance in Dying in Canada: An Interpretive Descriptive Study</i></p> <p>Global Qualitative Nursing Research</p>	<p>To explore how nurses construct good nursing practice in the context of MAID</p>	<p>Various health regions across Canadian provinces</p>	<p>59 nurses (RNs, NPs, CNSs)</p>	<p>Telephone or in-person interviews using a semi-structured interview guide asking nurses to describe how they constructed good nursing practice within the context of MAID</p>	<p>MAID</p>	<p>Legal</p>	<p>Five major themes were identified:</p> <p>A caesarean death:</p> <p>Nurses used this analogy to describe the difference between natural deaths and MAID deaths, and experienced patient reasoning and the impact of how MAID was different as</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>important components of this difference</p> <p>The nursing lens: Nurses held diverse views about the moral acceptability of MAID and whether the practice was a fit with nursing, how conscientious objectors struggled to accept MAID as a fit with nursing practice, and how exclusionary practice impacted their experiences of participating (or not) in MAID</p> <p>A familiar conversation with new options: Nurses had prior experiences with patients requesting death, but with MAID</p>

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							<p>implementation, more options were available to offer those patients. These conversations had temporal effects for providers and families, and caused nurses to reflect on pre-existing biases during conversations with patients</p> <p>Artful practice: Nurses constructed artful practices once patients had chosen MAID, specifically thought establishing a relational context, planning the process, orchestrating the act of assisted death and providing support to families after MAID was complete</p> <p>Competence and confidence:</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							RNs experienced MAID as a practice with little guidance or practical supports. They had to create new knowledge, expressed a desire for mentorship and legislative guidance, and wanted enhanced education, support and debriefing opportunities both during and after MAID
Pesut et al., 2020b <i>Riding an elephant: A qualitative study of nurses' moral journeys in the context of Medical Assistance in Dying (MAID)</i>	To describe nurses' moral experiences with Medical Assistance in Dying in the Canadian context	Various health regions across Canadian provinces	59 nurses (RNs, NPs, CNSs) Same sample as used in Pesut et al., 2020a	Telephone or in-person interviews using a semi-structured interview guide asking patients to describe their experiences with participating, or choosing not to participate, in MAID	MAID	Legal	3 main themes were discovered: Willingness to participate in MAID – Morally relevant factors: Nurses' decision to participate in MAID were influenced by family and community factors, such as

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Journal of Clinical Nursing							<p>sources of support and community interpretation of MAID, by influential colleagues and their clinical experiences with suffering, by their own professional values, and by their proximity to the act of administering MAID medication</p> <p>Experiences of MAID: The decision to participate was influenced by nurses' ongoing experience with MAID, including their emotional experiences for both those who participate and for conscientious objectors. Attributing factors, such as the culture of doing no harm, the quick</p>

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							<p>transition to death when assisted, and the lasting moral impact(s), had both positive and negative effects upon individual nurses</p> <p>Moral waypoints: Moral waypoints helped nurses make sense of their experiences with MAID. These included patient choice, control and certainly when choosing MAID and the idea that MAID was not about nurses. The relationship between how nurses' own values impacted their practice was described, and nurses' role in alleviating suffering and the moral imperative to participate in MAID that this</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>produced was experienced.</p> <p>When making morally consistent choices, such as relating MAID to other morally contentious acts such as abortion, nurses were required to reflect on their moral experiences. Their reflections on the afterlife and natural patterns in life and death were described. The waypoints which resulted from how “peaceful” MAID deaths were and the gratefulness that families and patients expressed for nurses’ participation impacted nurses’ experiences</p>

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<p>Pesut et al., 2020c</p> <p><i>The rocks and hard places of MAID: a qualitative study of nursing practice in the context of legislated assisted death</i></p> <p>BMC Nursing</p>	<p>To better understand the implications of a legislated approach to assisted death for nurses' experiences and nursing practice</p>	<p>Various health regions across Canadian provinces</p>	<p>59 nurses (RNs, NPs, CNSs)</p> <p>Same sample as used in Pesut et al., 2020a, Pesut et al., 2020b</p>	<p>Telephone or in-person interviews using a semi-structured interview guide asking nurses to share their in-depth experiences with MAID</p>	<p>MAID</p>	<p>Legal</p>	<p>Nurses described great variability in how MAID was enacted, and how that influenced their experiences. 3 main themes were identified:</p> <p>Systems- influential leaders setting the tone:</p> <p>Leaders influenced nurses' experiences either through quickly establishing policies and procedures, or allowing MAID to operate within a policy and practice void.</p> <p>Limited leadership decision-making influenced experiences, and the range of a leader's moral response was impactful. Physicians particularly influenced</p>

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							<p>nurses' experiences, both positively and negatively</p> <p>Teamwork-two's a team: Nurses' participated in MAID teams in various ways, either alone in isolation or well-integrated with members of the MAID team. The scope of team support impacted nurses' experiences, as did their level of involvement with MAID care. Teamwork supported effective organization of the complex MAID process</p> <p>Processes-patient-centred aspirations in a complex system:</p>

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							Nurses experienced the complexities of participating in the patient-oriented complexities of MAID. They wanted to get the process right, and prioritized MAID-related care over other duties. The ability to negotiate responsibilities/adjuvant services impacted nurses' experiences, legislative requirements to provide good care, and subsequent legal risks were significant factors which also influenced nurses experiences
Schwarz, 2002	Dissertation; to explore how nurse	Various hospital and community	10 nurses	One-on-one interviews (1 by telephone) asking participants about their	Aid in dying (AID)	Illegal	4 major themes were identified:

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<i>Assistance in Dying: The Nurse's Experience</i>	experience and respond to patients' requests for assistance in dying	settings across the USA		experiences and responses to a patient's request for AID			<p>Being open to hear and hearing the request:</p> <p>This described what is was like for nurses to actually hear a request for AID; non-hospice nurses considered this an uncommon experience</p> <p>Interpreting and responding to the meaning of the request:</p> <p>Nurses described the steps they took to uncover what was really meant by the request, and frequently found patients wanted help to experience a "good" death. Some nurses appealed to the principle of double effect for justification of hastening death, but many</p>

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							<p>struggled to explain how they distinguished morally acceptable instances of hastening death from those deemed not acceptable</p> <p>Responding to persistent requests:</p> <p>This described a continuum of nurses' responses that included refusal, respecting and/or interfering with patient or family plans to hasten death and providing varying amounts and kinds of AID. Nurses' responses were context-driven rather than rule-directed; they did not refer to the profession's position statements of code of ethics, and did not consult</p>

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							<p>or collaborate with colleagues</p> <p>Reflections: Nurses reflected on their thoughts about these experiences and speculated about future responses. Many nurses experienced a desire to remain silent because they feared professional or legal sanctions</p>
<p>Sheridan, 2017</p> <p><i>When Patients Ask to Die; The Role of Nurses in Medical Assistance in Dying</i></p>	<p>Dissertation: to explore the perspectives of nine palliative care nurses regarding best practices in</p>	<p>Various palliative care locations (homecare and residential hospice sites) in Western Ontario, Canada</p>	<p>9 nurses</p>	<p>In person, open-ended interviews using a semi-structured interview guide asking participants to share their perceived role and palliative care practices when caring</p>	<p>MAID</p>	<p>Legal</p>	<p>3 overarching themes were identified:</p> <p>Business as usual: This reflected participants' perspectives that MAID is an aspect of existing practices in end-of-life</p>

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	care related to MAID			for patients within the context of MAID			<p>decision-making in palliative care</p> <p>Nursing role within MAID: This discussed the importance of patient centered care and included assessing patients and their requests for MAID, liaising with other members of the healthcare team, providing MAID-based interventions and supporting bereavement for families, colleagues and their own selves</p> <p>Support for nurses to provide MAID care: This reflected the support which nurses required when providing MAID and included palliative</p>

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							education, support for conscientious objection to MAID, and the “give and take” during the final intervention of assisted death
Van de Scheur & Van der Arend, 1998 <i>The Role of Nurses in Euthanasia: A Dutch Study</i> Nursing Ethics	To describe the role nurses play in euthanasia, how they experience this role, and describe what nurses’ ideal role should be in the process.	One Dutch hospital	20 nurses	Semi-structured in-depth interviews which asked participants to describe their role during the euthanasia process	Euthanasia	Legal	4 major themes were identified: Observing a request for euthanasia: Nurses experienced varied language used by patients during a request. They then checked to see if they were interpreting the request correctly and/or if there was a concealed appeal for help behind the request Decision-making:

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							<p>Nurses described consultations between nurses and doctors as both formal and informal. Nurses provided information to the care team, but did not always have a say in the final decision regarding the euthanasia request. Many nurses did not need a formal say, but thought they should have a voice given their ongoing and intimate involvement with patients</p> <p>Carrying out euthanasia: Nurses supported patients and relatives during euthanasia, and tried to do everything the patient wanted. During euthanasia, nurses prepared drugs; they</p>

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							<p>were differing in their opinions regarding actually administering the medication. While nurses were more aware of the technical aspects of IV systems, the hierarchical relationship between nurses and physicians impacted their experiences with medication administration</p> <p>Aftercare: Nurses were often present for conversations with family and physicians after the patient's death. The evaluation of a euthanasia case and team-based debriefing was different across care environments</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>Nurses with conscientious objections (CO):</p> <p>Nurses who were COs were limited to providing care during the phase in which euthanasia was requested. They experienced difficulties in sharing their point of view with patients, as the patients might not understand it</p> <p>Nurses reported difficulties in caring for patient before the day of euthanasia, and experienced significant moral conflict. As a result, some nurses refused to care for patient, or refused to work with the team/be on duty on the actual euthanasia day; this was seen as a kind</p>

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							<p>of protest against the decision.</p> <p>However, the relationship between nurses with/without CO was characterized by mutual respect for each other's convictions</p>
<p>Volker, 1999</p> <p><i>Oncology Nurses' Experiences with Requests for Assisted Dying from Terminally Ill Cancer Patients</i></p>	<p>Dissertation; to explore oncology nurses' experiences with receiving requests for assisted dying from terminally ill patients with cancer</p>	<p>Various care settings across USA</p>	<p>40 nurses</p>	<p>Mailed sequential survey which asked how the act of receiving a patient's request for assisted dying was experienced by participants</p>	<p>Assisted dying</p>	<p>Illegal</p>	<p>4 main themes and 11 subthemes emerged during analysis</p> <p>The 4 main themes were: control, conflict, covert communication and enduring influence</p> <p>The 11 subthemes were: the cry for help, hastening the process, what if, managing the morphine, countering with palliative care, collision</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							of values, sense of distress, dialogue around the request, silent knowing, the unforgettable, and reflections on lessons learned. These themes and subthemes constituted the essence of nurses' experiences of receiving requests for assisted dying
Wosnick, 1999 <i>Nurse-Assisted Suicide and Nurse-Assisted Dying: Compassion and Ambiguity</i>	Dissertation; to explore the experiences of nurses who have assisted or been asked to assist in the suicide of terminally ill patients	Various geographic regions of the USA	12 nurses	One-on-one, open ended (occasionally telephone) interviews which asked how participants make meaning of their experiences of requests for assisted suicide	Assisted suicide	Illegal	Various themes emerged from analysis For example, an understanding of the moral aspects of nursing evolved from the data and gave meaning to the choices and behaviours described by nurses.

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							<p>The topic organically shifted to focus on the ambiguities inherent in the principle of the double effect, practices of assisting in dying and on hastening death</p> <p>This shift became a central finding as many nurses did not make moral or ethical distinctions between hastening death and letting die because they believed that dying was “already in process”. Other nurses did make moral distinctions and believed that directly hastening death was wrong; they stayed within the limits of ethical codes and laws, yet they also described the</p>

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							ability to hasten death through other strategies
Wright et al., 2017 <i>Engaging with patients who desire death: Interpretation presence, and constraint</i> Canadian Oncology Nursing Journal	To explore how oncology nurses understand and respond to their patients with advanced cancer who may desire death, and to better understand nurses' own perspectives about their therapeutic relationships in this context	Various care settings within the same large university-affiliated teaching hospital with a well-recognized oncology program in an urban area of Quebec	11 nurses	In-person semi-structured interviews which asked about the ways they see desire for death manifest, what challenges they face, how they respond when they suspect a patient may desire death, their thoughts on what might underlie patients' desire for death and about their overall experiences of caring for these patients	MAID	Illegal	3 main themes emerged: Interpreting the patient's desire for death: Nurses experienced the request for assisted death as an act of interpretation, and looked to understand what a desire for death "might actually mean". They attempted to uncover potentially hidden meanings, such as identifying a request as a reaction to living through loss during advanced illness. Enacting therapeutic presence:

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							<p>This appeared as a core value for nurses, wherein they wanted to be available and provide gentle accompaniment for patients. There were complexities in the idea of being present, but it was an important experience for nurses. Even when they couldn't "fix" their patient's issue, they expressed a desire to remain present. The desire to remain present involved a sensitivity to the moral implications of engagement, and the resulting experiences of feeling compelled to act</p> <p>Forces that constrain engagement:</p>

Author/Journal	Purpose/Aim	Setting/Location	Sample/Participants	Methods/Instruments	Type of Assisted Death	Legal Context at Time of Study Implementation	Findings
							<p>Nurses experienced a lack of time as a factor which impeded their ability to engage with patients and provide the close care that assisted death required.</p> <p>Legislative forces also constrained nurses' ability to engage given the illegal status of MAID in Canada at the time of the study</p>

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