“IT’S A BIG DIFFERENCE BETWEEN HAVING AN OPINION ON SOMETHING AND ACTIVELY DOING IT:” PHYSICIAN AND NURSE PRACTITIONER NON-PARTICIPATION IN MEDICAL ASSISTANCE IN DYING

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By

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ABSTRACT

Medical assistance in dying (MAID) became legal in 2016 with the Royal Assent of Bill C-14. There are numerous considerations and several challenges when developing safe and sustainable MAID programs in Canada. In the face of these challenges, competent and compassionate healthcare practitioners (HCPs) who are willing to participate in the formal MAID processes of patient assessment and MAID provision are essential. This thesis included a scoping review which identified, analyzed, and synthesized the factors that influenced HCPs' non-participation in ethically complex, legally available healthcare and a qualitative exploratory study that illuminated the factors that influenced physicians and nurse practitioners (NPs) when deciding not to participate in the formal MAID processes of determining a patient's eligibility and providing MAID.

Five themed factors that influenced HCPs' non-participation in ethically complex, legally available care were identified in the scoping review. While conscientious objection (CO) frequently dominated the discourse regarding HCPs' non-participation care, it was clear that multiple factors beyond ethical, religious, or core moral belief also influenced HCPs' non-participation. Thirty-five non-participating HCPs were interviewed over five months in Saskatchewan, Canada in the qualitative exploratory project. Considering Social Contract Theory and Ruggerio's approach to moral dilemmas and decision-making, the endogenous and exogenous factors that influenced their non-participation threshold were identified. Endogenously HCPs' were influenced by their (1) previous personal and professional experiences, (2) comfort with death, (3) conceptualization of duty, (4) preferred EOL care approaches, (5) faith or spirituality beliefs, (6) self-accountability, (7) consideration of emotional labour, and (8) concern regarding future emotional impact. Exogenously, HCPs' non-participation was influenced by (1) the healthcare *system* they work within, (2) the *communities* where they live, (3) their current *practice* context, (4) how their participation choices were *visible* to others, (5) the *risks* of participation to themselves and others, (6) *time* factors, (7) the impact of participation on the *patient's family*, and (8) *patient* relationship and contextual factors. Non-participation in formal MAID processes occurred along a spectrum and was influenced by these complex, interwoven, and diverse endogenous and exogenous factors.

This dissertation's key findings are that non-participation in ethically complex, legally available care (including MAID) includes both conscientious objection to care and non-participation in care and culminated in the development of the Model of Non-Participation in Formal MAID Processes. Practice considerations to support patients and HCPs in the evolving social contract of end-of-life care are offered to support safe and satisfying workplaces and patients' access to care.

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DEDICATION

I dedicate this thesis to my husband, Pete, and my parents Martin and Corinne. Pete, thank you for your unfaltering support, patience, and taking care of so much while I was “at the computer.” Your love blesses me and I look forward to our next chapter. Mom and Dad, I am who I am because of you. Thank you for teaching me about unconditional love, perseverance, hard work, and staying true. This dissertation is the embodiment of your unconditional love and support.

> “Not having to die is a desire that’s as old as humankind itself. Even if life expectancy has increased and medicine has made tremendous progress, every life must come to an end at some point. Our own mortality forces each of us to reflect on life and what constitutes our human condition and our individual personality. Dying, death and grief are things that are very personal and intimate, and yet they are also aspects of our lives as a community. The way we as individuals deal with these existential situations and emotions is shaped by the way society itself deals with death” (German Hygiene Museum, Dresden, Germany)

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LIST OF ABBREVIATIONS

CAMAP	Canadian Association of MAID Assessors and Providers
CCA	Council of Canadian Academies
CHPCA	Canadian Hospice Palliative Care Association
CMA	Canadian Medical Association
CMPA	Canadian Medical Protective Society
CNA	Canadian Nurses Association
CNPS	Canadian Nurses Protective Society
CO	Conscientious Objection
CPSS	College of Physicians and Surgeons of Saskatchewan
CSPCP	Canadian Society of Palliative Care Physicians
EOL	End-of-Life
HCP	Healthcare Professional
ID	Interpretive Description
MAID	Medical Assistance in Dying
NP	Nurse Practitioner
PAD	Physician-Assisted Dying
PC	Palliative Care
PRIMSA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
RN	Registered Nurse
SCT	Social Contract Theory
SHA	Saskatchewan Health Authority
SMA	Saskatchewan Medical Association
SRQR	Standards for Reporting Qualitative Research
SRNA	Saskatchewan Registered Nurses Association
VAE	Voluntary Active Euthanasia

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CHAPTER 1.0: BACKGROUND AND LITERATURE REVIEW

1.1 MAID in Canada

Medical assistance in dying (MAID) became legal in 2016 with the Royal Assent of Bill C-14. I will outline the legislated patient eligibility and program safeguard criteria, the patient and professional reception to Bill C-14, and specific legal challenges. I will then outline the national and provincial professional MAID guidance documents, national and provincial program delivery structures, and discuss family members’ and healthcare providers' experiences and MAID patients' experiences and profiles. Lastly, I will review the complex issues of freedoms of conscience and religion, conscience, conscientious objection (CO), moral distress, and conscientious objection versus non-participation. I will then conclude with the problem statement and research questions.

1.1.1 Historical Origins

Before June 2016, assisted suicide was a violation of the Criminal Code of Canada (1985), and euthanasia was viewed as murder under section 241.[1,2] Between 2000 and 2015, there were numerous attempts in the Parliament of Canada and the Supreme Court of Canada to legalize physician-assisted dying (PAD) or voluntary active euthanasia (VAE).[3] Quebec was the first Canadian province to legislate medical aid in dying (MAID), which was passed into law in December 2015.[1]

In 2010, Canadian Kay Carter died with the assistance of the Dignitas clinic[4] in Zurich, Switzerland, at the age of 89 after prolonged suffering from spinal stenosis.[5] In April 2011, the British Columbia Civil Liberties Association filed a lawsuit in conjunction with Kay Carter’s family and Gloria Taylor (who had amyotrophic lateral sclerosis), alleging that the Criminal Code of Canada's prohibition of assisted suicide was unconstitutional. They believed it denied individuals the right to control their health and dignity and restricted the practitioner's liberty in aiding such individuals.[6] In February 2015, the Supreme Court of Canada ruled 9-0 that the Criminal Code of Canada (1985) conflicted with Section 7 of the Charter of Rights and Freedoms, which assured the constitutional right to life, liberty, and security of the person.[7] The court's decision was suspended until new federal legislation was drafted, and, after Senate amendments, Bill C-14 received Royal Assent on June 17, 2016.[8]

1.1.2 Bill C-14

Bill C-14 was informed by the evidence submitted to the courts from international research, government parliamentary reports, the experiences of other international jurisdictions with assisted dying legislation, and consultations with expert panels and medical and other health advisory groups.[8] Bill C-14 sought to balance the interests and concerns of vulnerable persons and society with the autonomy of individuals seeking access to MAID.[9]

Bill C-14 amended the Criminal Code of Canada. The Bill (1) created an exemption for culpable homicide allowing physicians and nurse practitioners (NPs) to provide MAID, (2) specified the patient eligibility criteria and safeguards that must be met before provision, (3) required that physicians, NPs, and pharmacists provide information for monitoring and the development of reporting regulations, (4) created offenses for failing to comply with the safeguards of legislation, (5) ensured that MAID did not result in pension loss, (6) stated an investigation would not be required if a federal inmate received MAID, (7) commissioned an independent review related to mature minor, advanced and sole underlying mental illness MAID requests, and (8) called for a review of the state of Canadian palliative care within five years.[9] Within Bill C-14, MAID, is defined as

> "(a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they self-administer the substance and in doing so cause their own death."[9]

The Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying included NPs as assessors and providers to support MAID access across Canada.[10] Consequently, Bill C-14 specified that both physicians and NPs could conduct patient eligibility assessments and provide MAID. Canada is the only country that currently permits NPs to assess patients for MAID eligibility and provide MAID.[11,12] Lastly, Bill C-14 provided an exemption from culpable homicide to any individual who assisted physicians, NPs, or the patient in the course of MAID, while, of course, acting within the restrictions determined by the law.

1.1.2.1 Eligibility criteria. Patients eligible for MAID in Canada must meet the five legislated eligibility criteria. These criteria are that the patient (1) is eligible for Canadian health services, (2) is at least 18 years of age and capable of making health decisions, (3) has a grievous and irremediable medical condition, (4) voluntarily made the request for MAID, and (5) provided informed consent after being informed of means to alleviate suffering (including palliative care). Bill C-14 further defined a grievous and irremediable medical condition by stating that this means patients must (1) have a serious, incurable illness, disease, or disability, (2) be in an advanced state of irreversible decline in capability, (3) have illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and (4) have a reasonably foreseeable natural death, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

Legal scholars have pointed out several uncertain and ambiguous terms within Bill C-14.[13,14] They expressed concern that these ambiguous terms could result in a lack of uniformity in how HCPs interpret the eligibility criteria, which might result in differential patient access to MAID across the country and might also increase HCP concerns about criminal liability.[13] There has been particular practitioner and assessor debate about the interpretation of the criterion that death must be reasonably foreseeable. Of particular concern is that many, including Kay Carter's family, believe that Kay Carter would be ineligible for MAID under the current restrictions of reasonably foreseeable death,[15] and some HCPs have therefore expressed a need to amend the legislation to be more consistent with the original intent of the Carter decision.[16]In an attempt to respond to this, the Canadian Association of MAID Assessors and Providers (CAMAP) developed a clinical practice guideline to provide greater consistency in this eligibility criterion.[17]

1.1.2.2 Key procedural safe guards. Bill C-14 outlined several safeguards to be met before MAID provision. HCPs must confirm that (1) two independent assessors agreed that the patient met the eligibility criteria, (2) the MAID request was in writing, signed and dated by the patient in the presence of two independent witnesses (Table 1.1), (3) the MAID request was signed and dated after a medical or nurse practitioner informed the person of an irremediable and grievous medical condition, (4) the patient knew their request could be withdrawn at any time, (5) ten days elapsed between the written request and the provision (unless both assessors agreed that the person's death or the loss of their capacity to provide informed consent was imminent), (6) consent was confirmed immediately before provision, and (7) that all measures were undertaken to ensure the patient understood the information and was able to communicate their decision. Provisions were made for patients who could not write to have a proxy sign for them, with specific criteria listed identifying criteria for these proxies.

Criteria to Serve as an Independent Witness
• Must be at least 18 years of age and understand the nature of the request for MAID
Except if they:
• Know or believe that they are a beneficiary under the will of the person making the request, or a recipient, in any other way, of a financial or other material benefit resulting from that person's death;
• Are an owner or operator of any health care facility at which the person making the request is being treated or any facility in which that person resides;
• Must NOT be directly providing care services or personal care to the individual making the request

Table 1.1 Criteria to Serve as an Independent Witness[9]

The requirement of independent witnesses and the requirement to provide consent immediately before MAID administration safeguards have been noted as barriers to MAID access.[18]

1.1.2.3 Respect for conscience. The preamble of Bill C-14 states, "everyone has the freedom of conscience and religion under section 2 of the Canadian Charter of Rights and Freedoms...[and] nothing in this Act affects the guarantee of freedom of conscience and religion."[9] Although the Supreme Court of Canada noted some HCPs might have a CO, they did not comment on healthcare institutions' ability to decline MAID provision due to conscience.[1] The Special Joint Committee on physician-assisted dying recommended HCPs with a CO provide an effective MAID referral.[19]

1.1.3 Reception to Bill C-14

1.1.3.1 Public and patients. In 2007, 76% of Canadians supported the "right to die," which was noted to be "unchanged" from 14 years prior.[20] In 2016, 85% of Canadians supported the Supreme Court of Canada's decision on Carter v. Canada; [21] and in the six months after legalization, 1015 Canadians had MAID, of whom 11 resided in Saskatchewan.[22] In 2017, 12% of Canadian seniors and their families reported discussing MAID with their HCPs, and 64% were confident they would receive MAID if they requested it and were deemed eligible.[23] In Saskatchewan, these percentages were 8% and 68%, respectively.[23]

1.1.3.2 Professionals. The Canadian Medical Association (CMA) submitted a formal statement regarding euthanasia and assisted death at the Carter v. Canada hearing,[24] and submitted a brief to the Federal External Panel on Assisted Dying.[25] Before 2016, 29% of Canadian physicians stated they would not refer a patient for MAID, and 63% stated they would refuse to assist in dying.[26] According to the 2020 national MAID report, just over 1195 Canadian physicians have provided MAID since Bill C-14.[22]

The Canadian Nurses Association (CNA) "welcomed" the Supreme Court of Canada's ruling on MAID.[27] They also submitted a brief to the Federal External Panel on Assisted Dying[28] and suggested amendments to Bill C-14 to the House of Commons Standing Committee on Justice and Human Rights.[29] Bill C-14 has impacted nursing practice. This impact was especially notable for NPs compared to RNs, as their inclusion in Bill C-14 as assessors and providers was internationally unique.[11] In particular, the new bill enshrined very new ethical and legal responsibilities and substantially changed NPs' practice at the end-of-life (EOL).[12] However, involvement in MAID is still not common by nurse practitioners as according to national reports, only 75 Canadian NPs have provided MAID since Bill C-14.[22] Even when either nurse practitioners or physicians are involved, most are not involved intensively, as of all the Canadian NPs and physicians who have participated in MAID, just over 48% have participated in only one MAID death.[22]

The World Medical Association, an international physician organization with a purpose to "serve humanity by endeavoring to achieve the highest international standards…for all people in the world," have long viewed assisted death and euthanasia as unethical acts that devalues patients, puts patients at risk and lacks evidence as a medical treatment.[30] They further stated that most physicians do not wish to (1) facilitate suicide, (2) create ambiguity about what constitutes medical treatment, or (3) undermine practices that do not intend to hasten death. They stated their belief that law should not supersede good medical ethics.[30]

The Canadian Hospice Palliative Care Association (CHPCA) and the Canadian Society of Palliative Care Physicians (CSPCP) released a statement that PC and MAID are fundamentally and substantively different practices.[31] A CHPCA member survey noted dissatisfaction with the psychological and professional support provided by the healthcare delivery organization.[32] Shadd et al. noted that PC physicians recognized the philosophical distinction between MAID and PC, anticipated various impacts with MAID legalization, and noted variation in PC physicians' willingness to participate in MAID.[33] Specific to psychiatrists, a 2017 national survey found that most psychiatrists support MAID, but not the legalization of MAID for mental illness.[34]

1.1.4 Council of Canadian Academies

Bill C-14 specified that an independent review was required in three complex areas; advanced requests for MAID, requests for MAID when mental illness was the sole underlying medical condition, and MAID requests by mature minors. In December of 2016, the Minister of Health and the Minister of Justice and Attorney General of Canada asked the Council of Canadian Academies (CCA) to review these requests.[35] Over 40 experts from law, social sciences, bioethics, health sciences, nursing, and medicine convened to compile and assess the current evidence and inform subsequent discussions and decision making.[36] The reports outlined the state of knowledge, the related issues and uncertainties, relevant legislation, factors for consideration, international experiences, possible impacts of change, and potential safeguards. These reports are currently available on the CCA website.

1.1.5 Palliative Care Review

As part of the parliamentary review noted in Bill C-14, in December 2018, the federal government released the Framework on Palliative Care (PC) in Canada. Using the World Health Organization's definition of PC,[37] Canadian PC was reviewed, and the actions required to address gaps in PC access and quality were explored. Four priorities for action were identified. These included PC education and training for families and HCPs, enhanced PC research, support for PC providers, and the facilitation of equitable PC access.[38]

1.1.6 Specific Legal Challenges

There have been numerous legal challenges since Bill C-14. Two private members' bills were introduced into Parliament to protect the conscience rights of HCPs who do not wish to participate in MAID; however, neither was debated nor considered in committee.[39] The Christian Medical and Dental Society of Canada challenged the College of Physicians and Surgeons of Ontario's requirement that all physicians must provide an effective referral, stating this infringed on the right to freedom of religion.[40] However, in 2018, the Ontario Divisional Court, and later the Ontario Court of Appeal, found that although the policy infringed on the right to freedom of religion, the infringement was justified under section 1 of the Canadian Charter of Rights and Freedoms.[39]

In 2020, a MAID-eligible patient's spouse petitioned to have the Supreme Court of Nova Scotia declare that the patient did not meet the eligibility criteria and asked the court to prohibit MAID.[41] The court unanimously ruled that HCPs, not the courts, determine a patient's eligibility and that family members and other third parties cannot challenge the findings of MAID assessors and providers.[41]

In Quebec, in June 2017, Jean Truchon and Nicole Gladu made the legal challenge that the MAID eligibility criterion of a reasonably foreseeable natural death violated their Charter rights. In September 2019, the Superior Court of Quebec agreed that the reasonably foreseeable and end-of-life criteria of Bill C-14 were unconstitutional; consequently, this criteria in Bill C-14 was no longer valid.[42] The Government of Canada consulted with Canadians, stakeholders, provinces/territories, healthcare providers, and Indigenous groups and drafted Bill C-7, which proposes modifications to align the Criminal Code of Canada with the Truchon Gladu decision. As of October 9, 2020, this bill is in the second reading in the House of Commons.

1.2 Professional Guidance

Numerous medical and nursing professional associations at both the national and provincial/territorial levels guide HCPs in MAID.

1.2.1 National Guidance

The Canadian Medical Association (CMA) is the national professional association for physicians, and the Canadian Nurses Association (CNA) is the national professional association for nurses. Additionally, the Canadian Medical Protective Association (CMPA) and the Canadian Nurses Protective Society (CNPS) provide practice guidance and legal support for their members. Lastly, the Canadian Association of MAID Assessors and Providers (CAMAP) provide peer support, research, and advocacy and support to practitioners involved with and those HCPs supporting MAID.[43]

1.2.1.1 Canadian Medical Association. The CMA finalized its MAID policy in May 2017.[44] This policy recognized that the majority of Canadians see MAID as within the realm of medicine. Similar to Bill C-14, the CMA policy also included in its foundational principles: (1) the respect for autonomy; (2) respect for vulnerability; (3) respect for freedom of conscience;(4) accountability; (5) duty of non-abandonment; (6) duty to support interdisciplinary teams; and (7) duty to learners.

The CMA stated their acceptance of conscientious participation and conscientious objection (CO) to MAID. In particular, the policy does not require physicians to provide nor participate in MAID. However, physicians must (1) provide a timely response to patients' requests, (2) provide patients with comprehensive EOL information, (3) advise patients on how to access information, counseling, or referral service, (4) transfer the patient's care to another physician or institution if requested, (5) provide the patient's medical records, and (6) act in good faith. They further advocated that physicians monitor the impact of MAID participation and non-participation and "demonstrate solidarity with their team members as they navigate new legal and ethical territory together."[44]

1.2.1.2 Canadian Nurses Association. The CNA developed a National Nursing Framework on Medical Assistance in Dying.[45] The document outlined the core values and responsibilities of RNs and NPs in ethical MAID decisions. These included (1) providing safe, compassionate, competent, and ethical care, (2) promoting health and well-being, (3) promoting and respecting informed decision-making, (4) preserving dignity, (5) maintaining privacy and confidentiality, (6) promoting justice, and (7) accountability.

The CNA stated that objecting RNs and NPs must notify their employers (or, if self-employed, inform their patients) and ensure uncompromised continuity of care while transferring to an alternative provider or institution. They further stated that NPs' practices must align with their province's or territory's standards for MAID participation and referrals. NPs in Quebec are not authorized to provide MAID care.[46]

1.2.1.3 Canadian Medical Protective Association. The CMPA has stated that physicians have uncertainties regarding their rights and obligations relative to MAID. These included (1) interpreting ambiguous legislated terms (i.e., reasonably foreseeable, grievous, and irremediable), (2) applying the patient eligibility criteria and legislated safeguards (i.e., the required 10-day reflection period, independent witnesses), and (3) facilitating access in rural and remote regions when two assessors are required.[47] They further emphasized the need for interdisciplinary teams and adequate resources and the need to involve patients' families in MAID discussions while respecting patients' choice.

The CMPA emphasized that MAID was regulated by criminal law but provided at the provincial level, with provincial colleges and associations developing policies and guidance documents.[48] The CMPA recommended that physicians honour their personal views while complying with their regulatory bodies expectations regarding CO.[47] They also acknowledged that the requirement to refer patients for MAID was ambiguous as some physicians considered a referral the moral equivalent to providing MAID.[49]

1.2.1.4 Canadian Nurses Protective Society. The CNPS provides legal guidance to RNs and NPs. The CNPS emphasized that NPs can participate in MAID if (1) they have the requisite knowledge, skill, and judgment to fulfill their MAID responsibilities, (2) the practice is within the regulated scope of their province or territory, (3) MAID is within their employment parameters, policies and processes, and (4) impeccable documentation occurs at every step of the patient's MAID process.[50] The CNPS cautioned that RNs and NPs should not encourage a patient to seek MAID as counseling a person to commit suicide remains a criminal offense. The CNPS recommended RNs and NPs become familiar with their local resources and policies, uphold their legal duty of care, and obtain direction from their regulatory body and legal counsel as required when objecting to MAID participation.

1.2.1.5 Canadian Association of MAID Assessors and Providers. CAMAP provides advocacy and peer support to all HCPs (NPs, physicians, nurses, pharmacists, speech/language specialists, social workers) and other professionals, including (but not limited to) lawmakers, administrators, policy analysts, and counselors.[43] CAMAP has supported the practice of MAID with clinical guidance related to (1) intravenous[51] and oral MAID medication protocols,[52] (2) complications with MAID in community settings,[53] (3) the interpretation of reasonably foreseeable death,[54] (4) capacity assessment,[55] (4) MAID in patients with dementia,[56] (5) discussing MAID as an EOL option with patients,[57] (6) MAID and palliative care,[58] and most recently, (7) MAID during the COVID-19 pandemic.[59] CAMAP also actively fosters and supports research endeavors related to MAID to improve knowledge in this new area of clinical practice.

1.2.2 Provincial Guidance

As this doctoral project was undertaken in Saskatchewan, the provincial regulatory bodies' guidance was examined. The Saskatchewan Medical Association (SMA) represents the "collective view of the medical profession in Saskatchewan,"[60] and the College of Physicians and Surgeons of Saskatchewan (CPSS) is the provincial physician regulator. The Saskatchewan Registered Nurses Association (SRNA) currently functions as both the professional association and regulator of RN and NP practice in Saskatchewan.

1.2.2.1 Saskatchewan Medical Association. The SMA represents physicians on healthcare reform issues, promotes quality healthcare practices, advocates for quality in the Saskatchewan healthcare system, and negotiates and administers negotiated contracts.[61] The

SMA worked with the CPSS, Saskatchewan government, the health authorities, and stakeholders to create a provincial MAID framework, which is now supported by the provincial MAID program.

1.2.2.2 College of Physicians and Surgeons of Saskatchewan. The CPSS is the regulatory body for Saskatchewan physicians. The CPSS's MAID policy was approved in September 2016 and amended in November 2018.[62] This policy guided physicians' and patients' understanding of MAID and established the expectations of physicians involved in MAID. The policy's foundational principles included respect for patient autonomy, access, respect for physician values, consent and capacity, clarity, dignity, accountability, and duty to provide care. The policy also outlined the responsibilities of the prescribing and administering physicians, as well as the specific requirements related to assessing decision-making capacity, obtaining informed consent, utilizing the standardized forms, and collecting and reporting data.

Specific to CO, the CPSS stated that physicians must not abandon patients, must treat patients with dignity and respect, and provide sufficient information to make informed decisions and access care options.[63] They further stated physicians must not "provide misleading, intentionally confusing, coercive or materially incomplete information" and that the communication must not demean the patient's choice, beliefs, or values.[63]

1.2.2.3 Saskatchewan Registered Nurses Association. The SRNA currently functions as both the RN and NP professional regulator (including licensure, enforcing practice standards, implementing the continuing competence program, approving nursing education programs, and maintaining professional conduct process) and the professional association to promote the members' professional interests among partners and stakeholders.[64] Given the significantly different roles and responsibilities of NPs and RNs in Bill C-14, the SRNA provided separate guidelines for RNs involvement in MAID[65] and NPs involvement in MAID.[66] These practice guidelines outlined the shared roles and responsibilities, including upholding the code of ethics,[67] the applicable SRNA bylaws, the provincial MAID program guidelines, the standardized processes and protocols, employer policies, and of course, Bill C-14. The SRNA noted that RNs must *not* accept the delegation of medication administration from NPs or physicians. For Saskatchewan NPs to participate in MAID, they must be licensed with the SRNA, be supported by their agency or employer, and must not delegate their responsibilities to others. They also stated that agencies or employers may limit but cannot expand the NP scope of practice specific to MAID.

The SRNA affirmed that RNs and NPs are not compelled to participate in MAID, but they must not abandon a patient when providing care. NPs have the professional obligation to refer patients to a non-objecting practitioner or a designated contact person to continue care.[66]

1.3 Program Delivery

1.3.1 Government Oversight and Recommendations

Per Bill C-14, the Minister of Health was required to monitor MAID in Canada. This monitoring included collecting information regarding patients' requests and HCPs' provisions and analyzing and reporting it.[9] After extensive stakeholder consultations and over 43 written submissions,[68] the Federal Government developed the Regulations for the Monitoring of MAID[69] and a supporting guidance document.[70] Interim MAID reports were published from 2016 to 2019,[71–74] and the first comprehensive report on MAID in Canada was published in July 2020.[22]

Bill C-14 also stated that the Minister of Health would establish guidelines for the completion of death certificates.[9] The Government (1) identified the importance of identifying MAID deaths for accurate vital statistics reporting, (2) suggested using the World Health Organizations ICD-10 classification system in identifying the cause of death, (3) recommended an accurate report on the circumstances of death, and (4) emphasized the respect for the privacy of the deceased.[75] In 2017, the Government of Canada provided guidelines on completing death certificates but noted that these guidelines were not binding due to the divisions of powers between government levels.[75] The guidelines suggested that the immediate cause of death be documented as the toxicity of drugs administered for MAID, with the underlying cause of death recorded as the condition that precipitated the MAID death and the manner of death classified as natural.

1.3.2 Canadian MAID Programs

Legalizing MAID "transformed the practice and culture of medicine and health care in Canada" and resulted in numerous program implementation ambiguities.[76] Despite multiple sources of professional guidance documents and legal guidance, there was little national uniformity in implementing and funding MAID delivery, support of patient access, and balancing of patients' and providers' rights.[77] Given the provincial and territorial responsibility for healthcare delivery and further regional variations, it is not surprising that different MAID programs exist.[46,78] These differences may be attributed to diversity in existing healthcare delivery structures, provincial/territorial contexts and performance indicators, population values, interests, and resources.[79]

Each province and territory, and in some instances, regions have developed unique service delivery models. Some regions have implemented standard access processes and medication protocols, some incorporated MAID into existing HCP workloads, some devised patient care pathways,[79] and some have centralized case coordinators to support patients, families, and providers.[46] Furthermore, there is much variability in how provincial programs integrated patients' and families' experiences to guide their programming,[18,80,81] with some integrating MAID into home-based PC,[82] and others implementing hospital-based programs.[77] MAID became available in Canada as a result of a litigation process. Since legalization, scholars have suggested that MAID could reduce annual Canadian healthcare spending by between 34 and 138 million dollars.[83] This estimate was close, as the Office of the Parliamentary Budget Officer projected that the 2021 net financial impact of providing MAID under Bill C-14 would reduce healthcare costs by 86.9 million.[84] They further forecast that should Bill C-7 pass, a further savings of 62 million might be attained.

Downie and Oliver[85] reviewed the federal government guidelines on the completion of death certificates and suggested that MAID be recorded as the manner of death and the medical condition precipitating MAID as the cause of death. In 2018, a pan-Canadian review of practices reported inconsistencies in the completion of death certificates related to regionally different death investigating systems, provincial/territorial legislation, MAID oversight, and local policies.[86]

Access to MAID is an ongoing concern. Access challenges may arise due to a paucity of assessors and providers, some faith-based facilities refusing to allow MAID assessment and/or provision,[18,46,87,88] and a lack of available and accurate information for patients to navigate the MAID process.[89,90] Access to MAID was also noted to be hindered by concerns regarding program sustainability,[18,91] a lack of support for care choices, an inability to provide advanced consent, and the requirement for two independent witnesses for the formal MAID request.[18] In 2020, only 13% of Canadian primary care physicians and 11% of Saskatchewan primary care physicians reported feeling prepared to care for patients requesting MAID.[92]

1.3.3 Saskatchewan Program

The Saskatchewan MAID program has undergone significant evolution since Bill C-14. Before December 2017, healthcare in Saskatchewan was delivered in 12 smaller health regions, with each region having varying policies and procedures. There were MAID provincial guidelines for nurses,[66] physicians,[63] and pharmacists,[93] and all MAID inquiries were tracked regionally.[81] Commonly, the most responsible practitioner referred inquiring patients to the local Physician Staff Affairs office, and a small core group of physicians and NPs conducted MAID assessments and provisions. Before October 2018, the local coroner attended and investigated each MAID death and recorded the manner of death as a suicide.[86] After October 2018, this practice was amended, with the coroner's automatic involvement discontinued, and the manner of death was documented as unclassified.

In November 2018, regionally delivered MAID care was subsumed by a provincial MAID program.[94] This single program coordinates MAID for the whole province, of which approximately 38% live in rural and remote areas[95] across 651,036 square kilometers.[96] The provincial program is currently supported by a few salaried staff members, including one NP who can assess and provide MAID in each of the two major cities, Saskatoon and Regina. However, much of MAID-related clinical work is conducted on a case-by-case basis throughout the province by physicians and nurse practitioners hired by the program. The provincial MAID program reported that between November 2018 and February 2020 thirty-five physicians and NPs (seventeen participated in fewer than five occurrences) have participated in either or both MAID assessments or provisions (personal communication, M. Fischer, February 27, 2020). The provincial program develops, amends, and monitors policy, develops standardized forms and reports the Saskatchewan data to the appropriate Federal agency as required by the federal MAID reporting regulations. Patients, family members, and healthcare providers may access the provincial MAID program through the provincial Healthline that supports all patient, family, and provider-initiated referrals.

Once patients are connected to the provincial program, they, their family members, or even an involved healthcare provider receives information, and if appropriate, arrangements are made for detailed assessments by two independent MAID assessors. The provincial program maintains all forms and supplies the standardized written request to patients or healthcare providers to give the patients. Saskatchewan is currently only using an intravenous MAID protocol, and MAID occurs in a mutually agreeable setting to the patient/family and the practitioner. This can include acute care, long-term care, assisted living, individual residences, and possibly other settings if appropriate. The provincial program reimburses assessors' and providers' travel to rural settings to ensure that patients in rural settings have equitable access to end-of-life choices.

1.3.4 Patient Profiles and Experiences

According to the first national Canadian MAID report, over 5,630 Canadians had MAID in 2019.[22] As in other international jurisdictions,[97] this number is increasing, with a 26% increase reported between 2018 and 2019.[22] Of the reported Canadian MAID deaths, fewer than seven had self-administered MAID, with all others having MAID administered by an HCP. MAID accounted for 2% of 2019 Canadian deaths with significant regional variably documented, ranging from 0.3% in Newfoundland to 3.3% in British Columbia. In Saskatchewan, 250 individuals had MAID since 2016, with 97 MAID deaths in 2019 (which accounted for 1% of total deaths). Nationally, metastatic cancer was the most commonly reported underlying medical condition (67.2%), followed by respiratory illness (10.8%), neurological illness (10.4%), cardiovascular illness (10.1%), multiple co-morbidities (9.1%), other conditions (6.1%) and other organ failure (4.6%). The average age of MAID recipients was 75.2 years, with a similar proportion of men and women. 82.1% of MAID recipients received PC before death, and 89.6% had access to PC. Although significant variation was reported across provinces, nationally, 36.3% of MAID occurred in hospitals, 35.2% in residences, 20.6% in PC facilities, and 6.9% in residential care facilities.

Internationally, patients who requested assisted dying reported medical, psycho-emotional, social-environmental, and existential suffering, specifically "fatigue, pain, decline, negative feelings, loss of self, fear of future suffering, dependence, loss of autonomy, being worn out, being a burden, loneliness, loss of all that makes life worth living, hopelessness, pointlessness and being tired of living."[98] A British Columbia study noted the reasons for MAID differed by the patient's diagnosis.[99] For example, disease-related symptoms were reported by 39% of patients with cancer, and 6.8% of patients with neurological diseases, whereas loss of autonomy was reported in 16% of patients with cancer and 36.4% of patients with neurological diseases. Patients who requested MAID deemed it essential to have autonomy and control over EOL decisions, expressed fear over future suffering, reported an unacceptable quality of life, and seldom discussed pain as a cause of suffering.[100] A 2020 Ontario cohort study reported that (1) patients reported physical (99.5%) and psychological (96.4%) suffering, (2) that PC was involved with 74.4% of MAID patients, (3) the 10-day reflection period was abbreviated in 26.6% of deaths, and (4) patients were more likely to be from a higher income level, less likely to live in an institution, more likely to be married and most commonly had cancer.[101] When patients' and families' perspectives informed the development of a patient and family-centered MAID program, the importance of emotional, physical, spiritual, and relational care considerations were emphasized.[81]

1.3.5 Family Member Experiences

There have been some surveys exploring family experiences with medical assistance in dying. One such survey found that family members, even if they were initially opposed to the patient’s MAID choice, understood how it aligned with the patient’s values, and supported (but found “strange”) the planning of death, and disclosed that the death experience was “interesting,” “unusual,” and “peaceful.”[102] Others have reported positive experiences and discussed the support they provided to their family member and the support they received from the MAID providers.[103] The MAID experiences of family members and healthcare providers have been influenced by relationships, the social and political influences on decision-making, their complex responsibilities and roles, and the uniqueness of a MAID death experience.[104]

Family caregivers have also described experiential and operational challenges in their MAID experiences.[80] Operational improvement opportunities identified by family members included clarifying the MAID process, working through scheduling challenges with the care team, and waiting the 10-day reflection period before MAID provision. Experiential improvement opportunities included feeling a sense of judgment or objection from care providers and a sense of burden in keeping the decision to have MAID private. Families have also discussed the complexities to assisted death relative to relational difficulties (miscommunication, ambiguous process, invisible suffering) and managing unexpected patient-related situations such as facility transfers and uncertain disease trajectories.[105] A 2019 systematic review concluded that despite differences in international laws and program approaches, it generally appears that bereavement after an assisted death was “not worse than that of other types of death.”[106]

1.3.6 Healthcare Providers Experiences

There is little academic literature supporting HCPs who participate in MAID.[107] Oliphant and Frolic found HCPs who participated in MAID were motivated by (1) their personal and professional values and identities, (2) their experiences related to death and dying, and (3) their practice's organizational context, including supportive leadership, models of care, teams, and peer support.[107] Some participating HCPs have reported that working with patients and families was satisfying and rewarding,[16] that the work enriched their capacity to care and assisted in the rediscovery of the art of medicine through intimate, personal contact with patients and families,[108] and that participation was a privilege.[109] Participating HCPs have discussed the complexity of MAID participation, emphasizing the importance of relationships and clear communication between healthcare teams and patients/families, the importance of collaboration and engagement with interdisciplinary teams (which were not always present), and recognition of the complex emotions in participation and the importance of coping.[78,110] Participating HCPs have reported patients' and families' gratitude in knowing MAID was an option in the face of unbearable suffering,[111] commenting that MAID availability and the sense of control elevated the patient's mood and noted increased patient comfort at the time of death.[112] Pesut et al. noted that systems that supported the entire spectrum of moral responses also supported well-being during this time of practice change.[78] They further noted that without these supports, some HCPs have chosen to limit their MAID participation.

Participating HCPs have also described several challenges related to MAID participation. Some HCPs have suggested that institutional supports, including communication tools, interdisciplinary collaboration, human resource planning, and standardized care pathways, would enhance quality patient care and[113] that HCPs require clear guidelines that outline all team members' legal boundaries, scopes, and practices.[18,114] Participating HCPs sometimes report struggling to (1) facilitate equal access to MAID,[113] (2) provide support to patients and families, and (3) support patients who were ineligible for MAID.[16,113] The sustainability of HCPs' participation was related by some to (1) the administrative demands of participation,[109,115] (2) training and education needs,[109,113,114] (3) fair remuneration,[113,115] (4) significant workload and sacrifices to personal time,[16,109,113,115] (5) the emotional impact of participation,[16,109,113] (6) professional isolation and collegial disapproval,[16,109,114,115] and (7) lack of collaboration.[89,92] Some participating HCPs also identified concerns about the stigma of participation, a concern that patients would make their participation known, and professional risk and liability.[116] Lastly, the relationship between MAID providers and PC providers has been characterized as varying from "collegial with good communication about their shared patients, to hostile and fractious."[46]

1.4 Conscientious Objection

1.4.1 Freedoms of Religion and Conscience

Bill C-14 noted that nothing in the legislation negates the guarantee of freedom of conscience and religion. Freedom of religion encompasses the right to practice one's faith as one chooses, declare one's beliefs without fear of reprisal, and manifest one's belief through worship, teaching, or practice.[117] Among HCPs, disapproval of active euthanasia is associated with religious commitment,[118–120] and Tarabeith et al. noted the relationships between religious observances, beliefs, and attitudes and euthanasia were not affected by the local law.[121] However, a 2017 systematic review of five religions' views on various EOL practices (including assisted dying) identified the influence of culture and laws on religious practices and further identified variations in beliefs among religious sub-groups.[122]

Some believe that freedom of conscience, which allows individuals to "manifest their moral commitments," is often neglected compared to the discourse regarding freedom of religion.[123] Freedom of conscience has been described as doing what one "must" do.[124] Both freedoms are deemed essential to healthcare delivery, as a loss of moral integrity results in shame, guilt, remorse, a loss of self-respect, and a decline in moral character.[125,126] Attention to current conscience issues is critical in healthcare delivery and requires education, awareness, and respect.[127]

1.4.2 Conscience

Lamb[128] defined conscience as "an internal moral decision-making process that holds someone accountable to their moral judgment and for their actions." Conscience is further described as a "private and insular mechanism"[129] that is concerned with the individual's inner peace, integrity, and harmony.[130] Conscience is both retrospective (or judicial) and prospective (legislated).[131] Retrospective conscience is contemplating what was done or not done and is associated with guilt, whereas prospective conscience is contemplating anticipated actions and is where most healthcare ethical discourse lies.[131]

Conscience must move beyond intuition and feelings, as intuition and feelings are rarely explained or reliable.[131] Further, Fitzgerald noted self-awareness and the monitoring of implicit attitudes, education, and training are necessary parts of conscience if HCPs are to “develop consciences worthy of protection.”[132] Birchly explained that conscience is essential to HCPs as it:

> “provides a mental space where practitioners can reflect upon their experiences and improve their practice… allows them to remain sensitive to both their own and their patients’ needs… provides a voice to moral objection that is independent of dominant mores and hierarchy and [is] an instant alarm when events begin rapidly to outpace the speed in which we can consider them.”[129]

Complicity or cooperation with a morally wrong action[133] is often a grey area when discussing conscience. Grisez suggested individuals consider the following related to complicity (1) the necessity of the cooperation, (2) the proximity of the action to the event, (3) the duress experienced at the time of participation, (4) the potential for habitual or normalized participation, (5) if others would view the participation as endorsing moral permissibility, (6) if there is a role that would be violated in participating, and (7) the importance of the morally significant good that could result from participating.[134]

1.4.3 Conscientious Objection

HCPs, both as members of society and their profession, are morally and culturally diverse.[125] There are an increasing number of healthcare options that raise ethical concerns in a morally pluralistic society;[135] and HCPs may find the care a patient desires is different from the care they wish to provide. Conscientious objection (CO) is when an HCP refuses to provide legally available care accepted by their professional body because the care is against their core moral beliefs. There is a spectrum of positions regarding CO in healthcare. This includes the (1) absolutist view; that CO should be honoured regardless of the grounds precipitating the refusal, (2) the incompatibility view; that CO and modern healthcare delivery are incompatible, and (3) the compromising view; that CO should be supported under certain conditions.[125,133] Weinstock, a proponent of the compromising view, explained that HCPs should have a limited right to CO as it (1) respects the moral agency of all, (2) allows for the exploration of the objecting reasons and, (3) allows reflection on the rules, policies, and laws that impact healthcare practice.[136]

While facilitating the individual choices of the HCP, CO may adversely impact the patients and others in the healthcare team. Fry-Bowers noted that CO interrupts the patient’s healthcare delivery, which may burden other HCPs and employers.[135] She further noted that CO and moral disagreements are often a pretext for discrimination, which disproportionally affects females, people of colour, rural dwelling, disabled and nonbinary patients.[135] Others noted that objection to legally available care might result in patients being pitted against providers in the bid to access their right to care.[137]

1.4.3.1 Application of conscientious objection. Several approaches attempt to guide the application of the compromising view of CO. These included the Lynch approach,[138] the Wicclair approach,[125] the Cantor and Baum approach,[139] the Lachman approach,[140] and the Magelssen approach.[141] The Magelssen approach suggests that CO ought to be accepted if (1) the participation would harm the HCP’s integrity, (2) the objection is grounded in plausible religious or moral rationale, (3) the action is not an essential component of the HCP’s work, (4) the patient's burdens are acceptably small, and (5) the burdens to colleagues and institutions are acceptably small. Magelssen added that a CO claim is strengthened when the care area is new or morally uncertain and when the objection aligns with the generally accepted values of medicine.

Christie et al. noted that a CO is essentially an appeal to be exempt from professional duty.[142] The nursing code of ethics states CO must be “motivated by moral concerns and an informed, reflective choice and not [be] based on prejudice, fear or convenience.”[67] The physician code of ethics advises physicians to “act according to (their) conscience” while meeting (their) duty of non-abandonment, and respond to (their) patient's concerns, and requests whatever (their) internal moral commitments may be.[143] Shaw and Downie noted that provincial CO policies were riddled with controversy, confusion, inconsistencies, and vagueness.[144] Despite the various CO approaches, statements, and policies, it is not surprising that HCPs are “divided about whether they ever have a professional obligation to do things they may personally believe are wrong,”[145] and that CO can be understood and applied by two HCPs in two different ways.[146] This may lead to a disconnect between the theory of CO, the suggested CO approaches, the CO practice guidance documents, and actual clinical practice.[147,148]

1.4.3.2 Conscientious objection to MAID. Specific to MAID, national,[45,149] and provincial practice statements[63,65,66] have attempted to guide CO's application within the compromising view. Christie et al. noted two conflicting duties when HCPs object to MAID- the duty to respect the right to liberty, life and security of person, and duty to respect their conscience or religious beliefs.[142] Some HCPs may not express a CO due to a fear of patient abandonment, the perception they must always honour patient choice or fear of collegial disapproval. However, systems that create undue burdens on patients, or HPCs using CO to avoid poorly compensated, complicated, time-consuming, or legally risky patients or procedures, cannot be tolerated.[150] One of the first Canadian studies specific to CO and MAID concluded CO was frequently used to opt-out of MAID for numerous reasons, many of which were for reasons other than moral or religious objection.[151]

Two specific areas related to CO have additional considerations; claiming a CO in rural areas and mandating effective referrals. HCPs who work in rural areas and are the sole or most consistent HCP may be approached for MAID. In this context, if the rural HCP objects, there is a lack of alternative HCPs, and the patient would have to travel to seek alternative care. When the patient is grievously ill, this creates an undue burden.[152] However, concerning mandating effective MAID referrals, Warren and Ross noted the complicity challenge.[153] They viewed MAID referrals as forcing "moral conformity" and warned this could result in HCPs refusing to accept patients who are likely to request MAID.[153] They also claimed that it also might result in HCPs with a CO delaying the initiation of the referral until the patient loses capacity and the opportunity of MAID.[142]

1.4.3.3 Moral distress. CO is often associated with moral distress.[150] However, moral distress is prevalent in much of the rest of healthcare and is described as a "pervasive, everyday phenomenon."[125] Moral distress, first identified in 1984,[154] is self-directed negative emotions or attitudes that arise with involvement in morally undesirable situations,[155] or encountering perceived injustices.[125] Corley et al. suggested that moral distress could be related to (1) unsafe staffing levels, (2) avoiding EOL conversations with patients at the families' request, (3) implementing unnecessary tests and treatments, (4) observing when patients are not treated with dignity, (5) continuing treatment when it is not in the best interest of the patient, (6) observing students practice on patients for skill development, (7) working when feeling incompetent, and (8) avoiding the reporting of colleagues' unsafe practices.[156] Moral distress has been reported to result in sadness, anger, frustration, mental exhaustion, helplessness, depression, distress,[157] and physical effects such as nausea, gastrointestinal upset, physical exhaustion, tearfulness, sleeplessness, and migraines.[158] Thus, accommodating conscience might allow HPCs to operate without compromising their moral integrity and supporting their holistic well-being.

1.4.4 Conscientious Objection versus Non-Participation

Scholars have noted that some refusals to participate in care might not be conscience-based.[125,140,151,159–164] Distinguishing refusals grounded in conscience from non-participation is challenging.[165] Wicclair noted that HCP refusals could derive from self-interest or protection of professional integrity.[125] In particular, self-interest refusals may stem from a concern for their well-being, or the well-being of someone they care about, work schedule predictability, concern about litigation, or financial considerations. On the other hand, protecting professional integrity may arise from HCP's application of professional norms/standards, preference for other care options, belief that providing the care would harm the patient, applying a clinical standard, or believing that the care is futile. A systematic review of the reasons midwives and nurses objected to pregnancy termination identified moral, practical, religious, and legal reasons underlying the objection.[159] Bouthillier and Opatrny[151] found that most physicians who refused to participate did not have a general opposition to MAID, but might be more concerned about emotional burden and fear of psychological repercussions.[151]

1.5 Problem Statement

There are numerous considerations and several challenges when developing safe and sustainable MAID programs in Canada within the parameters of Bill C-14. These operational challenges include (1) an increasing number of MAID patients seeking MAID every year,[22] (2) concerns about provider availability and faith-based facilities refusing MAID,[46,81,87,91] (3) supporting timely access to MAID across the rural expanse of Canada,[95,96,152] (4) evolving legal landscapes and their accompanying uncertainties,[35,39,166] (5) the complexity of MAID assessment and provision as evident by the early experiences of participating HCPs,[16,78,108,109,113–116] (6) the uncertain reasons for refusals to participate in ethically complex care,[125,140,151,159,161] (7) ambiguous and inconsistent application of key legislated terms,[12–14,47,167] (8) diversity of models of care and supporting practice policies,[12,46,77–79,82,86,144] and (9) the importance of respecting conscience and mitigating moral distress.[125,129,130,134,136,153,157,158]

In the face of these numerous operational challenges and considerations, competent and compassionate HCPs who are willing to participate in the formal MAID processes of patient assessment and MAID provision are pivotal in delivering high-quality holistic MAID care. Without participating HCPs, MAID is not an EOL option. Thus, in the context of these many challenges and considerations, understanding HCP's non-participation in MAID needs to be a high priority for research. The findings of this work will inform necessary supports for HCPs in this emerging practice area, and identify possible policy and practice gaps, thus supporting patient access to legally available EOL care.

1.5.1 Research Questions

This doctoral research was undertaken as two separate projects that have culminated in a thesis to fulfill the College of Medicine's Health Sciences doctoral program requirements. The totality of this work will foster an enhanced understanding of HCPs' non-participation in MAID. The research question of project one is:

- "What is known regarding the factors that influence physicians and registered nurses who do not participate in the ethically complex and legally available care areas of EOL (including assisted death), reproductive health and technology, genetic testing, and organ or tissue donation?"

The research question of project two is:

- "What are the factors that influence physicians and NPs when deciding not to participate in the formal MAID processes of determining a patient's eligibility for MAID and providing MAID?"

CHAPTER 2.0: METHODS

This thesis incorporated research that used both scoping review methods[168] and qualitative interpretive descriptive methods.[169]

2.1 Scoping Study

A scoping study was undertaken as an entry point to examine non-participation in ethically complex, legally available care. Scoping studies are frequently the first step in research development[170] and knowledge synthesis[171] as they identify the types and sources of available information, identify research gaps and critical concepts, and inform policy and practice.[172] Their proliferation in healthcare is significant, underscoring their utility in these areas.[173] Typically, scoping studies are not linear and result in a broad understanding of the research area.[168,170] Although some authors have noted ambiguity and controversy in the methodology of scoping studies,[174,175] I used the Arksey and O'Malley[168] framework and Levac et al.'s enhancements[176] to anchor our study methods. As with other review methodologies, scoping studies require rigorous and transparent methods as a marker of trustworthiness.[174] The scoping study method was chosen as it was appropriate to identify key concepts within the thesis research area, identify the range and nature of the existing research, summarize the research findings, and to identify research gaps.

2.1.1 Introduction

Numerous considerations influence healthcare professionals' (HCPs') professional practices. These considerations include changing legislation, policies or best-practices, evolving medical technology, advancing biomedical and drug research, and shifting patient demographics and care expectations. Consequently, the care a patient requests or desires may not align with HCPs' internal moral values,[177] their moral convictions,[178] or how they apply their professional and ethical codes. Conscientious objection (CO) is when HCPs do not participate in care because it is contrary to their moral, ethical, or religious beliefs.[125] Medical assistance in dying (MAID) was legalized in Canada in June 2016.[179] As I entered into this field of study in September 2017, I sought, but was unable to locate, robust Canadian MAID CO research. However, I did find publications related to CO, mostly specific to pregnancy termination, with some international research specific to euthanasia or assisted suicide (terminology used in other jurisdictions).

There are variations in Canadian CO professional guidance policies, which result in uncertain care expectations, inconsistent patient care options, increased healthcare delivery costs, and tension in healthcare delivery teams.[144] Compounding the confusion and challenges in actualizing CO policies is a lack of clarity regarding what precipitates non-participation in care,[160] and recognition that non-participation is not always rooted in conscience.[125] Given the evolving practice landscape for HCPs, ambiguity in the underpinnings of non-participation in care, and its impact on practice and policy, this scoping review was undertaken to ascertain the factors that influenced non-participation in legally available, ethically complex care.

2.1.2 Research Approach

The research approach followed the steps suggested by Arksey and O'Malley[168] in concert with Levac et al.'s[176] enhancements. I led the research team with the guidance and support of my co-supervisors. The team included my co-supervisors, an academic librarian, and a systematic review researcher. In preparation for this scoping study, a protocol was published,[180] and the following information documents the final methods of our iterative research approach.

2.1.2.1 Identifying the research question. As indicated above, this scoping study was undertaken to identify, analyze, and synthesize the factors that influenced HCPs' non-participation in ethically complex, legally available healthcare. Our research question was: "What is known regarding the factors that influence physicians and registered nurses who do not participate in the ethically complex and legally available care areas of end-of-life (EOL) (including assisted death), reproductive health and technology, genetic testing, and organ or tissue donation?" We delineated the population and the concept to support an effective search strategy within the broad research question.[176] We used our research and clinical practice experiences to identify the ethically complex practice areas.

2.1.2.2 Identifying the relevant articles. A search protocol was developed by the academic librarian and refined by the team. The protocol included MeSH keywords and synonyms to broadly encompass the concepts related to non-participation (Appendix A). We searched from January 1 1998, to January 15, 2020, on the Medline, CINAHL, EMBASE, PsychINFO, Sociological Abstracts, JSTOR, and Theses Global databases. These dates were identified to capture some early research related to pregnancy termination and encompassed the period shortly after the first American state (Oregon) passed their Death with Dignity Act.[181] The first search was limited to articles published in English; however, a second search was completed to account for the availability of published literature in English and non-English. Grey literature (including advanced reports, institutional reports and statistics, pre-prints, advanced reports, market research, and bibliographies)[182] and conference abstracts were not included in the project. This was to meet the objective of establishing what was known and after identifying the volume of articles found in the initial search strategy. This approach aligned with scoping methods that explain inclusion parameter decisions can be made after understanding the scope and volume of items in the area.[168]

2.1.2.3 Selecting the relevant articles. The web-based systematic review program, Covidence,[183] was used to facilitate, coordinate, and organize the identified articles. In the first phase, two research team members evaluated each article's title and abstract against the article selection eligibility criteria. In the second phase of article selection, the residual articles' full-texts were reviewed against the additional eligibility criteria.

To support inter-rater reliability in applying the eligibility criteria, the research team members independently evaluated a minimum of thirty articles and then cross-checked the results in both phases. Articles with conflicted screening results (in both phases) were reviewed by two team members who, by consensus, determined their inclusion or exclusion. If additional article information was required, the article's authors were contacted before determining its inclusion or exclusion. Lastly, the reference lists of included articles were examined for additional relevant articles for possible screening. Consistent with accepted practices for conducting a scoping study, a quality appraisal was not incorporated into the selection process.[168,171,176] 12494 articles were identified in the database search, of which 10664 underwent title and abstract screening, resulting in 172 articles that underwent full-text screening. Sixteen articles were identified for inclusion, with one article located by examining the included articles reference lists. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram was used to report the article identification, screening, and eligibility processes and results.[184]

2.1.2.4 Charting the data. Once the 16 included articles were selected, the articles' identifying information (i.e., year, first author's name, country of study), information on study design (i.e., profession, sample size, care area, methodology), and their key findings were extracted into an excel spreadsheet (Appendix B). The team members cross-checked this spreadsheet against the original articles for accuracy. The 16 articles were uploaded into the NVivo qualitative data analysis software. This program was used to conduct the first stage of open coding, where the data was organized conceptualized into broad concepts and categories.[185]

Open coding was followed by content analysis of the articles, leading to eventual codebook thematic analysis.[186] A codebook was developed, and all team members and members of the doctoral committee reviewed, discussed, and refined the interim and final findings.

2.1.3 Reporting of Results

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) extension for scoping reviews[173] was used to report our findings in Chapter 3, which were submitted to BMC Medical Ethics for peer review. Further, the findings supported the framing of our qualitative exploratory study results and thesis discussion.

2.2 Qualitative Exploratory Study

2.2.1 Research Problem and Objectives

Medical assistance in dying (MAID) in Canada was legalized with the Royal Assent of Bill C-16 in June 2016.[179] MAID accounted for 2% of all deaths in Canada in 2019,[22] and, consistent with international jurisdictions,[97] MAID deaths in Canada have increased from 2018 to 2019 by over 26%.[22] Although Bill C-14 is a federal law, the provinces and territories that administer Canadian healthcare must develop the regional policy, procedures, and processes to support MAID. This regional delivery has resulted in different MAID practices across Canada.[79,86] However, all provinces and territories must follow the Canada Health Act and ensure accessibility as a prime healthcare delivery criteria.[187] Rural-dwelling Canadians experience challenges in accessing healthcare and consequently have poorer outcomes.[188] This access discrepancy likely extends to access to MAID.

The province of Saskatchewan encompasses 651,036 square kilometers,[96] and with approximately 38% of its population located in rural and remote areas,[95] is served by over 2,600 provincially licensed physicians and 267 registered nurse practitioners (NPs).[189,190] As of February 2020, thirty-five physicians and NPs (0.012%) had participated in the process of patient eligibility assessments or MAID provision, with seventeen participating in fewer than five instances (personal communication, M. Fischer, February 27, 2020). Since MAID legalization, Saskatchewan has also reported 250 MAID deaths.[22] Based on this data, there are relatively few HCPs actively participating in the formal MAID processes of determining patient eligibility and providing MAID in spite of a significantly large geographical area in a time of increasing patient requests.

National research is emerging on the experiences of HCPs who participate in the formal processes of MAID.[107] Participating HCPs have been noted to be motivated by their personal and professional values and identity as well as their experiences with death and dying.[107] HCPs have reported their participation as rewarding[16] or a "life-transforming gift."[109] However, MAID is a complex care area,[110] influenced by much discourse as it emerges as an EOL care option.[31,58] HCPs who have assessed patients and provided MAID have reported significant workload issues, time and administrative demands, isolation, and a lack of team support.[109] They also reported that MAID participation was complicated by dealing with family and friends' grief, working within institutions with a CO, and working with patients who did not qualify for MAID.[16] Participating HCPs have also noted challenges of strained relationships with objecting colleagues, inadequate remuneration, and personal time sacrifices.[115] While there is research exploring the experiences and perspectives of HCPs in MAID participation, there is little research on the factors influencing Canadian HCPs' non-participation in MAID.

This research aimed to identify the factors that influenced physicians and NPs when deciding not to participate in the formal MAID processes of determining a patient's eligibility for MAID and providing MAID. Identifying the factors that influenced non-participation will illuminate the professional supports for HCPs and potential policy and practice gaps to support the patient's MAID access.

2.2.2 Interpretive Description

The interpretive description (ID) method was chosen for this qualitative exploratory study. The origin of ID as a qualitative study method began in 1991 with Dr. Sally Thorne's reappraisal that traditional qualitative methods (i.e., phenomenology [psychology], grounded theory [sociology], ethnography [anthropology]) may not always support (1) the development of knowledge about human health and illness experiences,[191] (2) the study of applied health and clinical problems,[192] and (3) the needs of the qualitative health research community.[169] ID was derived from a need for health disciplines to address research questions that arose "from the field"[169] and to conduct applied qualitative research that would generate an understanding of complex clinical phenomena. As such, ID research projects are driven by the research question and grounded in sound methodological reasoning, not rigid methodological formulas.[193] ID retains its theoretical integrity while supporting justified and logical reasoning in method variation to account for the research's context and objectives.[169]

Within an ID method, both data description and interpretation are essential. Data description relates the phenomena to the research consumers, creates a basis for new research questions, and documents the "manifestations of the complex and messy world of human health and illness."[169]Data interpretation is the practical and analytical reflection of what the data means. The researcher highlights the associations, relationships, and patterns within the data by using reflective clinical reasoning, scholarship, and the lens of their health discipline.[169]

Dr. Thorne discusses the importance of scaffolding a study from which to build the research design and methods. Essential to scaffolding is (1) the literature review and (2) locating and positioning the researcher within the field of study.

2.2.2.1 The literature review. My doctoral studies began in September 2017, when MAID had been legal for fifteen months. At this juncture, to my knowledge, there was a significant gap in the research regarding MAID in Canada, and there was no research regarding HCPs' non-participation in MAID. This paucity of information related to non-participation prompted the scoping study to examine the factors influencing non-participation in ethically complex and legally available care.

2.2.2.2 The researcher. The second essential element of scaffolding is locating myself as a researcher in the study. Specifically, this has meant documentation of my theoretical allegiances, disciplinary orientation, and experiences and ideas relative to the study field.[169]

My beliefs regarding knowledge acquisition and the researcher and participant's relationships resonate with the constructivist/interpretivist research paradigm. Within this approach, individuals construct their experiences and situation-specific meanings through their interactions with others and their history, language, and behaviors.[194] As a result of this human reflection and intellect, these multiple, valid, socially-constructed realities may change over time.[195,196] The participant-researcher interaction aims to understand the world from the participant's perspective through an iterative, inductive knowledge process generating co-constructed knowledge between the researcher and the participants.[194–196]

I am proud to be a registered nurse, and my nursing practice is rooted in relationships and connections. I believe that nurse-patient-family relationships are built on trust and that walking with patients and families in their most beautiful and challenging life moments is a privileged position. As authors of their stories and owners of their experiences, patients and families are at the center of the healthcare team. I view my role as fostering meaningful connections, sharing balanced information, and providing unconditional positive regard to support individuals' autonomy in health decision-making. My approach in the fostering of meaningful connections, balanced information, unconditional positive regard, and autonomous decision-making is extended to not just patients and families but also my fellow HCPs.

I believe that healthcare teams are needed to meet the patient’s and family’s needs. These teams are built on mutual respect and open communication, and must work together to support patients, families, and each other in the modern healthcare delivery context. I have worked in urban and rural areas and with remote Indigenous communities. I have worked with incarcerated women and older adults in long-term care. I have worked as a bedside nurse, community health nurse, nurse educator, and coroner. Through the totality of these experiences, I have developed a systems view of healthcare delivery in Saskatchewan and an appreciation of how the social determinants of health and individual contexts impact the experiences of patients, families, and HCPs.

I completed my elementary and high school in a rural Saskatchewan agricultural community and attended weekly Baptist church services. My mother and grandmother were both registered nurses, and my great-grandmother was a mid-wife and bone-setter. My earliest familial experience with death was when I was eleven. My aunt was diagnosed with metastatic cancer one month after she married my uncle, and she died six months later. My mother and grandmother cared for her at her home, and the extended family, myself included, were there when she died. In my memory, this experience is marked by her physical pain, deterioration, and the anguish of my uncle and my family. In my previous work as a coroner, I also attended to the deaths of individuals who chose to end their life. Some of these individuals were individuals living with terminal illnesses.

I have engaged in self-reflexivity during this doctoral journey. I have dialogued with my supervisors and doctoral committee, and have had heart-to-heart conversations with my husband and immediate family. These dialogues have supported an honest assessment of my strengths, shortcomings, biases, and motivations. My introspection expanded as I have served as an independent witness for patients formally requesting MAID and as I have engaged with provincial, national, and international scholars in the research area of MAID, euthanasia, and assisted suicide.

2.2.3 Theoretical Frameworks

Two theoretical frameworks were chosen to support the qualitative exploratory study; Social Contract Theory (SCT) and the Ruggiero approach to moral dilemmas and decision-making.

2.2.3.1 Social Contract Theory. Social contract theories are informed by issues common to philosophy, religion, and politics, and they extend back to the mid-1600s with their modern development attributed to Locke, Rousseau, and Hobbes.[197] Social contracts have a range of applications and may be used to conceptualize the macro-relationship between a nation and its people or extend to micro-social contracts within different society's segments (i.e., marriage contracts, professional groups, universities role within society).[197,198] Medicine and nursing both contend that a social contract exists between the profession and patients/society.[197–200]

Social contracts explain how groups interact for society's mutual benefit, and social contracts are said to exist when "two groups within a society, between which a state of mutual dependence exists, recognize certain expectations of one another and conduct their affairs according to those expectations"[199] (Table 2.1).

Patients/Society Expect Medicine To:	**Medicine Expects Patients/Society To:**
• Fulfill the role of healer	• Trust them to meet the patient's needs
• Be competent	• Allow autonomy to exercise judgment
• Support timely access to quality care	• Accept their role in healthy public policy
• Provide altruistic service	• Be responsible for their health
• Act with honesty, integrity, morality	• Have a balanced lifestyle
• Be trustworthy	• Provide financial and non-financial rewards of caring (respect, status)
• Be accountable and transparent	
• Respect patient autonomy	
• Be a source of objective advice	
• Promote the public good	
Patients/Society Expect Nursing To:	**Nursing Expects Patients/Society To:**
• Provide dignified compassion and care	• Allow nurses to work within their scope and standards
• Ensure the patient's needs and interest supersedes others	• Support self-governance through a self-regulating profession
• Be competent, knowledgeable, and skilled	• Protect the title and practice of Registered Nurse
• Provide care under challenging conditions (pathogens, natural disasters, violence)	• Provide respect and just remuneration
• Be responsible and accountable	• Support nurses to practice to the full extent of their education
• Incorporate and participate in scientific advances	• Support work sustainability

• Uphold the code of ethics	• Support the needed protections to minimize the risk of service
• Work with others	
• Promote the health of the greater public	

Table 2.1: Mutual Expectations Between Patients/Society and Medicine and Nursing: Adapted from Cruess and Cruess[198] and Fowler[197]

Health care social contracts may be implicit, explicit, unwritten, or written,[198] and are subject to evolution as healthcare changes,[198,201] and society diversifies.[199] Inherent to the social contract is a mutual trust that individuals, groups, and institutions are working towards “the good.”[202] However, tension can exist when individuals' expectations are marginalized, when individuals' needs are responded to inappropriately, or there is a disconnect between the care desired and the care provided.[199,201] The legalization of MAID introduced a new facet to the social contract of EOL care, with patients and HCPs integrating MAID into the mutual expectations of the social contract.

2.2.3.2 Ruggiero Approach to Moral Dilemmas and Decision-Making. Ruggiero posits that neither law nor religion can replace ethics, that representations of feelings are often unreliable, and that conscience is susceptible to outside influences and error.[203] He further highlights that respect for persons is essential in most ethical systems and should underlie the practice standard that should be used to guide the treatment of others. The Ruggiero approach to moral dilemmas and decision-making explains, “a moral action is one that demonstrates respect for persons by producing favorable consequences and honouring the [individual’s] relevant obligations and ideals.”[203] Associated with respect for persons and the necessity for honest, ethical dialogue are the three criteria of consequences, obligations, and moral ideals.

The relationship between actions and consequences is a cause-and-effect type relationship made challenging by the unpredictable nature of human behaviour.[203] Therefore, balancing possible consequences with the probability of their occurrence must be considered. Ruggiero states consequences are the beneficial or harmful outcomes that affect all people involved and may be apparent immediately or develop over time, may be emotional or physical, may be unintended or intended, may be complex or pinpoint, or evident or subtle. Consequences explored should include not just the actual (fact-based) outcomes but must also include possible and probable outcomes.

Human action occurs within the context of relationships with others, which results in obligations.[203] Ruggiero notes that obligations may restrict options and also compel, or prevent individuals from acting. Obligations may be formal or professional and outlined in contractual or professional agreements. However, obligations may also be considered within the individual's friendships, citizenship, or employment relationships with others. When obligations conflict, individuals weigh the relative importance of each and prioritize one over the other, or attempt to seek a compromise.[203]

Ideals promote harmony within oneself and with others and help achieve respect for persons in our moral judgments.[203] Ruggiero notes moral ideas can include cardinal virtues (prudence, justice, temperance, and fortitude), theological virtues (faith, charity, hope), and the virtues of forgiveness, honesty, reparation, beneficence, loving-kindness, and charity. He further explains that the differentiation between ideals and obligations is not always clear for some individuals, as some may view their ideals ***as*** obligations and personal standards to which they hold themselves accountable. When there is a conflict between ideals and obligations, Ruggiero notes that individuals generally choose the action that achieves the greater good or results in lesser harm.

2.2.3.3 Integration of Social Contract Theory and the Ruggiero Approach. The integration of SCT and the Ruggiero Approach to moral dilemmas and decision-making is integrated into the qualitative exploratory study, as noted in Figure 2.1. MAID legalization stimulated an evolution in EOL care's social contract between HCPs and patients (cog 1). Consequently, HCPs consider their participation in formal MAID processes (cog 2) by contemplating the consequences, obligations, and ideals relative to participation. Through this process of considering the consequences, obligations, and ideals, HCPs determine their participation or non-participation (cog 3). This either results in a successful evolution of the social contract of care (cog 4a) or non-participation in MAID whereby alternative mechanisms to support the social contract of care may be required to avoid the tension of a non-fulfilled social contract (4b).

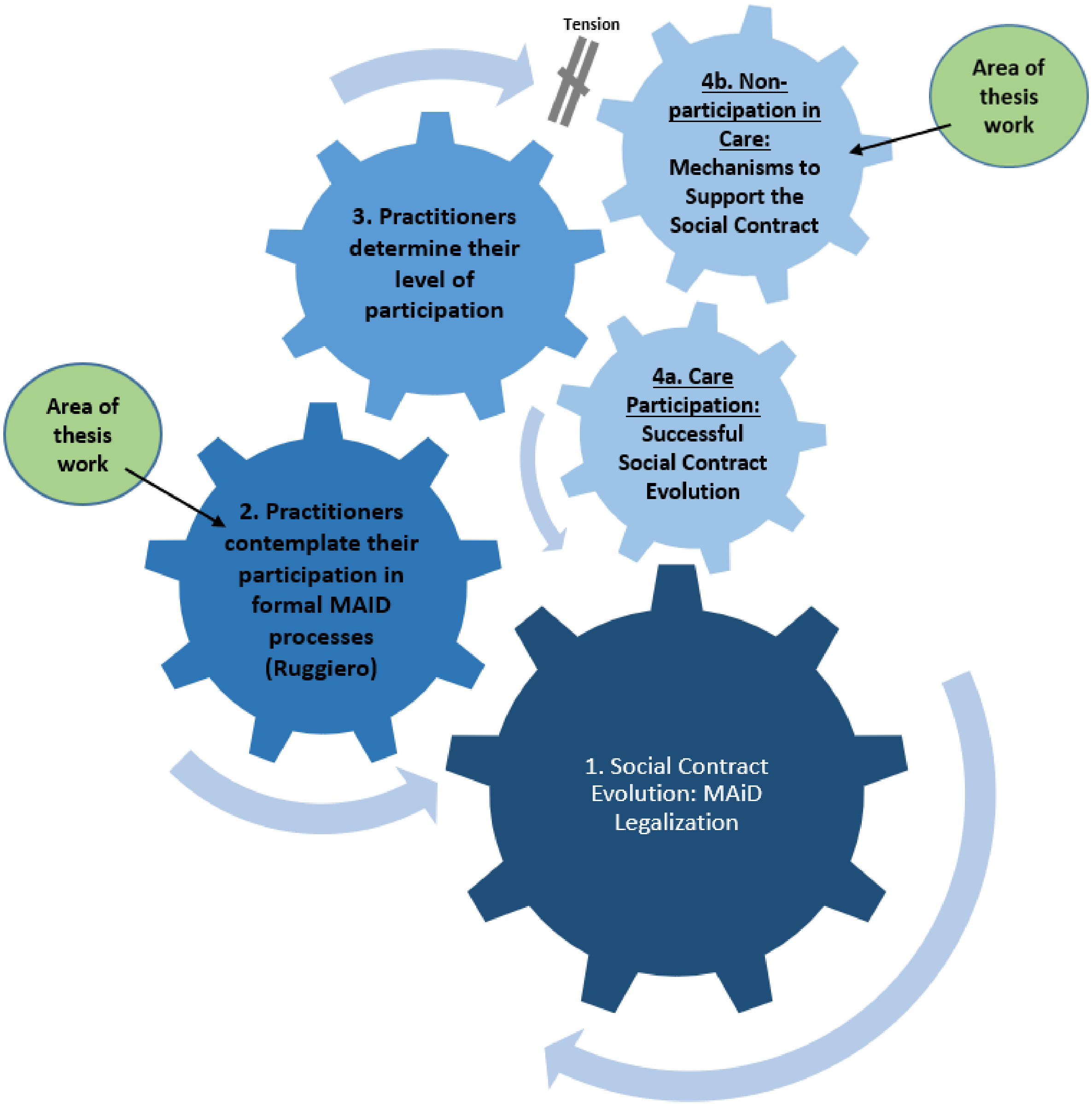

Figure 2.1: Integration of Theoretical Frameworks

2.2.4 Methods

2.2.4.1 Setting. This research took place between May and June 2019, approximately three years after MAID legalization. In 2017 there was a merger of smaller health regions into a publicly funded provincial health authority responsible for healthcare delivery. In November 2018, regionally delivered MAID programs were consolidated into a provincial MAID program.[94] Since the development of the provincial MAID program, patients, family members, and HCPs could initiate referrals to the MAID program through the provincial Healthline.

The provincial MAID program has several salaried employees and a full-time NP in the two largest provincial cities. While the program NPs complete some of the patient MAID assessments and provisions, additional physicians and NPs from across the province also provide MAID assessments and provisions on a case-by-case basis. As noted previously, approximately 0.012% of Saskatchewan NPs and physicians have participated in determining a patient's eligibility or providing MAID within our province’s significantly large, rural, and remote geographical area.

2.2.4.2 Sample. This study’s potential participants included provincially licensed NPs and physicians who self-identified as non-participators in MAID. This was further subdivided into individuals who were (1) unsure how they would respond to a patient who requested a MAID assessment or provision, (2) reluctant to engage in any MAID-related processes, or (3) would not participate in any aspect of MAID. As persons under the age of 18 are currently ineligible for MAID, HCPs who worked exclusively with that group were excluded from the sample. Given the relative lack of existing research in this area and the research question's exploratory nature, we aimed to recruit 40 participants. This sample size would adequately represent a diverse group of potential participants' experiences and support practice-orientated results through responsible analysis.[204] However, consistent with my beliefs about knowledge acquisition, I acknowledge there may be participant perspectives beyond the recruitment goal of 40 participants.

2.2.4.3 Ethical considerations and approval. Ethical approval for this project was received through the University of Saskatchewan (REB#902) (Appendix C). Specific to informed consent, all agreeable participants received the project information and consent form (Appendix D) via email in advance of the interview. The participant’s verbal consent was recorded on the interview tape, and I confirmed that consent was obtained on the written consent form. Additionally, participants confirmed consent on the online contextual information collection tool (Appendix H). As death and dying and MAID may be emotional and sensitive topics, we provided information to participants on NPs’ and physicians’ support programs for follow-up as required. All participants were advised that their participation was voluntary and that they could stop at any time or answer only the questions they wished. Participants were informed that their data could not be withdrawn after the interview was completed due to the concurrent data production and interpretation processes.

Within the ethics application form, we noted that the researcher and members of the doctoral committee might have pre-existing relationships with potential participants. As Saskatchewan's healthcare community is relatively small, and these relationships are professional, we did not exclude these potential participants. We also noted that the transcriptionist would sign a confidentiality agreement. Additionally, we built strategies into the ethics approval to share the aggregate findings with the participants for member checking. We noted that the data would be accessible to all doctoral committee members, and we outlined the data security and storage procedures.

2.2.4.4 Saskatchewan Health Authority operational approval. Once ethical approval was obtained, we obtained operational approval from the Saskatchewan Health Authority (SHA) (Appendix G). This partnership was essential to the recruitment strategies noted below.

2.2.4.5 Recruitment strategies. Purposive and snowball sampling approaches were employed to ensure robust representation in the sample, including representation from general and specialty practices across remote, rural and urban geographical areas, and diversity in the participant’s years of practice, age, gender, and faith/spirituality background. A total of three approaches were used for recruitment, (1) collaborating with the SHA and professional agencies and groups, (2) snowball sampling, and (3) direct referral.

First, we asked the SHA, The Saskatchewan Cancer Agency, the Saskatchewan Registered Nurses Association, the College of Physicians and Surgeons of Saskatchewan, Colleges and Faculties of Nursing and Medicine, the Saskatchewan Association of Nurse Practitioners, Emmanuel Care, Saskatchewan Hospice Palliative Care Association, and Northern Medical Services to distribute an invitation to participate. All agencies except Emmanuel Care, the Saskatchewan Hospice Palliative Care Association, and the College of Medicine responded to the recruitment partnership email. The agencies distributed the research ethics board approved recruitment letter (Appendix E), posters, or social media scripts (Appendix F). To augment the first approach, snowball sampling was employed by asking consenting participants to forward the project information through their networks. Lastly, members of the doctoral committee sent the invitation to participate through their professional networks.

The recruitment information asked that potential participants contact me via email. I confirmed potential participants’ eligibility through the email communication, sent them the full information and consent form, and we determined a mutually agreeable time, and interview modality to proceed.

2.2.4.6 Data production. Multiple points of data were collected in the qualitative exploratory study. Data included (1) the participants' contextual and demographic information, (2) interview data obtained using vignettes and exploratory, clarifying, follow-up questions, and (3) interviewer field notes and reflective content. First, we collected the participants' contextual and demographic data via a university-approved online survey/data production tool. This data production aligned with ID and was used to understand the context of the participants.[169] The demographic and contextual information included age, marital status, gender, the significance of faith, religion or spirituality, belief system, years in practice, professional group, location of practice, practice area, and the proportion of patients with a life-limiting illness. We also explored whether an actual or hypothetical MAID request informed their interview responses (Appendix H). This online data production link was sent to the participants via email and completed either in advance of or during the interview.

A semi-structured interview, steered in part by vignettes, was used to collect the qualitative interview data. Given the “newness” of MAID and the desire to speak to individuals who did not participate in formal MAID processes, we recognized there was a significant chance that participants had not had exposure to MAID. Vignettes are narratives that may range from short to lengthy and complicated[205] that are used to explore judgments and decision-making processes of HCPs.[206] Vignettes are a useful data production approach when they are interesting, relevant, and realistic.[205] They can be used to “allow actions in context to be explored, to clarify people’s judgments, and to provide a less personal and therefore less threatening way of exploring sensitive topics.”[207] I developed three vignettes with my co-supervisors' support to explore different facets of MAID participation based on our practice experiences and case histories. The vignettes explored (1) participation in the clinical process of MAID (providing information, emotional support, formal assessment or MAID provision), (2) participation in discussion about MAID with colleagues, and, (3) participation in MAID continuing education (Appendix I). The vignette content was contextual (i.e., nuanced differences to account for the different code of ethics for physicians and NPs) and controlled (i.e., consistent patient variables).[206] Before the vignettes were used in data production, two physicians and two NPs reviewed them for suitability and realism, and their feedback was incorporated before the first interview. During the interview, the participants responded to the vignette scenarios, followed by direct, exploratory, or clarifying questions. After four interviews, the researcher and the supervisors reviewed the interview data to ensure the vignettes supported robust data production. No revisions were required, and the interviews continued.

Lastly, as part of self-reflexivity and to account for the context of the data production event, I collected extensive field notes and reflexive content using pre-developed collection tools (Appendix J, Appendix K). Field notes formed an essential aspect of the research data to document the interview background material for future reference and elaboration.[169] Field note data included observations of the physical environment and the participant's appearance, behaviours, mannerisms, a description of the data production event, specific words or phrases, and notation of significant interview events or statements. The collection of reflective content is an intellectual practice that supports concurrent data production and construction as well as facilitates inductive reasoning and the creation of data linkages.[169] The collected reflected content included ideas, impressions, thoughts, unanswered questions, concerns, emerging themes, future areas for exploration, and notations of salient, fascinating, illuminating, or essential items. These reflections were collected immediately following the data production event, and were considered in the iterative interview and data interpretation process, and informed future interviews.

2.2.4.7 Data processing and interpretation. Data production, processing, and analysis occurred concurrently, while considering the theoretical frameworks, I remained open to emerging patterns and themes. The audio-recorded interviews were transcribed by an experienced research interview transcriptionist who had signed a confidentiality agreement. The transcriptionist removed names, other identifying participant information, as well as the researcher's filler words. Participant's emotional inflections or discussion pauses were noted. As the interviews occurred, the demographic and contextual data were used to gauge the sample's diversity, comprehensiveness, and depth. After thirty-five interviews, data production ceased as the range of demographic and contextual differences within our participants had covered the broad spectrum of the available target research population. At this juncture, the data set comprised over 105 single-spaced field notes and reflective content pages and over 452 single-spaced interview transcript pages and had a significant degree of code redundancy to support responsible data interpretation. The demographic and contextual data was downloaded from the online data collection program and underwent a descriptive analysis, including distribution analysis of the categorical data and distribution and dispersion analysis of the nominal data. Analysis of the data included comparisons between those who would not participate beyond the facilitation of a referral and those who identified different non-participation thresholds in the clinical care vignette. These personal and practice contexts were subsequently used to frame the results and inform the qualitative data interpretation.

The interview transcripts, the field notes, reflective content, and demographic/contextual data were uploaded into NVivo data management software as they were available. I read the data repeatedly to support data familiarity. Inductive coding occurred across the entire data set while reflecting on SCT and Ruggerio's approach to moral dilemmas and decision-making. A comparative analysis of the responses from NPs, physicians, rural and urban participants was undertaken to determine if there were any marked response differences across those demographics. These initial patterns of meaning were developed and shared with the participants (Appendix L) with the invitation to add, correct, or expand the data interpretations.

While considering the researcher's field notes and reflections and the participant demographic data, the codes then underwent reflexive thematic analysis.[208] The interim results were shared with the research supervisors and the doctoral committee, which supported code refining and eventual theming.). The data was presented in a codebook by theme, code, and exemplar supporting data. The supervisors and the doctoral committee cross-checked this as part of the expert analysis check.[169]

2.2.5 Planning for Quality and Excellence

Several articles outline the criteria to support excellence in qualitative health research.[209–211] Specifically, I will describe how the Tracy[209] criteria of rich rigor, sincerity, credibility, and resonance were prioritized in the study.

2.2.5.1 Rich rigor. Rich rigor is characterized by an abundance of data that offers evidence of due diligence, time, care and effort, and attention to the care and practice of data production and analysis.[209] Evidence of rigor in this study included using multiple data sources, vetting the vignettes for realism and suitability, confirming that the vignettes supported exposition of the research question, using a single transcriptionist and preliminary coder, and the supervisor's cross-checking of the codes to the transcripts. Further, we aimed to recruit 40 participants to reflect the broad geographical and practice contexts of HCPs within the sample, and we documented the study's context and used two frameworks to support the study's theoretical construction. Lastly, we offered ample information on the data production and analysis processes when reporting the findings.

2.2.5.2 Sincerity. Sincerity in quality qualitative health research can be achieved through "self-reflexivity, vulnerability, honesty, and transparency."[209] Self-reflexivity was supported in this project through open, supportive dialogue between my supervisors and the doctoral committee. Sincerity was further supported by collecting field notes and reflective content at the end of each interview. Transparency was supported by using a codebook and having the field notes and reflective content available to the supervisors and doctoral committee.

2.2.5.3 Credibility. Credible research has thick descriptions and concrete details and incorporates crystallization, multivocality, and member reflections.[209] Thick description is abundant detail[212] that accounts for the participants' context,[213] that allows readers to make decisions about the transferability of findings.[214] In this research, we chose to use ample participant quotations and accounted for the context, time, and place that the research was conducted. As "making the use of multiple researchers, data sources, methods, and theoretical lenses are still considered valuable by a host of researchers from different paradigms,"[209] multiple data sources and methods were used, and an expert committee supported the project to support a complex, robust understanding of the area of study. Multivocality was honoured in the study by including multiple participant voices with broad representation across the demographic data in the analysis and project.

We determined that sharing the aggregate preliminary findings with the participants for member reflections was of great importance. The incorporation of member reflections provided an opportunity for questions, feedback, and additional information to support the collaborative co-creation of knowledge.[209] Further supporting credibility, the preliminary findings were shared with the doctoral committee as part of an expert panel review.[169]

2.2.5.4 Resonance. Resonance can be achieved through "evocative writing, formal generalizations, as well as transferability."[209] In putting forth the findings, the data was presented to encourage the readers to think and react. This will further support transferability, in which the readers determine if the research findings resonate or may apply to their situations and contexts.[209] To further support transferability, we provided ample contextual information, including information on the sample and the data production event's time and location.

2.2.6 Reporting of Results

This project produced data beyond what could be responsibly reported in a single article. Two manuscripts were submitted to Qualitative Health Research for peer review (Chapters 4 and 5). In the submission process, we submitted the Standards for Reporting Qualitative Research (SRQR)[215] checklist to support comprehensive and transparent data reporting.

CHAPTER 3.0: FACTORS INFLUENCING PRACTITIONERS' WHO DO NOT PARTICIPATE IN ETHICALLY COMPLEX, LEGALLY AVAILABLE CARE: SCOPING REVIEW (PAPER ONE)

This chapter was submitted as an article to BMC Medical Ethics. It is currently under peer review (as of March 15, 2021). This article status is subject to change as the article peer review process unfolds. This study was planned as part of the thesis proposal and is foundational to synthesizing the existing literature and critical concepts in the area of non-participation in ethically complex, legally available care. Further, this study's findings supported the framing of the qualitative exploratory results and thesis discussion.

Author contributions:

Janine Brown: Conceived and designed the study, collected the data, led the data interpretation, wrote the paper.

Donna Goodridge: Contributed to the conception and design of the study, collected the data, cross-checked the data interpretation, reviewed and approved the paper.

Lilian Thorpe: Contributed to the conception and design of the study, collected the data, cross-checked the data interpretation, reviewed and approved the paper.

Alexandra Hodson: Collected the data, data interpretation, reviewed and approved the paper.

Mary Chipanshi: Collected the data, cross-checked the data interpretation, reviewed and approved the paper.

3.1 Abstract

Objective: Our objective was to identify, analyze, and synthesize the factors that influenced healthcare practitioners (HCPs) who did not participate in ethically complex, legally available healthcare.

Design: We used Arksey and O'Malley's framework while considering Levac et al.'s enhancements and qualitatively synthesized the evidence.

Methods: We searched Medline, CINAHL, JSTOR, EMBASE, PsychINFO, Sociological Abstracts, and ProQuest Dissertations and Theses Global from January 1, 1998, to January 15, 2020, and reviewed the references of the final articles. We included articles written in English that discussed the factors that influenced physicians and registered nurses (RNs) who did not participate in end-of-life (EOL), reproductive technology and health, genetic testing, and organ or tissue donation healthcare areas. Using Covidence, we conducted title and abstract screening, followed by full-text screening against our eligibility criteria. We extracted the article's data into a spreadsheet, analyzed the articles, and completed a qualitative content analysis using NVivo12.

Results: We identified 10,664 articles through the search, and after the screening, 16 articles were included. The articles sampled RNs (n=5) and physicians (n=11) and encompassed qualitative (n=7), quantitative (n=7), and mixed (n=2) methodologies. The care areas included reproductive technology and health (n=11), EOL (n=3), organ procurement (n=1), and genetic testing (n=1). One article included two care areas; EOL and reproductive health. The themed factors that influenced HCPs who did not participate in healthcare were: (1) HCPs' characteristics, (2) personal beliefs, (3) professional ethos, 4) emotional labour considerations, and (5) system and clinical practice considerations.

Conclusion: The factors that influenced HCPs' who did not participate in ethically complex, legally available care are diverse. There is a need to recognize conscientious objection to healthcare as a separate construct from non-participation in healthcare for reasons other than conscience. Understanding these separate constructs will support HCPs' specific to the underlying factors influencing their practice participation.

3.2 Introduction

Evolving medical technology, advancing biomedical and drug research, and changing laws and legislation impact patients' healthcare options and influence healthcare practitioners' (HCPs') practices. In June 2016, Bill C-14 became law in Canada, which supported eligible patients' right to access medical assistance in dying (MAID).[179] This newly available end-of-life (EOL) healthcare option cultivated interest at the convergence of HCPs' care participation, conscientious objection, and patients' access to care.

HCPs consider their care participation within the greater systems in which they practice. Healthcare delivery systems are regulated by federal and provincial law, influenced by local, regional, and national culture, and guided by employer policies. HCPs also practice within their professional codes of ethics and standards, the universal moral rules,[216] and their individual moral convictions.[178] When navigating these considerations, some HCPs find their practices do not align with the care a patient requests and have a conscientious objection to care.

HCPs engage in conscientious objection when they decline to provide care because their participation is incompatible with their ethical, religious, or core moral beliefs.[125] Conscientious objection is a complex and sometimes polarizing topic of debate. Schuklenk noted that patients are "entitled" to receive care from HCPs because they became HCPs by voluntary choice.[217] Others contend that conscientious objection is unethical and constitutes an abandonment of professional obligation.[218] Weinstock, however, posits that there are reasons to support a "limited right" conscientious objection in healthcare.[136] These reasons include that conscientious objection (1) provides HCPs the opportunity to reflect on their practice demands relative to their sense of self, (2) allows HCPs to deliberate complex moral issues and reflect on the laws, rules, and codes that regulate their practice, (3) accommodates the moral agency of HCPs with alternative views, and (4) fosters the examination of the underlying reasons for dissent.[136] Canadian HCPs' professional codes of ethics address conscientious objection and non-abandonment of patients.[67,143] However, a pan-Canadian review of conscientious objection policies noted "considerable potential for practitioner confusion exists based on the bewildering array of policies existing in many provinces and territories" and further noted significant variability in how to address conscience conflicts.[144]

Conscientious objection policy confusion and variability can arise as it may occasionally be unclear what underpins non-participation. Dean noted that HCPs' non-participation may not always be precipitated by conscience,[160] and Lachman highlighted the need to distinguish conscience claims from non-participation influenced by cowardice, dislike, self-interest, discrimination, or prejudice.[140] For instance, claims of conscience were noted in some care refusals that were based on HCPs' convenience, irrational fear, or reluctance to treat patients because of the patient’s unhealthy lifestyle choices.[144] Card proposed that HCPs be required to declare their reasons for the objection.[217] He explained this evaluation would assess the objection's reasonability and would ensure the non-participation (1) did not result in unreasonable harm to patients, (2) respected the power inequality between HCPs and patients, (3) was non-discriminatory, and (4) did not violate the duty of care. Shaw and Downie noted that confusion and variability surrounding conscientious objection could result in inconsistent patient care options and outcomes, increased healthcare costs, friction within the care team, and patient and provider uncertainty regarding care.[144]

3.3 Methods

Our research project used a scoping review methodology. Scoping methodologies are useful for charting the relevant literature in an area of interest and exploring broad topics with multiple study designs.[168] Specifically, scoping reviews (1) examine the nature of the research activity in a given field, (2) determine the potential value of undertaking a full systematic review, (3) summarize and disseminate research findings, and (4) identify gaps in the existing research.[168] Using this methodology, we identified, analyzed, and synthesized the factors that influenced HCPs who do not participate in ethically complex, legally available care and further identified the research gaps to inform future areas of inquiry. The Arksey and O’Malley methodology framework,[168] Levac et al.’s enhancements,[176] and the PRISMA Scoping Review Checklist[173] were used to guide the research and its reporting. A protocol was published,[180] and this paper reflects the final project.

A team of five researchers conducted this project. JB is a Registered Nurse (RN) educator and doctoral candidate. DG is an RN, and LT is a physician, and both are experienced researchers and co-supervisors of JB’s doctoral studies. AH is an RN educator with experience in systematic reviews. MC is an academic librarian with literature searching experience.

3.3.1 Identifying the Research Question

This scoping review explored factors of conscience and non-conscience origins that influenced HCPs’ who do not participate in ethically complex, legally available healthcare.

Specifically, our research question was, “What is known regarding the factors that influence physicians and registered nurses who do not participate in the ethically complex and legally available care areas of EOL (including assisted death), reproductive health and technology, genetic testing, and organ or tissue donation?”

3.3.2 Identifying the Relevant Articles

The search protocol was developed by the team librarian and included MeSH, keywords, and synonyms (Appendix A). We chose these terms to capture the concepts broadly related to care non-participation. We accessed the Medline, CINAHL, JSTOR, EMBASE, PsychINFO, Sociological Abstracts, and ProQuest Dissertations and Theses Global databases and searched the period from January 1, 1998, to January 15, 2020. Our STARLITE[219] search strategy summary is in Table 3.1.

Sampling Strategy	Comprehensive survey
Type of study	Any article that might contribute to answering the research question
Approaches	Electronic database searching and manually reviewing the reference lists of the articles that eventually met all inclusion/exclusion criteria
Range of Years	January 1, 1998, to January 15, 2020
Limits	Excluded grey literature and non-English articles
Inclusion/exclusion criteria	Per Table 2: Eligibility criteria for article selection
Terms used	Appendix A for initial literature search protocol
Electronic Databases	Medline, CINAHL, JSTOR, PsycINFO, ProQuest Dissertations and Theses Global, EMBASE and Sociological Abstracts

Table 3.1 STARLITE Literature Search Strategy Summary

We completed a second search of the databases inclusive of non-English articles to thoroughly account for all articles relative to our project, which resulted in 1,537 non-English articles. Given the abundance of identified articles, we did not search beyond our initial article inclusion date, and grey literature and non-English articles were excluded. We also reviewed the reference lists of the articles identified through the selection process to identify other potentially relevant articles.

3.3.3 Article Selection

Our clinical and research experience was used to outline the article selection criteria and specify the ethically complex, legally available care areas (Table 3.2).

TITLE AND ABSTRACT ELIGIBILITY CRITERIA:	
Inclusion	Exclusion
• Physicians and/or Registered Nurses (RNs) in the sample, AND, • Must include reasons or factors that precipitate or influence individual non-participation in legally available care, AND, • Must be within one of these healthcare areas: end-of-life care, reproductive technology, and health, genetic testing, organ or tissue donation, OR • The article speaks to the physician or RN CO in one of the identified healthcare areas.	• Non-English studies, OR • Studies that included other health professional groups, OR • Studies included nursing or medical students.
ADDITIONAL FULL-TEXT ELIGIBILITY CRITERIA:	
Additional Inclusion	Additional Exclusion
• Must be a research study (as opposed to a theoretical discussion of constructs), AND • Care must be legally available where the study was conducted.	• Conference abstract, OR • The findings had aggregate results that included students or individuals other than RNs or physicians in the sample, OR • The study included multiple jurisdictions, and the care is not legally available in all areas identified in the study, OR • The care area was not identified.

Table 3.2 Eligibility Criteria for Article Selection

We used Covidence[183] to organize and facilitate the article selection process. First, two team members evaluated each article's title and abstract against the eligibility criteria. After screening a minimum of 30 studies, we cross-checked the screening results to support reliability in our understanding and application of the criteria. When we were satisfied with our cross-checking, we continued screening the articles. Articles with conflicted screening results were identified in Covidence, and subsequently, two team members determined their inclusion or exclusion by consensus. We refined the eligibility criteria prior to the full text-screening to support the exposition of the research question. Two team members then assessed the articles' full-text, and again, the conflicted articles were discussed by two team members to determine their inclusion or exclusion by consensus. Article quality was not assessed, which was consistent with a scoping review methodology.[168]

3.3.4 Charting the Data

As this scoping review formed part of a doctoral dissertation, the first author, supported by the second and third authors, led the data extraction, collation, and analysis. We populated the article's information (including year, authors' names, country, and journal), the article's design (including methodology, objectives, care area, sample profession, and size), and tOhhhhe article's findings into our data extraction spreadsheet. This spreadsheet was shared with all the research team members for cross-checking. With the support of NVivo 12,[220] the first author qualitatively analyzed the articles through open-coding and content analysis. Subsequently, through a process of code combining and refining, we developed a codebook and conducted thematic analysis.[208] All the team members had the opportunity to discuss and refine the interim and final findings.

3.3.5 Patient and Public Participation

We did not involve patients or families in this research. However, as we are able, knowledge translation activities will occur to disseminate findings to knowledge users.

3.4 Results

3.4.1 Included and Excluded Articles

Through our literature search strategy, we identified 12,494 articles. In Covidence, we removed the duplicate and non-English articles that were not excluded through the database searches. Consequently, we had 10,664 articles available for the title and abstract screening. One hundred and seventy-two (172) articles remained after we applied our initial eligibility criteria, and 15 articles remained after we conducted the full-text screening against our refined eligibility criteria. We located one additional article by reviewing the reference lists of the included articles (Figure 3.1).

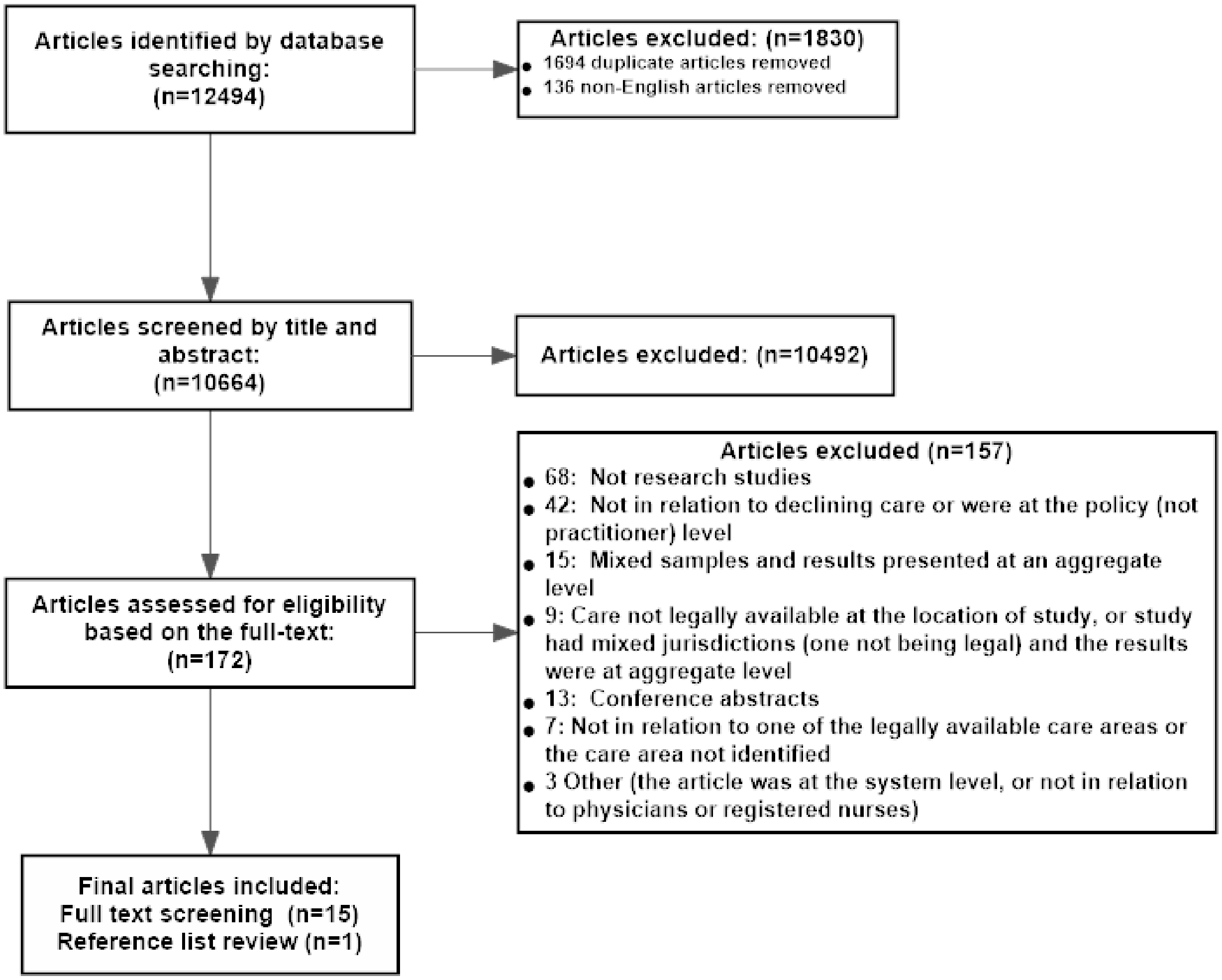

Figure 3.1 Study Selection Flow Diagram

3.4.2 Analyzing the Articles

The article's summary and contextual information are provided in Table 3.3 to frame our thematic findings.

First Author:	Year:	Country:	Methodology:	Legally Available Care Area:	Profession:	Sample Size:
Botes [221]	2000	South Africa	Qualitative	Reproductive health	RN	n=1200 (open-ended questionnaire) and 22 focus groups
Bouthillier [151]	2019	Canada	Qualitative	Medical assistance in dying	Physician	n=22 individual interviews
Clymin [164]	2012	Washington, USA	Mixed Methods (qualitative analysis of open text responses)	Physician-assisted dying	RN	n=582
Curlin [163]	2008	Illinois, USA	Qualitative	Reproductive health	Physician	n=19
Dawson [162]	2017	South Wales, Australia	Qualitative	Reproductive health	Physician	n=28 and one focus group
Diniz [222]	2014	Brazil	Mixed Methods	Reproductive health	Physician	n=1690 quantitative n=50 qualitative
Escher [223]	2000	Switzerland	Quantitative	Genetic testing	Physician	n=259 (response rate of 64%)
Harris [224]	2011	USA	Quantitative	Reproductive health	Physician	n=1154 (response rate of 66%)
Holt [225]	2017	USA	Quantitative	Reproductive health	Physician	n=744 (response rate of 29%)
Marek [226]	2004	California, USA	Quantitative	Reproductive health	RN	n-75 (response rate of 49%)
Nordberg [227]	2014	Norway	Qualitative	Reproductive health	Physician	n=7 individual interviews
Seelig [228]	2006	USA	Quantitative	Reproductive health	Physician	n=419 (response rate 53%)
Smith [229]	2017	Australia	Qualitative	Organ procurement	RN	n=35 individual interviews
Stevens [230]	2017	Massachusetts, USA	Quantitative	End-of-Life, Physician-assisted dying, reproductive health	RN	n-297 (response rate 42%)
Tilburt [231]	2013	USA	Quantitative	Reproductive health[a]	Physician	n=1032 (response rate 54%)
Willems [232]	2000	Oregon (USA) & Netherlands	Qualitative	End-of-Life, Physician-assisted dying, Euthanasia	Physician	n=152 in Oregon n=67 in the Netherlands

Table 3.3: Summary of Included Studies

[a] Study included two care areas: Reproductive health and Euthanasia. As euthanasia not legal in all US jurisdictions, data used from the reproductive health findings only.

The included articles were published between 2000-2019, and eleven studies included physicians, and five included RNs. The articles originated in the United States (n=8), Australia (n=2), South Africa (n=1), Brazil (n=1), Norway (n=1), Switzerland (n=1), and Canada (n=1). One article compared findings from the United States and the Netherlands. The articles comprised qualitative (n=7), quantitative (n=7), and mixed (n=2) methodologies. The articles spanned multiple care areas and included reproductive health (n=10), EOL care (including physician-assisted dying and medical assistance in dying) (n=3), genetic testing (n=1), and organ procurement (n=1). One article included two care areas; EOL and reproductive health.

3.4.3 Thematic Findings

We categorized the factors that influence HCPs who do not participate in ethically complex, legally available care into five themes. These themes are (1) HCPs' characteristics, (2) HCPs' personal beliefs, (3) HCPs' professional ethos (4), emotional labour considerations, and (5) system and clinical practice considerations (Figure 3.2). Table 3.4 outlines the content-coding matrix, including the themed factors, the content codes, and the articles where the content code was applied.

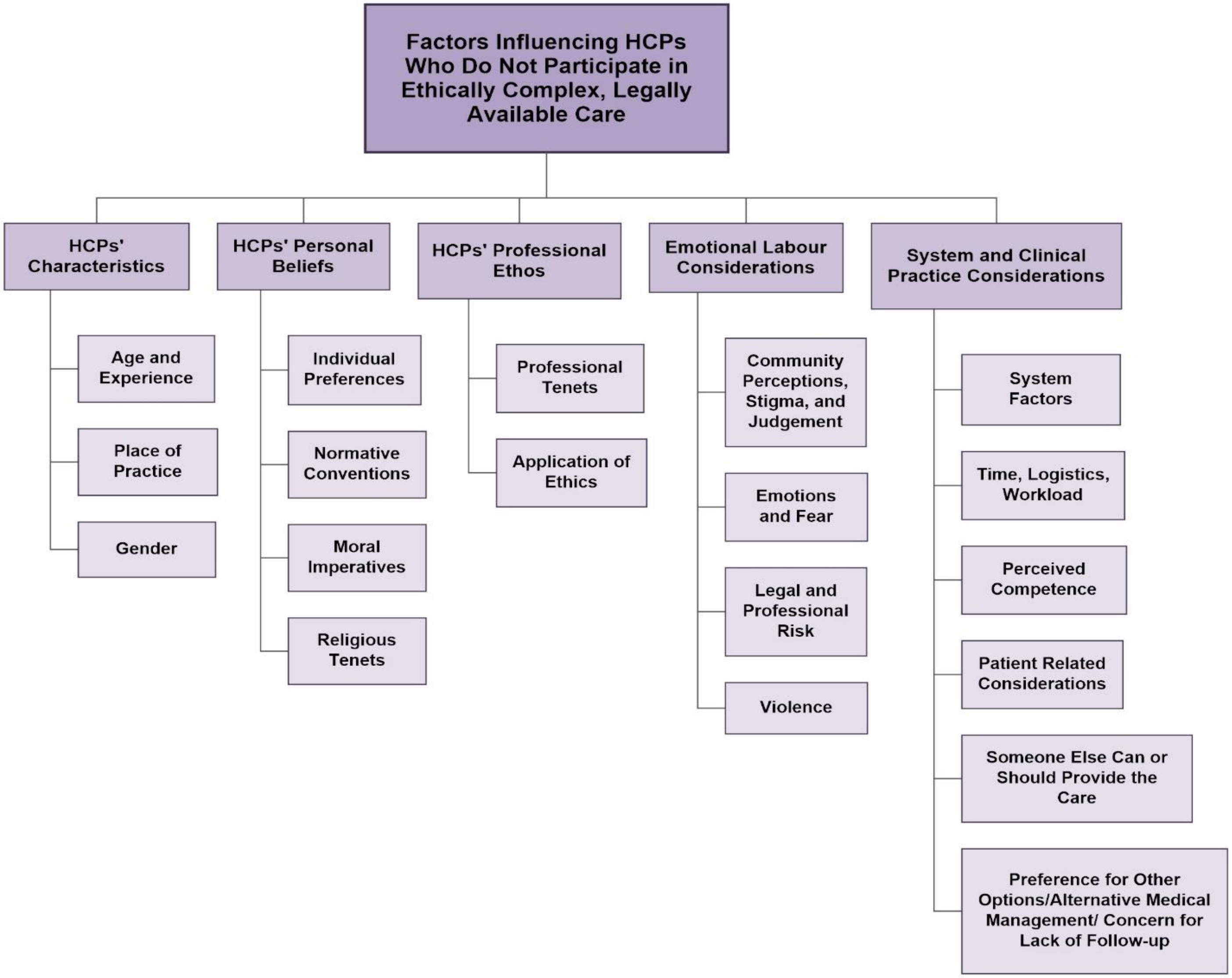

Figure 3.2 Visual Representation of Results

Themed factors:	**Content codes**	**The number of times the content code was applied:**	**The article where the code was applied (by the first author):**
HCPs’ characteristics	Age and experience	4	Harris, Holt, Marek, Nordberg
	Gender	3	Willems, Holt, Harris
	Place of practice	3	Harris, Holt, Seelig
HCPs’ personal beliefs	Individual preferences	6	Botes, Dawson, Stevens, Marek, Holt
	Normative conventions	3	Botes, Tilburt, Curlin
	Moral imperatives and conviction	8	Bouthillier, Clymin, Dawson, Tilburt, Nordberg, Marek, Smith, Diniz
	Religious tenets	13	Botes, Bouthillier, Clymin, Diniz, Harris, Holt, Nordberg, Tilburt, Willems, Curlin, Stevens, Smith, Dawson
HCPs’ professional ethos	Professional tenets	3	Botes, Bouthillier, Curlin
	Application of ethics	6	Escher, Holt, Nordberg, Curlin, Smith, Marek
Emotional labour considerations	Community perception, stigma, and judgement	4	Dawson, Smith, Bouthillier, Diniz
	Emotions and fear	3	Bouthillier, Dawson, Clymin
	Legal and professional risk	4	Bouthillier, Clymin, Diniz, Willems
	Violence	1	Seelig
System and clinical practice considerations	Perceived competence/lack of knowledge	5	Bouthillier, Clymin, Dawson, Holt, Smith
	Time, workload and logistics	3	Bouthillier, Dawson, Smith
	Preference for other care options, concern for lack of available follow-up care, alternative medical management.	4	Escher, Harris, Bouthillier, Clymin

	Someone else can or should provide the care	6	Seelig, Botes, Clymin, Dawson, Holt, Nordberg
	System factors	4	Clymin, Dawson, Holt, Smith
	Patient-related considerations	6	Diniz, Harris, Holt, Marek, Willems, Curlin

Table 3.4: Included Study Content Coding and Themes

3.4.3.1 HCPs' characteristics. Age, years of experience, location of practice (including geographical region or clinical practice area), and gender were the identified characteristics of HCPs who do not participate in ethically complex, legally available care. One article highlighted that some HCPs developed opposition to care participation over time.[227] Conversely, other articles identified HCPs who had more experience,[225] and HCPs who identified as "older"[224] were less likely to object to ethically complex, legally available care. Additionally, HCPs' previous work experience specific to the care area influenced their care non-participation.[226] Non-participation in ethically complex, legally available care was more likely among HCPs who practiced in rural settings,[224] and among HCPs who were located in the South or Midwest of the United States.[224,225] Private practices (compared to hospital-based settings),[225,228]and religiously affiliated practices (compared to non-religiously affiliated practices)[225] were associated with non-participation in ethically complex, legally available care, and non-participation was more likely among male HCPs.[224,225,232]

3.4.3.2 HCPs' personal beliefs. Personal beliefs influenced HCPs who did not participate in ethically complex, legally available care, and we coded these as individual preferences, normative conventions, moral imperatives or convictions, and religious tenets. HCPs' individual preferences were noted in the articles as "personal beliefs,"[162] "personal objections,"[225] "attitudes,"[226] "non-religious reasons,"[230] as care being an "unpleasant service,"[162] or as a "waste of taxpayers' money."[221] Normative conventions, or the socially and culturally shared notions about the way things are usually done,[233] influenced HCPs' non-participation in ethically complex, legally available care and were noted as HCPs' consideration of rights and responsibilities,[221] fairness,[231] and if the request was counter to a "widely held societal norm."[163]

Non-participation was also influenced by a belief that the ethically complex, legally available care was fundamentally right or wrong,[233] and we coded these as moral imperatives or convictions. Moral imperatives included "moral objections," [162] "moral convictions,"[164] "moral duty,"[222] "moral beliefs,"[151,226,229] "sanctity,"[231] and that care refusal allowed HCPs "to be themselves" in care participation.[227] Lastly, some HCPs expressed care participation was counter to their religious tenets,[151,162,164,222,227,229–232] and identified that their participation would be "judged by God"[221] or would result in tensions between the HCPs' beliefs and the patient's care requests.[163] Specifically, HCPs who identified as Catholic, Protestant, Christian, Muslim, or who communicated the importance of religion were more likely to object to participation in ethically complex, legally available care.[224,225]

3.4.3.3 HCP's professional ethos. Professional ethos influenced HCPs who do not participate in care. Some HCPs believed the care conflicted with the tenets of medicine[151] or the Hippocratic Oath.[163] Other HCPs noted the care misaligned with the promotion of health or the Nurses' Pledge.[221] HCPs frequently noted that care participation was counter to their application of professional ethics.[163,223,225–227,229] Specifically, this included beliefs that the care would "do more harm than good,"[223] that the care would "harm the patient's health,"[225] and that HCPs had a "commitment to the patients' medical good."[163]

3.4.3.4 Emotional labour considerations. Emotional labour, or the management of feelings,[234] was considered by HCPs who do not participate in ethically complex, legally available care. Fear was documented as a primary emotional response in multiple articles.[151,162,164] Expressly HCPs: (1) feared the emotional aspects of care provision and its sequelae for the care provider;[151] (2) feared a potential backlash from others if they participated in care;[162] (3) feared patient death;[151] and/or (4) feared potential job loss.[164] Additionally, HCPs contemplated the risk of violence,[228] the risk of medicolegal and/or professional repercussions,[151,164,222,232] and considered the stigma and judgment from their colleagues and the greater community.[151,162,222,229]

3.4.3.5 System and clinical practice considerations. System considerations influenced HCPs' non-participation in ethically complex, legally available care, including (1) "uncertainty about facility or professional policies"[164] (2) practices that "would not permit" the care option (i.e., employers believed the care to be outside the HCPs' scope of practice)[162]; (3) practices that restricted referrals;[225] and (4) availability of alternative care providers.[229] Clinical practice considerations that influenced non-participation in ethically complex, legally available care included time, workload, and logistical concerns.[151,162,229] HCPs also considered their participation in care relative to their self-assessed competency and lack of knowledge,[151,162,164,225,229] and considered whether another care provider could or should provide the care.[162,164,221,225,227,228] This non-participation was explicitly noted in some articles as due to a lack of interest in the care area,[162,228] a lack of a desire to participate in care,[221] or a belief that a specialist could provide better care.[162] Also influencing non-participation in ethically complex, legally available care was HCPs' preference for other care options,[151,164] and their assessment that the precipitating condition could be managed in alternative ways.[224] Lastly, HCPs' considered the circumstances that precipitated the patient's care request,[222,224–226,228,232] and the availability of adequate care follow-up relative to their care participation.[223]

3.5 Discussion

3.5.1 Main Findings

While conscientious objection frequently dominates the discourse regarding HCPs' non-participation in ethically complex, legally available care, the findings of this scoping review make clear that multiple factors beyond ethical, religious, or core moral beliefs[125] also influence HCPs' non-participation. The emotional labour of care, the consideration of patient factors, HCPs' care preferences and, practice logistics and complexities, as well as the larger system within which HCPs work also factored into HCPs' non-participation in ethically complex, legally available care. Our findings align with a systematic review of nurses' and midwives' reasons for declining to participate in pregnancy termination,[159]which identified moral, practical, religious, or legal reasons for objecting to care. Collectively, this highlights a need to distinguish between a *conscientious objection to care* and *non-participation in care* due to reasons other than conscience. This delineation is critical as the practice implications are different within each construct.

Non-participation in ethically complex, legally available care that results in a conscientious objection to care is complicated. Existing codes of ethics frequently do not adequately capture the complex realities of practice, and the processes to disengage from care are ambiguous.[235] Nurses who had a conscientious objection reported feeling alone, uncertain, and stigmatized and that their objection felt futile due to a lack of meaningful professional support.[128] Thus, healthcare systems must mitigate the confusion and variability in conscientious objection policies[144] and address the disconnect between having a policy in situ, and the pragmatic, practical realities of enacting an objection.[235] The importance of this is paramount, considering the continuous advancements in healthcare and the resultant shifts in HCPs' roles and responsibilities.[147]

Non-participation in ethically complex, legally available care for reasons other than conscience requires authentic and continuous discussions among healthcare regulators, leadership, administrators, unit managers, and HCPs. These discussions will illuminate HCPs' practice realities and support an enriched and nuanced understanding of the myriad of factors that are influencing non-participation. Self-assessed inadequate competence,[151,162,164,225,229] time, workload and logistical concerns,[151,162,229] uncertain policies,[164] workplace practice limits,[162,225] and patient-related practice considerations[163,222,224–226,232] all influenced HCPs' non-participation in ethically complex, legally available care. Thus, policy clarification, removal of practice barriers and workplace practice limits, providing time and logistical support for care provision, and continuing education opportunities may positively support HCPs' participation. Additionally, professional regulators and associations must elucidate HCPs' roles and obligations where duty, abandonment, and non-participation for reasons other conscience intersect. Elucidating these roles and responsibilities is crucial for all HCPs. However, for HCPs who practice in rural, remote, single-provider practices or practice in areas where there are limited referral options, this clarification is more acutely required.

3.5.2 Strengths and Limitations

The inclusion of two of the largest practicing groups of healthcare providers (physicians and RNs) and the inclusion of multiple care areas were project strengths. An additional strength was the inclusion of articles where the care was legally available, thus removing the hypothetical factors influencing potential non-participation in care. Eight countries were represented in the included articles, and it was not possible to account for the diversity and impact of culture. Additionally, there may be different non-participation factors in different care areas or among the professional groups that were excluded from the project. Inclusion of specific ethically complex, legally available care areas may have excluded other care areas where non-participation in care occurs. Further, utilization of identified databases may result in the exclusion of articles indexed in other databases, and the use of English only articles could have resulted in the exclusion of relevant articles in other languages.

3.5.3 Areas of Future Research

With our article search and identification strategy, we discovered a significant body of literature (n=10,664). However, when the results were limited to research articles of physicians and RNs within defined ethically complex, legally available care areas, the final number of articles markedly decreased. This suggests that although CO is frequently debated, explored, and deconstructed in the literature, there is significantly less research into the precipitating factors or underpinnings of HCPs' care non-participation in ethically complex, legally available care. Equally important, as the discourse opens between CO and non-participation for reasons other than conscience, additional research into non-participation for reasons other than conscience is warranted. Of the included articles, the majority (14 out of 16) were concerning EOL and reproductive health (pregnancy termination and birth control) care areas. This suggests that research into the care areas of genetic testing, reproductive health and technology, and organ procurement may be underexplored. Lastly, future research could explore differences in the factors influencing HCP participation where care is legally available to those where it is illegal to distill the anticipated or hypothetical influencers of non-participation.

3.6 Conclusion

As healthcare evolves and patient care options change, a robust understanding of the factors that influence HCPs' who do not participate in ethically complex, legally available care is imperative. This understanding of the factors will further delineate CO and non-participation for reasons other than conscience as separate constructs such that HCPs are supported in a manner that is specific to the underlying factor influencing their non-participation.

3.7 Bridging Paper 1 to Paper 2

Paper 1 identified, analyzed, and synthesized the factors that influenced physicians and registered nurses who do not participate in the ethically complex and legally available care areas of EOL (including assisted death), reproductive health and technology, genetic testing, and organ or tissue donation. This approach was useful as it served to chart the relevant literature in the area and summarized the data from articles with multiple research designs.

Five themed factors influenced HCPs' non-participation. They included (1) HCPs' characteristics, (2) personal beliefs, (3) professional ethos, 4) emotional labour considerations, and (5) system and clinical practice considerations. The paper puts forward that while conscientious objection frequently dominates the narrative regarding non-participation in ethically complex, legally available care, there are factors beyond ethical, religious, or core moral beliefs that influenced non-participation. Paper one further identified the need to identify conscientious objection to care and non-participation in care and identified that the practice implications were different within each construct.

MAID became a legal end-of-life care option in June 2016. Paper 2 specifically explored the factors that influenced Saskatchewan licensed physicians and nurse practitioners when deciding not to participate in the formal MAID processes of determining a patient's eligibility for MAID and providing MAID. Although it was clear in Paper 1 that both conscience and non-conscience-based factors influenced non-participation within multiple care areas, the factors that specifically influenced MAID non-participation required elucidation. The collective findings will provide a detailed understanding of non-participation in MAID and inform the development of HCP support in this emerging practice area, identify practice and policy implications, support safe workplaces for all, and facilitate patient's access to MAID.

CHAPTER 4.0: “WHAT IS RIGHT FOR ME, IS NOT NECESSARILY RIGHT FOR YOU”: THE ENDOGENOUS FACTORS INFLUENCING NON-PARTICIPATION IN MEDICAL ASSISTANCE IN DYING (PAPER TWO)

This chapter was submitted as an article to Qualitative Health Research and was accepted for publication on March 18, 2021. This methodology and the subsequent paper were noted in the thesis proposal and presents key thesis findings in a rapidly developing and changing healthcare practice area. The findings from this paper and the others that encompass this thesis will be integrated in the discussion chapter.

Author contributions:

Janine Brown: Conceived and designed the study, collected the data, data interpretation, wrote the paper.

Donna Goodridge: Contributed to the conception and design of the study, cross-checked the data interpretation, reviewed and approved the paper.

Lilian Thorpe: Contributed to the conception and design of the study, cross-checked the data interpretation, reviewed and approved the paper.

Alex Crizzle: Contributed to the conception and design of the study, cross-checked the data interpretation, reviewed and approved the paper.

4.1 Abstract

Access to medical assistance in dying (MAID) is influenced by legislation, health care providers (HCPs), the number of patient requests, and the patients’ locations. This research explored the factors that influenced HCPs' non-participation in formal MAID processes and their needs to support this emerging practice area. Using an interpretive description methodology, we interviewed 17 physicians and 18 nurse practitioners who identified as non-participators in formal MAID processes. Non-participation was influenced by their (1) previous personal and professional experiences, (2) comfort with death, (3) conceptualization of duty, (4) preferred end-of-life care approaches, (5) faith or spirituality beliefs, (6) self-accountability, (7) consideration of emotional labour, and (8) future emotional impact. They identified a need for clear care pathways and safe passage. Two separate yet overlapping concepts were identified, conscientious objection to and non-participation in MAID, and we discussed options to support the social contract of care between HCPs and patients.

4.2 Introduction

Medical assistance in dying (MAID) is a legally available end-of-life (EOL) care option in Canada. Bill C-14, passed June 17, 2016, afforded an exemption from culpable homicide for physicians and nurse practitioners (NPs) who provide MAID to eligible Canadians.[179] This legislation stated eligible patients must (1) qualify for Canadian health services, (2) be mentally competent and at least 18 years and older, (3) have an irremediable and grievous medical condition, (4) request MAID voluntarily and without outside influence, and (5) provide informed consent. The Bill further outlined that an irremediable and grievous medical condition requires that (1) the illness, disease, or disability is serious and incurable, (2) the individual is in an advanced state of irreversible decline in capability, (3) that the illness, disease or disability causes the individual enduring psychological or physical suffering that is intolerable to them and cannot be relieved through means they find acceptable, and (4) that, taken into all the medical circumstances, that the individual's natural death has become reasonably foreseeable.

There are provincial, territorial, and regional variations to MAID programming[46,78] attributed to differing healthcare delivery structures, geographical contexts, interests, resources, and performance indicators.[79] However, all provinces and territories must abide by the Canada Health Act, which requires patient care accessibility in health services delivery.[236] As such, patients must have "uniform," "unprecluded," and "unimpeded" access to legally available insured healthcare services.[237]

From MAID legalization until December of 2019, 13,946 Canadians had a medically assisted death, with 80.6% of these deaths occurred in those aged 65 and older.[22] The number of MAID requests will likely increase as the Canadian population grows and the proportion of persons aged 65 and older rises.[238] Further, increases in MAID requests at all ages is plausible as MAID becomes more widely accepted in Canada. These projected increases are substantiated as research from international regions with assisted dying reported an increase in the number of patients accessing care over time.[97] Access to MAID varies throughout Canada.[18,113,152] Individuals in rural and remote areas experience health care access challenges and poorer health outcomes,[188] and so it is reasonable they will experience MAID access challenges as well. Thus, access to MAID is influenced not only by the availability of health care providers' (HCPs') but by the number of patients requesting MAID and the location of their residence.

This research was conducted between May and September 2019 in the Canadian province of Saskatchewan, with an approximate population of 1,170,000, and 38% of the population living in rural or remote areas.[239] In December 2017, individual health regions merged into a single publicly-funded provincial health authority, and in November 2018, formal MAID processes became the responsibility of a provincial MAID program.[240] The MAID program has a number of salaried employees, including one NP based in each of the two largest cities. Although program NPs perform MAID assessments and provisions, much of the clinical MAID work is provided on a case-by-case basis by NPs and physicians from diverse practice areas (e.g., family medicine, obstetrics, psychiatry, anesthesia). Access to the MAID program was initially through a HCP-initiated referral, but since the provincial program's development, patients, family members, or others may initiate referrals through the provincial Healthline.

There are approximately 2,600 licensed physicians[189] and 267 registered NPs[190] in Saskatchewan. These HCPs are essential to MAID access as they are the only two professional groups that can determine a patient's eligibility for MAID and provide MAID. From MAID legalization until December of 2019, Saskatchewan has reported 250 MAID deaths.[22] According to the provincial MAID program, between November 2018 and February 2020, thirty-five (or 0.012%) physicians and NPs participated in either or both MAID assessments and MAID provisions, with 17 of them participating in fewer than five instances (M. Fisher, personal communication, February 27, 2020). Canadian MAID assessors and providers characterized their participation as rewarding[241] and as an honour, a privilege, and as a "life-transforming gift."[242] It allowed practicing whole-person care, supported emotional engagement with patients, and resulted in "personal and professional well-being [that]is gained from satisfaction and appreciation of living core values."[108] However, participating HCPs also noted that the administrative demands of time, workload, "the learning curve," geographical isolation, and lack of team support were sources of stress.[242] Additional challenges for HCP's in participating in formal MAID processes included inadequate compensation, strained relationships with objecting colleagues, and sacrifices to personal time.[243] They also cited that working with institutions with a conscientious objection (CO), denying patients who did not qualify for MAID, working with family and friends through grief, and "feeling like they were on call all the time" complicated MAID provision.[241]

There is emerging yet limited research exploring the motivations of those who do and do not participate in MAID. Oliphant and Frolic explored the factors that precipitated conscientious participation in MAID and highlighted that participants were motivated by their personal and professional values and identity and influenced by their experience with death and dying and the organizational context where MAID occurs.[107] Conversely, Bouthillier and Opatrny explored CO to MAID and determined that the majority of physicians used CO "as a mechanism to opt-out of medical aid in dying for a multitude of reasons other than religious or moral objections."[151]

Patient requests for MAID are subject to increase over time,[97,238] and participating HCPs, who are essential to formal MAID processes, reported numerous practice rewards, challenges, and stressors.[108,241–243] Few HCPs in Saskatchewan participate in the formal MAID process, and there is limited evidence on the participation of HCPs in this practice context. Thus, understanding the factors that influence HCPs' non-participation in formal MAID processes is a high priority for research to support HCPs in this emerging practice area and patients' care access. This research aims to identify the factors that influence physicians and NPs when deciding not to participate in the formal MAID processes of determining a patient's eligibility for MAID and providing MAID and HCPs' needs in this emerging practice area.

4.3 Background

Health care providers balance multiple considerations in their professional practices. HCPs work within what Kinnier et al. proposed are the moral values common within diverse societies.[177] These common moral values include: (1) a commitment to something greater than oneself, (2) self-respect with humility, self-discipline, and acceptance of responsibility, (3) respect and caring for others, and (4) care for other living things and the environment. Professional codes of ethics also guide HCPs' practices. These codes include the virtues of compassion, honesty, humility, integrity, and prudence,[143] as well as the values of safe and compassionate ethical care, the promotion of health and well-being, informed decision-making, dignity, privacy, confidentiality, justice, and accountability.[67] Additionally, society expects that individuals, including HCPs, abide by federal, provincial, and municipal laws in their interactions with others. As HCPs contemplate their care provision within these professional and ethical constructs and societal moral values and laws, there may be tension. Consequently, HCPs may not participate in the full range of legally available care or the care requested by a patient, resulting in uncertainty regarding HCPs' obligations when responding to these requests.[244]

Bill C-14 expressly guaranteed HCPs' freedom of conscience and religion.[179] Some HCPs may have a CO to MAID, which is non-participation based on "a particularly important subset of an agent's ethical or religious beliefs – [or] *core* moral beliefs."[125] Conscience is an essential component of ethical care,[245] and Askin and Bouchard articulated that freedom of conscience is doing what one feels *must* be done.[124] Wicclair noted that CO views are placed along a continuum, ranging from where one's conscience is morally binding to where one's moral and ethical values are secondary to the profession's accepted standards.[125] Given the importance of conscience to ethical care provision, conscience clauses are embedded in national professional association documents.[246,247]

Although there is no requirement that Canadian physicians or NP must provide MAID, there is an expectation that physicians and NPs follow their provincial or territorial regulatory policies and guidelines when disengaging from care. In Saskatchewan, the physician must (1) not abandon the patient, (2) treat the patient with dignity and respect, (3) provide sufficient resources to make informed choices and access all care options, (4) arrange timely access to another physician or resources and advice, and (5) provide the patient's relevant information and chart when authorized by the patient to do so.[63] Nurse practitioners must (1) refer the patient to a physician, NP, or to a designated contact person to provide MAID if requirements are met, and (2) care for other health needs until care is provided by another HCP.[66]

Before MAID legalization, 63% of the Canadian physicians that responded to a Canadian Medical Association (CMA) survey would "refuse outright" to participate in assisted dying should it become legal.[26] The survey also captured physicians' opinions regarding what should be done if physicians did not participate in assisted dying. 19% stated physicians should refer a patient to a colleague, 17% stated physicians should refer to an independent third party, 17% stated physicians should refer to a medical administrator, and 29% stated they should not have to do anything.[26] Some non-participation may stem from the belief that MAID violates the Hippocratic Oath, religious convictions, or professional ethics.[248]

There are challenges in operationalizing conscience clauses. HCPs should not be forced to participate in MAID, yet there is "disagreement about what this means."[26] Brindley highlighted concerns that HCPs could use CO to avoid time-consuming or emotionally draining patients,[161] and Lachman stressed the importance of distinguishing CO from self-interest, discrimination, or prejudice.[140] HCPs with a CO to MAID are required to refer the patient to another HCP; however, MAID referral processes are often imprecisely defined and vary significantly across provinces.[150] Additionally, some HCPs view a referral as the moral equivalent to providing MAID.[249] However, a recent court decision supported the contrasting position and highlighted that patients would suffer harm without an effective MAID referral.[40] In contradistinction to the often dominant legal and rights-based discourse found in CO discussions is a relational decision-making approach,[250] which focuses on open and authentic communication amid moral uncertainty within teams of HCPs to seek the best possible patient outcomes.[251] This approach manages differences in conscience in a way “that does not heavy-handedly subvert one party’s values and moral reasoning for that of the other.”[250]

4.4 Theoretical Frameworks

Social Contract Theory (SCT) guided the conceptualization of this research project. Numerous health professions have utilized SCT to consider the social relations, obligations, and conditions under which HCPs carry out their functions and outline the reciprocal rights and responsibilities of HCPs and patients.[200] Waugh highlighted that social contracts evolve as laws and professional standards change, as individuals' needs or expectations advance, or as society diversifies.[199] MAID legalization brought a shift in the social contract of EOL care. Consequently, HCPs need to integrate these evolving rights and responsibilities into their practices, seeking a balance among beliefs and values, the law, practice context, and patient care requests.

Ruggerio’s approach to moral dilemmas and decision-making also guided this research project.[203] Ruggerio proposed three decision-making standards to support analytical and objective discourse among individuals. Within this approach, an individual makes decisions while considering the standards of consequences, obligations, and moral ideals. Consequences are the effects of the action on everyone involved. Consequences could be beneficial or harmful, physical or emotional, immediately obvious or evident over time, intended or unintended, clearly visible or subtle, complex, or pinpoint. Obligations are influenced by relationships with others and include formal and professional responsibilities and can take the form of friendship, colleagueship, citizenship, or business obligations. Lastly, moral ideals are identified as concepts that help individuals achieve respect for others and encompass ethical (i.e., prudence, temperance, justice, and fortitude) and religious values (i.e., faith, hope, and charity).

With MAID as an EOL care option, the expectations of the relationship between patients and HCPs in the existing social contract of care were altered. As a result, HCPs contemplate the consequences, obligations, and ideals relative to these expectations, informing their participation and practice threshold within this new care area. Alternative mechanisms to support the social contract of care may be required to support patients and HCPs relative to their participation threshold.

4.5 Methodology

This research is grounded in a constructivist/interpretivist paradigm and used an interpretive description methodology. Within this grounding, there are multiple, sometimes conflicting, socially constructed realities.[196] These realities are elicited through interaction between the participants and the researcher and may change as individuals evolve or become more informed.[195] Therefore, our research interpretations are specific to the time, participant, and research team context. An interpretive description methodology can support the development of health-related knowledge that is capable of informing and influencing clinical practice through the application of sound qualitative methodology, and it recognizes the researchers’ expertise in the selection of research techniques and approaches.[252] Further, interpretive description accounts for the researchers' context, the setting, and the participants and that the data interpretation occurs with the lens of the research team.

The positionality and reflexivity of the research team are essential in an interpretive description methodology. The co-authors and a doctoral committee support the first author. The first author is a Registered Nurse (RN) with experience in urban, rural, and remote nursing settings. She is currently a doctoral candidate who works as a nurse educator and has an emerging program of research in EOL care and MAID. The second author is an RN, and the third author is a physician, and both are professors in the College of Medicine and co-supervise the first author. The fourth author is a gerontologist and associate professor in the School of Public Health. Collectively, they have significant research programs in EOL care, MAID, aging, and program and policy evaluation. The authors met throughout the research process to discuss their underlying and emerging thoughts and opinions to support reflexive processes.

4.6 Methods

4.6.1 Sampling Strategy

Potential participants were provincially licensed physicians and NPs who self-identified as not participating in formal MAID processes. Specifically, this included participants who (1) were reluctant to engage in MAID related processes, (2) would decline participation in any aspect of MAID or, (3) identified they did not know how they would respond to a potential patient's request for MAID assessment or provision. We excluded HCPs who worked exclusively with patients under 18, as this patient group is ineligible for MAID. We aimed to include HCPs who worked in urban, rural, and remote areas and general and specialty practices, and we sought diversity within participants' gender, age, years of practice, and faith/spirituality background within this purposeful sample. Further, we considered that our sample size should be adequate to represent the experiences of a diverse group of participants that would contribute meaningful results through responsible analysis.[204]

We used three approaches for participant recruitment. First, the provincial health authority, the physician and NP regulatory bodies and professional associations, the cancer agency, the medicine and nursing faculties of the universities, and the division of northern medical care distributed an invitation to participate. This invitation was distributed either by emailing an invitation letter or using ethics board approved posters and social media scripts, which included pertinent study information such as participant inclusion criteria. Second, we used snowball sampling to augment our recruitment and asked consenting individuals to forward the request for participation through their respective networks. Lastly, the doctoral committee members sent the letter of invitation through their networks. Potential participants contacted the first author (the interviewer) to confirm their research participation eligibility and determine a mutually agreeable time and interview modality (in-person, telephone, or WebEx). The participants received the information and consent form in advance of the interview, and verbal consent was obtained on the interview recording. The first author confirmed that consent was collected on the written consent form, and the participants also confirmed consent on the online contextual information data collection tool.

4.6.2 Sources of Data and Data Production

Multiple sources of data were collected and included (1) participant contextual data, (2) interview data, and (3) interviewer reflective and field-note content. First, the participant's contextual data including gender, age, marital status, the significance of faith, religion or spirituality, belief system, professional group, specialty practice area, years in practice, location of practice, the proportion of patients with a life-limiting illness, and if an actual or hypothetical MAID request informed their interview responses were collected on a secure university-provided survey platform. We sent the online link to the participants via email, and they completed it in advance of or during the interview. Second, we collected data via a semi-structured interview that utilized vignettes and open-ended, exploratory, and probing questions. The use of vignettes would support exploring the participants' decision-making processes,[206] attitudes, perceptions, and beliefs.[253] We designed the vignettes to address different aspects of participation, including clinical processes (providing information and emotional support, formal MAID assessment, and formal MAID provision), MAID discussions with colleagues, and MAID continuing education (Appendix I). The vignettes were crafted from case histories and the research team's practice experiences and then vetted by two NP and two physician field experts for suitability to support validity. We invited the participants to respond to the short narratives or scenarios and followed-up with direct, exploratory, or clarifying questions. After four interviews, the research team reviewed the interview data to ensure the vignettes supported the elucidation of the research objective. No vignette adjustments were deemed necessary. After each interview, the interviewer recorded extensive reflective and field-note content to support self-reflexivity in the data production event and account for its context. Field notes and reflective content included journaling on what would be asked differently, what the interviewer thought was salient, what new lines of inquiry emerged, and how the interviewer felt during the interview process. This supported the iterative interview and data interpretation process and informed future interviews. The analysis included all the data as part of the interpretive approach.

4.6.3 Ethics and Operational Approval

We received ethical approval (REB# 902) (Appendix C) and provincial health authority operational approval (OA-UofS-902) (Appendix G) for this research. We provided access information to support programs, given the topic's potentially sensitive nature on the information and consent form. In the ethics application, we noted that the researcher and doctoral committee members might have relationships with potential participants. Nonetheless, we did not exclude these participants as these relationships were professional, and the health care community in this province is relatively small. The interviews were audio-recorded with the resultant audio file encrypted, transferred, and stored according to the approved ethics board process. The transcriptionist signed a confidentiality agreement and had no access to other study data. We noted that data were accessible to doctoral committee members, and procedures for sharing aggregate responses with participants were approved.

4.6.4 Data Interpretation

Data interpretation began following each completed interview and continued throughout the data production process. After the interviews were completed, they were transcribed by one transcriptionist who noted the participants' filler words and emotional content and redacted the interviewer's filler words and any identifying information. The participants' contextual data were summarized using frequencies and percent to account for their personal and practice contexts during data description and interpretation. The first author analyzed the interview transcripts, the field notes, and the reflective content using reflexive thematic analysis with the support of NVivo12. Inductive coding occurred across the entire data set while reflecting on SCT and Ruggerio's approach to moral dilemmas and decision-making. These initial patterns of meaning were developed and presented to the participants for member checking and the co-authors before the final data interpretation. Member checking allowed the participants to provide additional reflections, comment if the data descriptions were realistic and if the preliminary patterns of meaning were fair,[254] and provided a reflective space for participants[255] as they contemplated their subsequent interview experiences. Two participants responded to the aggregate finding email; no additional data to analyze was provided through this process. These initial patterns of meaning underwent combining, refining, and eventual interpretation and theming[186] and were presented to the doctoral committee. The resultant themes were collated with theme definitions and supporting participant data, which formulated the findings' structure. These documents were cross-checked by the co-authors and presented to the doctoral committee as part of an expert panel analysis check.[252]

4.6.5 Planning for Quality and Credibility

We prioritized quality and credibility throughout the research project. First, we ensured methodological and method congruence. Second, we accounted for the research team's positionality and self-reflexivity through the data production process via the collection of field notes and reflective content, and team meetings. We established rigor by using multiple data sources, vetting and trialing the vignettes, and using a single transcriptionist and preliminary coder. Rigor was further confirmed by cross-checking the codes to the transcripts by the co-authors, sharing the aggregate findings with participants, and considering the doctoral committee feedback as part of the expert panel analysis review. Lastly, we provided detailed descriptions and multiple participant exemplars to support the data interpretation.

4.7 Results

Once we interviewed 35 HCPs, our data production and concurrent interpretation ceased. We had broad representation within the contextual data and 452 single-spaced transcript pages and 105 single-spaced field notes and reflective content pages to support the research objective's exposition.

In response to the vignettes, all HCPs stated they would direct the patient to discuss MAID with an alternative HCP or refer the patient for continued care. Approximately 40% (n = 14) of HCPs stated they would not participate in MAID beyond this, whereas other HCPs (n=21) anticipated different non-participation thresholds (e.g., discuss MAID as an EOL care option, provide emotional support on the day of death for the patient and family) in the clinical care vignette. We provided the participants' contextual data in Table 4.1 to frame the themed qualitative results. The resultant endogenous factors that influenced non-participation themed consistently across the data set.

Item	Variable	Participants Who Would Not Participate Beyond a Referral n = 14 (40%*)	Participants Who Would Provide More than a Referral, but not Formally Administer MAID n = 21 (60%*)
Gender:	Female	9 (64%)	14 (67%)
	Male	5 (36%)	7 (33%)
Marital Status:	Single/Never Married	1 (7%)	-
	Married/Domestic Partnership	13 (93%)	17 (81%)
	Divorced	-	4 (19%)
Age (years):	25-34	3 (21%)	2 (10%)
	35-44	4 (29%)	5 (24%)
	45-54	2 (14%)	8 (38%)
	55 and older	5 (36%)	6 (29%)
Faith, Religion, Spirituality, Significance:	Extremely Significant	7 (50%)	-
	Very Significant	3 (21%)	5 (24%)
	Significant	2 (14%)	2 (10%)
	Neutral	2 (14%)	11 (52%)
	Not Significant	-	3 (14%)

Which of the following describes your belief system?	Protestant	4 (29%)	3 (14%)
	Non-denominational	3 (21%)	3 (14%)
	Christianity	-	4 (19%)
	Agnostic/Atheist	1 (7%)	-
	Islam	5 (36%)	8 (38%)
	Roman Catholic	1 (7%)	3 (14%)
	Did not disclose/Other		
Professional Affiliation:	Nurse Practitioner	6 (43%)	12 (57%)
	Physician	8 (57%)	9 (43%)
Years in Practice:	1-9	6 (43%)	6 (29%)
	10-19	3 (21%)	8 (38%)
	20-29	4 (29%)	4 (19%)
	30-39	1 (7%)	3 (14%)
Location of Practice:**	Large Population Centre	5 (36%)	11 (52%)
	Medium Population Centre	1 (7%)	2 (10%)
	Small Population Centre	3 (21%)	6 (29%)
	Rural area	5 (36%)	2 (10%)
Primary Work Area:	Family Medicine/Primary Care	8 (57%)	13 (62%)
	Specialty Practice Areas***	6 (43%)	8 (38%)
Percentage of Patients on Caseload with Life-Limiting Illness:	0-19%	8 (57%)	15 (71%)
	20-39%	4 (29%)	4 (19%)
	40% or more	2 (14%)	2 (10%)
Responses in the interview were informed by:	An actual patient request	4 (29%)	5 (24%)
	A hypothetical request	10 (71%)	16 (76%)

* May not add to 100% due to rounding.

** The Statistics Canada definitions were provided to the participants to support selection.

*** Including, but not limited to, emergency medicine, internal medicine, anesthesiology, surgery, critical care, psychiatry, and physical and rehabilitation medicine.

Table 4.1. Contextual Data of Participants (N=35)

Participants also discussed their needs relative to non-participation in formal MAID processes. As we were open to developing data patterns in the data interpretation, these data patterns were subsequently themed and presented as results.

4.7.1 Factors Influencing Non-Participation

Numerous factors contemporaneously influenced HCPs' non-participation in formal MAID processes. Some of these factors originated from within the individual HCP, while other factors originated external to the individual HCP. *Endogenous factors* are conceptualized as the factors that originated from within the HCP, and *exogenous factors* are conceptualized as the factors that originated from beyond the individual HCP. For some HCPs, non-participation in formal MAID processes was solely influenced by the endogenous factors, whereas exogenous factors limited non-participation for other HCPs. Because the data were so extensive, the exogenous factors will be detailed in subsequent articles.

4.7.2 Endogenous Factors Influencing Non-Participation

We themed the endogenous factors influencing HCPs' non-participation in formal MAID processes into eight areas. HCPs' were influenced by their (1) previous personal and professional experiences, (2) comfort with death, (3) conceptualization of duty, (4) preferred EOL care approaches, (5) faith or spirituality beliefs, (6) self-accountability, (7) consideration of emotional labour, and (8) future emotional impact. As noted previously, 14 HCPs identified how these factors culminated in their decision not to participate in MAID beyond a referral. Other HCPs considered different clinical MAID participation thresholds; however, none would formally administer MAID.

4.7.2.1 Previous personal and professional experiences. Some HCPs shared their personal accounts of living with a life-limiting illness, their personal accounts of watching a close family member with a life-limiting illness die, or their personal accounts of having a family member with a disability. Further, these HCPs shared how these experiences influenced how they viewed MAID as an EOL care option and their participation perspectives.

- *"I had a family member with a disability, and that family member said to me, 'the next time I get sick, do not kill me, okay?' He felt obliged to let the record show that he could still do things others could not and was trying to figure out if there was some magic line and make sure he was never over that line... If he were in a hospital now, I would not leave him unattended [fearing] a member of the care team would say, 'we are cruel to this person. I am going to do him in.'"*

Other HCPs discussed their professional practice experiences in caring for patients with life-limiting illnesses and EOL care. These experiences significantly shaped their perspectives on formal MAID participation and impacted their participation threshold.

- *"Once you go through a couple of bad [MAID processes], you will see patients unnecessarily suffering while waiting to get everything in place, and not being able to have pain medication because they have to be completely cognitive. In the few that I have been sort of, not involved as the person doing it, but involved as the most responsible practitioner and as a support for the family, it wasn't a positive experience."*
- *"I cared for a palliative patient, and I was pushing 2mg of morphine, and he stopped breathing. I nearly stopped breathing myself. And I know it was not my fault that he stopped breathing. That is what can happen. He just died at that point, and I will never*

forget that feeling. I cannot. So, no, I could never do anything like that [participate in MAID].”

4.7.2.2 Comfort with death. HCPs expressed varying degrees of comfort in EOL care and often reflected a general disquiet about death and dying. Further, some HCPs recognized that comfort with dying and death was not inherent to all HCPs and that this comfort with death influenced HCPs' non-participation in formal MAID processes.

- *“[Participation] would be uncomfortable or difficult for me. Umm, umm, viewing the dying process, yeah. Death is difficult, and seeing her die... I think it would make me uncomfortable.”*
- *“It [EOL care] are things that I think it does take a special human to do that comfortably.”*

4.7.2.3 Conceptualization of duty. Some HCPs described how MAID did not align with their professional practice, their profession's tenets, and their obligations to the patient and discussed how this influenced their participation in formal MAID processes. Some HCPs were clear that MAID was counter to their conceptualization of professional duty.

- *“It is something that I view as being very separate from me. It is not something that I see as my role in medicine. I don’t see myself as an agent of death. Can I help someone die well? Absolutely. Do I want to be the mechanism of death? No, I do not.”*
- *“My discussion [with patients] is, “is there anything to address your concerns in terms of your independence and your quality of life?” That is what my role as a doctor is. MAID is counter to my ethos as a doc.”*

4.7.2.4 Preferred end-of-life care approaches. Participants reflected on how MAID fit within the spectrum of the existing EOL care options. Some HCPs articulated how MAID did not align with their existing EOL care practices and approaches, while others discussed how MAID was not encompassed within their vision of palliative care.

- *“There are so many other options other than “let us just refer to MAID.” I have been in some very beautiful deaths in the palliative care approach. It is not just about the person dying. It is about the experience and what that brings to the family. If you do the MAID program, maybe that’s not going to happen.”*
- *“My job is to make death a positive experience by controlling symptom management. I am not there to bring on death quicker. I am there to support a natural process. The MAID program is not a natural process, it is the exact opposite of what I do.”*

4.7.2.5 Faith or spirituality beliefs. Some HCPs shared that MAID was counter to their core spiritual or faith beliefs and discussed their accountability to a higher power. These HCPs further spoke about the importance of aligning their clinical practice with their faith or spirituality beliefs as this provided a source of inner strength and comfort.

- *"To see someone have a peaceful death and go on their terms, I am happy for them, and I am good with that. But when it comes to if it was me actually administering something to take a life? You know, you kind of think about your own demise. When I get up to the pearly gates, how is that going to be viewed."*

4.7.2.6 Self-accountability. Some HCPs discussed their self-accountability, including their need to feel at peace and account for their practice and participation choices in MAID. This self-accountability also encompassed being assured that participating in formal MAID processes was the right thing for them to do.

- *"It is different knowing that someone has died in your care and knowing that you ended that life. It is really, it comes down to you are the person that did it. And, I am not ready to accept that right now."*
- *"It is such a paradigm shift… to actually be there as the one pushing the syringes, like, that I get stuck on. I just need to think about it a little more, yeah. I would have to be incredibly clear in myself, in my soul, and my brain that what I am doing is the right thing to do."*

4.7.2.7 Consideration of emotional labour. Many HCPs discussed the emotional labour or the management of feelings[234] of potential MAID participation and articulated how this consideration of emotional labour influenced their non-participation in formal MAID processes. Some anticipated isolation, guilt, or grief relative to formal participation in MAID. Others contemplated the emotional work of supporting patients and families while processing their own emotions. Other HCPs articulated how their participation perspectives were influenced by their belief that participation in formal MAID processes would compound the moral distress already present in their health care environments.

- *"I think it [participation] would be a train wreck on my part. I do not think I could be like, "okay, I am going to support this." Like, I couldn't support it and just sit back and provide emotional support. I almost feel guilty by association."*
- *"That sounds very hopeless, but that is my true and honest belief. We already have so much ethical and moral distress, to put ourselves in that [MAID participation] situation, I just cannot see it happening."*

4.7.2.8 Future emotional impact. Some HCPs considered the future emotional impact of participation in formal MAID processes on themselves and others. This concern for their future emotional well-being and the subsequent impact on their ability to provide care impacted their non-participation perspectives. They identified potential concerns such as post-traumatic stress disorder, HCP burnout, and the emotional impact of provider isolation.

- *"I would be worried about physician burnout... I think it [MAID] could be harder emotional work than one foresees it being at the start. That would be something that would concern me."*
- *"I would like to see the data that comes forward in the next five or ten years on these practitioners who drive around from place-to-place, just to give these provisions to people. I would like to see some data about whether any psychological adversity occurs or if there is any evidence of PTSD.*

Some also identified a concern that MAID participation would impact the meaning of caring for individuals and families at the EOL. They further discussed their apprehension that this would impact the quality of patient and family EOL care encounters.

- *"If a person is just doing end-of-life, umm, just doing MAID, I suppose, it might remove the significance of it [MAID participation] for them. And if they do not have that sense of significance anymore, that will affect the interaction, I think, and the experience for the patient."*

4.7.3 Health Care Professionals' Professional Needs

Within the interviews, two themes emerged regarding HCPs' professional needs relative to the endogenous factors. HCPs identified a need for (1) clear care pathways and (2) safe passage.

4.7.3.1 Clear care pathways. All HCPs stated they would facilitate care continuation and identified the need for pathways to do so. However, few HCPs could articulate the current referral processes and expressed confusion and uncertainty in where they would go for this information. Other participants identified that HCPs and patients would have challenges obtaining accurate MAID information and achieving seamless care when care pathways were uncertain. This need for clear care pathways was especially crucial considering recent health delivery reorganization and the MAID program's newness and evolving nature.

- *"So, I think initially, in each of the health regions, there was a contact. But, that information was really hard to find. Who do you call now?"*
- *Not even knowing the name of an assessor or provider to collaborate with is a problem. Unless you happen to know that assessor or provider personally, like through your practice, then that information is not even made known. Which I think is unfortunate because it is really then up to patients to seek that information on their own."*

4.7.3.2 Safe passage. Some participants articulated that they were hesitant to bring up their opinions on MAID for fear of losing esteem with their colleagues. Others described the discourse of broaching and discussing their MAID non-participation with their colleagues. While other HCPs identified a need to feel secure and empowered to dialogue about their non-participation in MAID processes with managers, professional bodies, patients, and families without fear of reprisal or disdain.

- *"Conversations with peers and colleagues are uncomfortable and polarized… people I know go, 'that [non-participation] is wrong.' It is not wrong! It is not wrong! Choose your language appropriately… what is right for me is not necessarily right for you, and mind your own business, right?"*
- *"I have a colleague who inserted a PICC line and ordered an x-ray. He went back to check the x-ray before telling them to go ahead and use the line. He could not find the x-ray. He went to the ward and could not find the patient. The line he had inserted had been used to kill the patient. He had no understanding that was what was going to be done, and it rocked him. He said, 'I want nothing to do with putting in lines to kill people,' and the manager said, 'Suck it up buttercup, it is not your job to question, it is your job to put lines in.'"*

Other participants identified the need for respectful, safe, and transparent processes to support their disengagement from MAID and recognition that their non-participation perspectives were valuable. Collectively, these perspectives were themed as the need for safe passage.

- *"I am very aware that there are some folks in the system that are just waiting for the old dinosaurs [the HCPs who do not participate in MAID] to disappear. I think there needs to be a very clear articulation of appreciation for different perspectives and not just tolerance and accommodation."*

4.8 Discussion

4.8.1 Reconciliation

HCPs' contemplation of the endogenous factors is conceptualized as reconciliation. Reconciliation is not an agreement or acceptance of MAID as an option, nor is it an expression of a willingness to participate in MAID processes. The reconciliation process harmonizes the endogenous factors with the HCP's formal MAID participation threshold relative to their current clinical practice. By reconciling the endogenous factors, some HCPs anticipated care participation beyond a referral's facilitation was not possible. Whereas other HCPs reconciled the endogenous factors and anticipated different MAID participation thresholds (while yet identifying as being unable to participate in provision) in the clinical care vignette. A visual representation of the results is in Figure 4.1. As noted previously, the exogenous factors will be noted in subsequent articles.

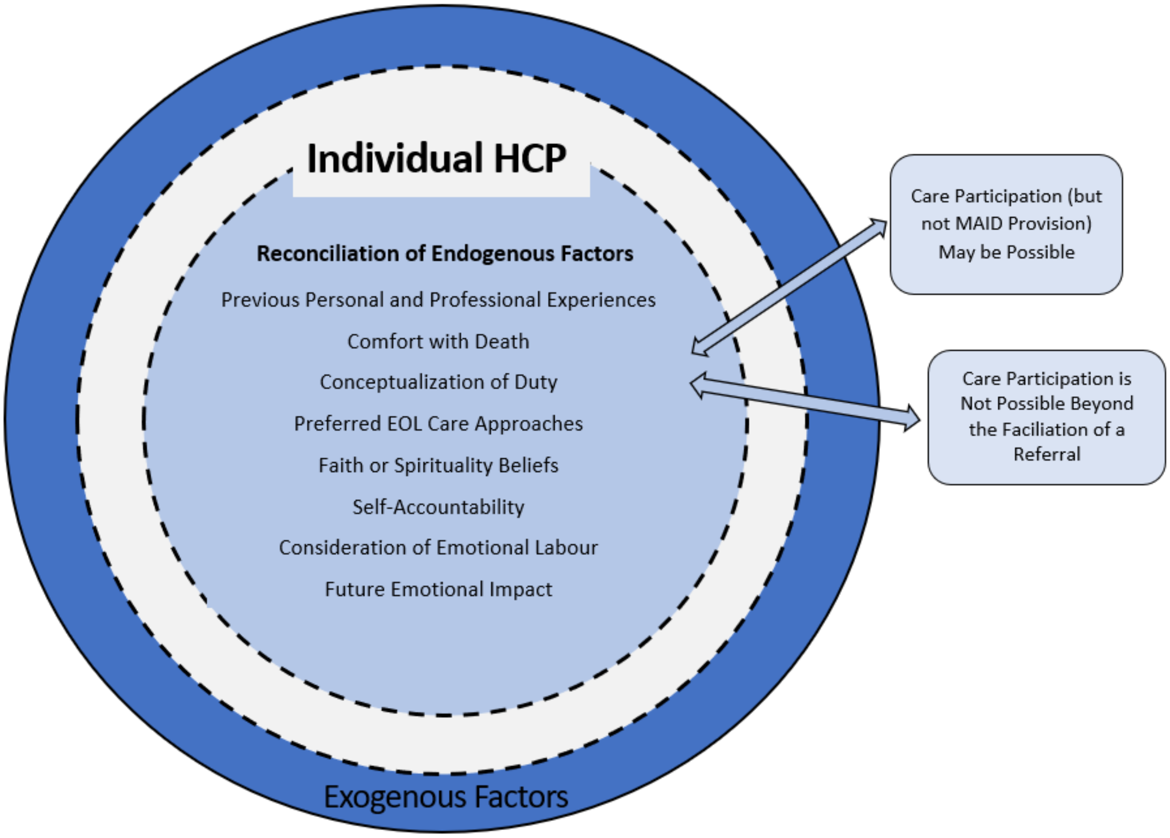

Figure 4.1: Endogenous Factors Influencing Non-Participation in Formal MAID Processes

4.8.2 Integration of Theoretical Frameworks

HCPs consider multiple factors regarding their non-participation in formal MAID processes. These include their (1) previous personal and professional experiences, (2) comfort with death, (3) conceptualization of duty, (4) preferred EOL care approaches, (5) faith or spirituality beliefs, (6) self-accountability, (7) consideration of emotional labour, and (8) future emotional impact. Considering Ruggerio's framework, the factors influenced how HCPs consider and eventually reconciled their obligations and moral ideals relative to the consequences of participation. As HCPs engage with and integrate new personal and professional experiences, their conceptualization of the other factors may shift. Hence, their participation perspectives may also change. This illustrates the dynamic interplay between the endogenous factors influencing HCPs and suggests, for some HCPs', their perspectives on formal participation in MAID processes may evolve.

Moral ideals promote notions of excellence, and for "highly ethical people, the line between obligations and ideals tends to be blurred… [as] people tend to view ideals as obligations that they hold themselves for meeting."[203] The blurring of obligations and ideals may be particularly pertinent for HCPs, given their responsibility to ethical codes, which was confirmed by how HCPs' ethics, EOL care approaches, and professional duty beliefs were intertwined. In the reconciliation of ideals and obligations, some HCPs were most influenced by their ideals, which resulted in HCPs' non-participation in formal MAID processes and a desire to fulfill the social contract obligations through alternative means. Ruggerio's standard of consequences was evident by the depth to which HCPs contemplated their self-accountability, the emotional labour of participation, and identified concerns regarding the future emotional impact of participation. According to Ruggerio individuals will choose actions that have favorable consequences (or avoid negative consequences) while honouring the weighting of their obligations and ideals.[203] In our research project, in alignment with our sampling criteria, these choices resulted in all participants avoiding all participation in formal MAID processes beyond the facilitation of a referral.

4.8.3 Practice Implications

Considering these results, we bring forward system-level recommendations, including opening the discourse, referral pathways attentive to moral space, safe passage grounded in respect, and attention to emotional labour.

4.8.3.1 Opening the discourse. HCPs may not participate in formal MAID processes due to reasons of conscience. Conscience is “an internal moral decision-making process that holds someone accountable to their moral judgment, and for their actions.”[128] However, as Wicclair noted, not all non-participation is conscience-based, and non-participation may derive from self-interest (i.e., concern for individual health and safety) and individual HCP’s consideration of professional integrity (i.e., understanding and application of clinical and professional norms and standards).[125] Thus, in alignment with Wicclair’s description of non-conscience-based refusals, there are non-conscience-based limiters to participation in formal MAID processes within our themed results.

Our regional research findings align with the emerging literature regarding non-participation in MAID in Quebec and international research in non-participation in assisted dying. Canadian research identified conscience-based and non-conscience-based reasons to refuse to perform MAID; conscience-based reasons included “moral” and “religious“ grounds, and non-conscience-based reasons encompassed “emotional reasons,” capacity, and competency reasons.[151] Internationally, HCPs' refusals to participate in assisted dying were based on conscience-based reasons such as “religious opposition,” “personal values and ethics,” and “strong moral convictions” as well as non-conscience based reasons such as considerations of legal and professional risk, patient factors, personal competence, their preference for other care options, emotions, and fear.[164,232] Collectively, we recognize that ethical, religious, or core moral beliefs (conscience-based factors) and non-conscience-based factors both influence HCPs' non-participation in formal MAID processes. Thus, we bring forward the need for two separate yet overlapping concepts; CO to MAID and non-participation in MAID for reasons other than conscience, both impacting the social contract of care.

4.8.3.2 Referral pathways attentive to moral space. HCPs need referral pathways to facilitate MAID access and support the social contract of care. Referral pathways will mitigate the tensions that can occur when one party's expectations in the social contact are ignored or “responded to in a way that is thought to be inappropriate.”[199] Actualizing referral pathways for MAID access is essential yet complex. Accommodating conscience provides a “moral space” that allows HCPs to practice without compromising their moral integrity.[125] Moral distress or the emotions and attitudes that arise in response to being involved in morally undesirable situations occurs when conscience is not accommodated.[155] Moral distress, in turn, can harm HCPs' wellbeing and can impact job retention.[256] Thus, care referral pathways should facilitate timely and unencumbered access to care while being attentive to the moral concerns of HCPs. As some HCPs consider their complicity in and shared responsibility for morally objectionable practices, referrals for MAID care may be challenging. As Trigg explained, "it should not be the responsibility of any professional to help someone on the first steps to something if they are not willing to go with that person the rest of the way."[257] Therefore, a relational and compromising approach would be to have multiple MAID access pathways, including HCP-initiated *and* patient-initiated referrals.

HCP-initiated referrals may be imperfect in all practice areas due to missing or sparse clinical information and variation in referral expectations and processes.[258] Therefore, mechanisms to optimize, expedite, and clarify the referral process, including those for MAID, are essential to support the social contract of care. Patient-initiated referrals are based on assumptions that patients know of their ability to self-refer and have the agency to do so. However, patients at the end-of-life are vulnerable, as they live with their care burdens, have restricted activities, fears, insecurities, loneliness, and the prospect of facing death.[259] Patients may also believe HCP-initiated referrals are required, given the traditional "gatekeeping" and "patient navigating" roles of HCPs.[40] Patient-initiated referrals are also imperfect as they may lack the essential clinical information required by the receiving assessors. Despite these concerns, patient-initiated referrals do provide an additional pathway for patients to access care. Both HCP-initiated and patient-and-family-initiated referrals were options for care continuation at the time of our research, yet many HCPs were unaware of this. Thus, just as crucial as the need to have multiple referral pathways is the need to communicate their availability to patients, patient's families, patient advocates, and all health care team members. Only when all parties within the social contract are aware of the referral pathways and are empowered to use them will the social contract truly be fulfilled.

4.8.3.3 Safe passage grounded in respect. Safe passage is to "go somewhere without being attacked" or a protection "offered to someone in danger or who is traveling through a dangerous place"[260] or creating a caring "environment in which people are assured that it is safe."[261] Within the context of these findings, safe passage, or the ability to work within one's moral space in safe and satisfying work environments, is required by HCPs as they traverse the terrain of non-participation in formal MAID processes. HCPs brought forward the importance of having a safe passage, which is conceptualized as the ability to work within one's moral space in safe and satisfying work environments. HCPs, care teams, and administrators must have authentic, respectful, and open conversations grounded in relational ethical decision-making to support HCPs who do not participate in formal MAID processes. This caliber of discourse (1) allows HCPs to reflect on their practice demands and the laws, rules, and policies that impact their practice, (2) respects the moral agency of those who hold dissenting views, and (3) fosters an examination of the reasons for dissent.[136] Further, health systems must move beyond policy level support for CO to actually "identifying how the facility and staffing logistics are managed concerning MAID, and how, when, and to whom objection will be communicated to ensure the continuation of safe care."[18] There is very little research that has explored how HCPs make their objections known and very little research that has identified the consequences to HCPs when declaring a CO on HCPs,[245] so clarifying and evaluating these processes are especially crucial.

4.8.3.4 Attention to emotional labour. HCPs are considering the emotional labour of formal MAID process participation. Emotional labour in EOL care is often overlooked.[262] Caring for dying persons and their families is a source of emotional distress, and HCPs' grief may be suppressed, prevented through emotional detachment, or may "spillover" into HCPs' private lives.[263] EOL care is complex,[264] is challenged by various communication barriers,[265] and how HCPs view EOL teamwork.[266] MAID assessors and providers identified rewarding elements to care participation and care participation challenges. MAID has been viewed as a calling and as an act of service,[267] and those who participate in MAID noted its significant responsibility, how "meaningful the practice of MAID was to them and their patients," and the gratitude extended by patients and families.[241] On the other hand, care participation stressors were noted, including isolation, lack of support, challenging relationships with objecting colleagues, sacrifices to personal time, working with institutions with a CO, denying patients who did not qualify for MAID, and the grief of family and friends.[241–243] Thus, participants in our project were justified when anticipating emotional labour in formal MAID processes. Additionally, the process of reconciling the availability of MAID relative to their formal participation inherently also involved emotional labour. In agreement with Brighton et al., it is vital to acknowledge EOL care's emotional labour (which includes participation in formal MAID processes) and normalize the need for HCPs' support. We further extend the need to acknowledge and support the emotional labour of reconciliation.

4.8.4 Areas of Future Research

Future research could evaluate if there are variations in the endogenous factors across other subgroups or regions of Canada. As this study occurred approximately three years after MAID legalization, a follow-up study could ascertain if the factors identified as influencing non-participation in MAID change or evolve the longer MAID is legally available. With increased utilization of patient-initiated referrals, research to explore the patient and family perspectives on accessing care through this manner would help understand their contributions to the social contract of care. Future inquiry into HCPs' and patients' perspectives on the reciprocal rights and responsibilities in the MAID social contract of care would provide insight into care provision as this social contract evolves. Lastly, it is highly essential to examine the necessity and efficacy of practice and emotional supports for HCPs who participate in MAID processes and evaluate the long-term impact of participation in formal MAID processes on HCPs' mental and emotional health.

4.8.5 Limitations

Our research team interpreted the participants' experiences and perspectives in our geographic location at a specific point in time; thus, we have provided rich contextual information to assess the findings' transferability. Although we had a deep, rich data set and a significant degree of code redundancy, we acknowledge that additional participant perspectives may be discovered in alignment with our research paradigm and methodology. As several participants had not experienced an actual patient request for MAID, their responses were hypothetical. Lastly, there is little available Canadian research in this area to position our findings, and the referenced international research may not approximate Canadian culture, laws, and health care delivery.

4.9 Conclusion

The factors influencing HCPs' non-participation in formal MAID processes are complex, diverse, and interwoven. In exploring these factors, we identified two separate yet overlapping concepts; CO to MAID and non-participation in MAID. To support the evolution of social contract relative to MAID, HCPs require referral pathways attentive to the moral space and safe passage. Having both HCP-initiated and patient-initiated referral pathways in place may support this; however, the pathways' availability and the process must adequately be communicated to all stakeholders. Further, there must also be recognition and support for the emotional labour of reconciliation and MAID non-participation. Lastly, health systems should support HCPs' CO at the point of care by clearly identifying the mechanisms to disengage from care for HCPs, and openly discuss, with appreciation, the diversity of MAID participation perspectives.

4.10 Bridging Paper 2 to 3

Paper two presented the endogenous factors that influenced HCPs’ non-participation in formal MAID processes of MAID assessments and provisions. Social Contract Theory and Ruggerio’s approach to moral dilemmas and decision-making guided the study's conceptualization, informed the development of the interview guide, and was considered during data interpretation. The Interpretive Description qualitative exploratory approach, using vignettes and multiple data sources and robust presentation among the demographic participants produced an in-depth, rich data set. Through the data interpretation, both endogenous and exogenous factors influencing non-participation were identified.

Endogenously, HCPs’ non-participation was influenced by their (1) previous personal and professional experiences, (2) comfort with death, (3) conceptualization of duty, (4) preferred end-of-life care approaches, (5) faith or spirituality beliefs, (6) self-accountability, (7) consideration of emotional labour, and (8) future emotional impact. Considering Social Contract Theory in the data interpretation and being open to data patterns, we also themed the HCPs’ identified need for clear care pathways and safe passage. In alignment with paper 1, there were both non-conscience-based limiters and conscience-based limiters to participation in formal MAID processes.

For some HCPs, non-participation in formal MAID processes was solely influenced by the endogenous factors, whereas exogenous factors limited non-participation for other HCPs. To meaningfully and responsibly report the results, the endogenous (Paper 2) and exogenous factors (Paper 3) were reported separately. These exogenous factors and decision-making considerations will be outlined in Paper 3.

CHAPTER 5.0: “I’M OKAY WITH IT, BUT I’M NOT GOING TO DO IT”: FACTORS INFLUENCING NON-PARTICIPATION IN MEDICAL ASSISTANCE IN DYING (PAPER THREE)

This chapter was submitted as an article to Qualitative Health Research. It is currently being revised and resubmitted (as of April 30, 2021). This article status is subject to change as the article peer review process unfolds. This methodology and the subsequent paper were noted in the thesis proposal and presents key thesis findings in a rapidly developing and changing healthcare practice area. The findings from this paper and the others that encompass this thesis will be integrated in the discussion chapter.

Author contributions:

Janine Brown: Conceived and designed the study, collected the data, data interpretation, wrote the paper.

Donna Goodridge: Contributed to the conception and design of the study, cross-checked the data interpretation, reviewed and approved the paper.

Lilian Thorpe: Contributed to the conception and design of the study, cross-checked the data interpretation, reviewed and approved the paper.

Alex Crizzle: Contributed to the conception and design of the study, cross-checked the data interpretation, reviewed and approved the paper.

5.1 Abstract

Medical assistance in dying (MAID) processes are complex, shaped by legislated directives, and influenced by the discourse regarding its emergence as an end-of-life care option. Physicians and nurse practitioners (NPs) are essential to MAID to determine the patient’s eligibility and conduct MAID provisions. This research explored the factors influencing physicians' and NPs' non-participation in formal MAID processes. Using an interpretive description methodology, we interviewed 17 physicians and 18 NPs who identified as non-participators in MAID. Numerous factors and decision-making considerations influenced non-participation. The overarching theme of intentional contemplation reflects the purposeful and profound deliberation of the extensive and inter-related factors influencing non-participation in formal MAID processes. Practice considerations to support the evolving social contact of care were identified and included (1) referral options, (2) a clarified regional MAID model of care, (3) practice-focused education, (4) policy clarification, (5) time, and (6) practice enhancements.

5.2 Introduction

Medical assistance in dying (MAID) became legal in Canada in June 2016 with the royal assent of Bill C- 14.[179] Bill C-14 created an exemption in Canada's Criminal Code such that physicians and nurse practitioners (NPs) can provide MAID without the charge of culpable homicide. According to the legislation,[9] MAID is

> (a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death, or (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they self-administer the substance and in doing so cause their own death.

At the time of its legalization, 85% of Canadians supported medical assistance in dying,[21] and 1015 Canadians chose MAID within the first six months of its availability as an end-of-life care option.[22]

The Bill identifies the patient eligibility criteria and the required programming safeguards to balance individual autonomy and protect the vulnerable. For Canadians to be eligible for MAID, they must (1) be mentally competent and at least 18 years and older, (2) qualify for Canadian health services, (3) provide informed consent, (4) have an irremediable and grievous medical condition, and (5) request MAID voluntarily and without outside influence. Within the Bill, an irremediable and grievous condition requires that (1) the disease, disability, or illness is serious and incurable, (2) the individual is in an advanced state of irreversible decline in capability, (3) the disease, disability, or illness causes intolerable and enduring physical or psychological suffering that cannot be relieved through means they find acceptable, and (4) considering all the medical circumstances, the individual’s natural death is reasonably foreseeable. The legislation also called for a parliamentary review on the state of palliative care (PC) in Canada. This culminated in the 2018 Framework for PC in Canada.[268]

The Bill also outlined the mandated MAID program safeguards. Participating physicians and NPs must confirm that (1) the MAID request was in writing, signed, and dated by the patient in the presence of two independent witnesses, (2) the MAID request was signed and dated after a medical or nurse practitioner informed the person of an irremediable and grievous medical condition, (3) two independent assessors agreed that the patient met the eligibility criteria, (4) the patient knew their request could be withdrawn at any time, (5) ten days elapsed between the written request and the provision (unless both assessors agreed that the person’s death or the loss of their capacity to provide informed consent was imminent), (6) consent was confirmed immediately before provision, and (7) all measures were undertaken to ensure the patient understood the information and the patient was able to communicate their decision.

Bill C-14 noted that everyone has the freedom of conscience and religion under the Canadian Charter of Rights and Freedoms and highlighted that nothing in the legislation affected that guarantee. As such, conscientious objection (CO) is embedded in provincial professional regulatory association statements.[65,66,269] Healthcare institutions associated with religious groups have some policy autonomy. As such, some theorize that CO could extend to healthcare institutions.[142] However, within the Canadian publicly funded healthcare system, this has been increasingly challenged.[270] Bill C-14 does not directly state that MAID must be available in all healthcare facilities; however, it was recommended that healthcare facilities allow MAID assessments or provisions or facilitate patients' safe transfer to an alternative healthcare facility.[10]

Bill C-14 and the amendment of the Criminal Code of Canada was a change in federal law. However, Canadian provinces and territories are responsible for health care delivery, and as such, provincial/territorial and regional healthcare MAID program delivery varies across Canada.[46,78] Although interdisciplinary teams may support MAID programs,[77]Bill C-14 specifies that only nurse practitioners (NPs) and physicians can participate in the formal MAID processes of determining patient eligibility and providing MAID. Although legal for less than five years, MAID has changed end-of-life (EOL) options for patients, families, and health care providers (HCPs). In response, health care systems are developing accessible, high-quality MAID programs that are patient-and-family centered and sustainable.

Palliative care (PC) is a holistic care approach that (1) seeks to improve the quality of life for patients and families with life-threatening illnesses, (2) intends to “neither to hasten or postpone death,” and (3) should be “integrated with and complement prevention, early diagnosis, and treatment” of health challenges.[37] Sercu et al. identified a framework of four PC phases, which included the advanced illness phase, the end-of-life phase, the terminal phase, and the dying phase,[271] and Funk et al. noted PC providers often “struggled to find the time and space to deal with grief and [are] faced normative constraints on grief expressions at work.”[263] In Canada, the term “hospice palliative care” recognizes PC and hospice care convergence as they share principles and practice norms.[272]

MAID and PC philosophically diverge as MAID actively hastens death. Despite this philosophical divergence, Wales et al. reported successful integration of MAID into home-based PC, and Dierickx et al. found that assisted dying and PC were not “contradictory practices.”[82,273] However, the co-existence of MAID and PC within EOL care in Canada is viewed differently among the CHPCA, the Canadian Society of Palliative Care Physicians (CSPCP), and the Canadian Association of MAID Assessors and Providers (CAMAP). The CHPCA and CSPCP believe that MAID is not part of hospice PC practice as they are fundamentally different,[31] whereas CAMAP encourages the integration of PC and MAID.[58] Understanding these differences in the fundamental beliefs related to EOL care is essential because HCPs’ response to MAID inquiries is influenced by their conceptualization of MAID relative to other EOL care options.[274]

Numerous factors influence HCPs' participation in the full spectrum of legally available care. HCPs work within their religious or spiritual beliefs, the laws and policies that regulate their practice, and their professional codes of ethics. HCPs additionally work within their moral convictions, which are defined as “attitudes that people perceive as grounded in a fundamental distinction between right and wrong.”[178] HCPs also work within what Curry et al. proposed are universal moral rules, including helping your family and group, returning favors, being brave, deferring to superiors, fairly dividing resources, and respecting property.[216] Harmonizing these considerations may result in HCPs choosing not to participate in the care requested by the patient or legally available. Specific to MAID, HCP non-participation in formal MAID processes directly impacts a patient’s MAID access as NPs and physicians are the only professional groups that can conduct eligibility assessments and provide MAID. In the province of Saskatchewan, thirty-five NPs and physicians have participated in the formal MAID processes of assessment and provision, with approximately half participating in fewer than five occurrences (M. Fisher, personal communication, February 27, 2020). Since legalization, there have been 250 MAID provisions in Saskatchewan.[22]

MAID is a complex care area[110] influenced by legislated imperatives and discourse regarding its emergence as an EOL care option. Additionally, many factors influence HCPs’ professional practice, resulting in HCPs’ non-participation in the full range of care available or requested by the patient. Specific to MAID, previous research has examined the experiences of HCPs who participate in formal MAID processes, yet there is limited data on what influences

HCP's non-participation in the formal process of MAID. This research was guided by the question: What factors influenced physicians and NPs when deciding to not participate in the formal MAID processes of determining a patient's eligibility for MAID and providing MAID? Identifying the factors that influence HCPs' non-participation will foster a better understanding of the professional supports for HCPs and potential policy and practice gaps, which will therefore support patients' care access.

5.3 Background

The preamble of Bill C-14 upholds section 2 of the Canadian Charter of Rights and Freedoms,[179] which guarantees freedom of conscience and religion. Freedom of religion is defined by the Supreme Court of Canada as:

> The right to entertain such religious beliefs as a person chooses, the right to declare religious beliefs openly and without fear of hindrance or reprisal, and the right to manifest religious belief by worship and practice or by teaching and dissemination.[117]

Medicine, religion, and spirituality share an extended narrative, including priests' historical role as healers, hospitals founded by religious organizations, and the values of compassionate service.[275] Practicing in alignment with religious or spiritual views is an essential component of moral integrity.[125] A review of Christianity, Islam, Buddhism, Hinduism, and Judaism beliefs relative to EOL practices (including assisted dying) found significant deficits in the available knowledge base, identified dramatic variations in subpopulations studied and noted the influence of national cultural practices and laws on religious perspectives and practices.[122]

While freedom of religion has been given "extensive legal attention," freedom of conscience is often forgotten.[123] The values that shape conscience (i.e., fair or unfair, just or unjust) are influenced by an individual's cultural, economic, and political environments.[276] Conscience is "an internal moral decision-making process that holds someone accountable to their moral judgment and for their actions,"[128] and freedom of conscience allows individuals to "manifest their moral commitments."[123] According to Wicclair, moral integrity has intrinsic value as it is an essential component of a meaningful life, and a loss of moral integrity can result in a loss of self-respect, feelings of shame, remorse, or guilt, and a decline in moral character.[125] As such, both freedoms of conscience and religion are critical to HCPs and health care delivery.

Professional associations and regulatory bodies include CO or respect for freedom of conscience statements in their MAID practice policies and frameworks.[44,45] However, Wicclair explained that not all refusals to participate are grounded in HCPs' core moral beliefs or conscience and that reasons for refusing can include self-interest and professional integrity. Specifically, HCPs' non-participation in ethically complex legally available care was influenced by HCP's characteristics, personal beliefs, professional ethos, as well as emotional labour, system, and clinical practice considerations.[277] It is crucial to fully explore the underlying factors contributing to conscience claims so that conscience claims are not used to avoid care that is prejudicial, time-consuming, emotional, or discriminatory.[140,150] Focusing on MAID specifically, the emotional burden of care participation, the concern regarding psychological repercussions, as well as moral and religious grounds, were the most often expressed reasons that physicians conscientiously objected.[151] Although some non-participation in MAID stems from conscience and religious beliefs, other non-conscience-based factors influence HCPs' non-participation in formal MAID processes.

This research was conducted in the province of Saskatchewan, Canada, where 38% of the approximate 1,170,000 population was located in rural and remote areas.[95] Data was collected in Saskatchewan approximately three years after MAID legalization, during the summer and early fall of 2019. At this juncture, health care delivery was the responsibility of a single, publicly-funded health authority. The provincial MAID program, which came into effect in November 2018.[94] had salaried employees and an NP in each of the two largest cities. These NPs and other NPs and physicians on a case-by-case basis, conducted MAID eligibility assessments and MAID provisions. Access to MAID was generally through a referral to the provincial MAID program housed within the provincial Healthline. Referrals could also come directly to MAID assessors from patients, family members, or other HCPs. A physician referral was not required.

5.4 Theoretical Frameworks

We considered HCP's non-participation in MAID processes within the context of Social Contract Theory and Ruggiero Model of moral decision making.[203] Health professions use social contracts to establish their identity and relationships with society.[200] Social contracts are fluid and shift with changing professional standards, laws, patients' needs, and advancing patient expectations as society diversifies.[199] With the royal assent of Bill C-14, HCPs and patients are integrating MAID into the social contract of care.

Ruggiero stated that individuals consider their obligations, moral ideals, and consequences when making decisions.[203] He identified that individuals' actions create positive consequences when aligned with the individual's obligations and ideals. Obligations are affected by relationships (including friendship, colleagueship, or business relationships) and formal and professional responsibilities. Moral ideals are the ethical values and religious values that assist in achieving respect for persons. Consequences encompass the actual, possible, or probable, beneficial, or harmful outcomes. These consequences could be physical or emotional, immediately apparent or apparent over time, intended or unintended, or readily apparent, subtle, complex, or specific.

5.5 Methodology

The methodology and methods are outlined previously.[278] This research was grounded in a constructivist/interpretivist paradigm, and we acknowledge that our interpretations are specific to our research team, setting, time, and the participants. We acknowledge there are socially constructed, sometimes conflicting realities[196] and that these realities may change as individuals change.[195] We used interpretive description,[169] which addresses the research objective by capturing and interpreting the participants' perceptions, seeking patterns, and generating themes to create applied knowledge that informs clinical care.

The first author led the research with the support of the co-authors and a doctoral committee. JB is a registered nurse, a nurse educator, and a doctoral candidate with an emerging end-of-life and MAID program of research. DG is a registered nurse, and LT is a physician, and both are professors in the College of Medicine. AC is an associate professor and gerontologist in the School of Public Health. We frequently met during the research process to discuss underlying and emerging views and perceptions that supported the team's reflexive processes.

5.6 Methods

5.6.1 Sampling Strategy

Provincially licensed physicians and NPs who self-identified as (1) being uncertain of their response to a patient request for MAID assessment or provision, (2) being reluctant to engage in MAID related processes, or (3) declining participation in any aspect of MAID were invited to participate in this research. We excluded HCPs who practice exclusively with patients under the age of 18. We initially planned to interview 40 participants representing variation in geographic location, profession, practice patterns, and participant demographics. We employed multiple strategies for participant recruitment. We asked the physician and NP regulatory bodies and professional associations, the medicine and nursing university faculties, the division of northern medical care, the provincial health authority, and the cancer agency to distribute ethics-approved invitation letters, posters and, social media scripts. Additionally, consenting individuals and doctoral committee members were asked to forward the research information through their networks. Potential participants contacted JB (the interviewer) via email. JB confirmed the participant's eligibility and sent the potential participants the information and consent form. If the participants chose to proceed, a mutually agreeable time and interview modality were determined. JB obtained verbal consent during the interview and confirmed consent on a written consent form. Participants confirmed consent on the online contextual information questionnaire.

5.6.2 Data Production

This research included participant contextual data, participant interview data, and the field notes and reflective content produced by JB. Contextual data were collected via an online questionnaire, which was completed before or during the interview. This data was collected to gauge the sample's representation during data production and frame the participants' personal and practice contexts within the data. Interview data were collected using a theoretically informed semi-structured interview guide and vignettes. The use of vignettes was essential to our data production, as we were aware that not all participants might have had experience in MAID or patient MAID inquiries. The vignettes encompassed multiple aspects of MAID and were developed through the team's clinical and practice experiences (Appendix I) and reviewed by two NPs and two physicians to support validity before use. We read the vignettes to the participant, allowed the participant to respond, and followed-up with exploratory or clarifying questions as required. After four interviews, we reviewed the data to ensure the exposition of the research's objective. No vignette adjustments were made. After each interview, JB produced field notes, with notations on the data production event itself, and reflections on emerging perspectives, striking and illuminating content, and emerging questions to bring forward to the next interview. This supported researcher reflexivity and informed future interviews, data interpretation, and interpretation.

5.6.3 Ethics and Operational Approval

We received research ethics (REB#902) and provincial health authority operational approval (OA-UofS-902) for this research. We made it clear that the doctoral committee would access the data within the ethics approval, and we identified procedures for sharing the aggregate data with the participants. We indicated that the research team members might have pre-existing relationships with potential participants, but we would not exclude them, as our healthcare community is relatively small, and these relationships are professional. Lastly, we provided the participants with information on how to access HCPs' support programs to recognize the potentially sensitive nature of the topic.

5.6.4 Data Interpretation

We used NVivo12 to organize the transcripts, contextual data, field notes, and reflective content. JB, with the support of the co-authors, concurrently collected and analyzed the data. Using a process of inductive coding as outlined by Boeiji, coding was conducted within a single interview, followed by code comparison between interviews and, lastly, across the entire data set.[279] JB developed the initial patterns of meaning and shared them with the participants with an invitation to provide any additional information, insights, comments, or reflections. Subsequently, these initial patterns underwent combining, refining, and eventual interpretation and theming.[186] Documents outlining the resultant themes, definitions, and supporting participant quotations were cross-checked by the co-authors and presented to the doctoral committee as part of an expert panel analysis check.[169]

5.6.5 Quality and Credibility

Research quality and credibility were given high priority throughout the research. We aligned our methods with our methodology and accounted for our positionality and reflexivity. We included multiple sources of data, vetted and trialed the vignettes, and used a single transcriptionist and primary coder. DG and LT cross-checked the codes, and a codebook was utilized to account for the results. Lastly, the results were shared with the participants, and feedback was obtained from an expert panel review.

5.7 Results

We determined that we had adequate data to fulfill our research objective and found a broad representation of contextual data after 35 interviews (Table 5.1).

Contextual Data	Would Not Participate Beyond a Referral n = 14 (40%*)	Participants Who Would Provide More than a Referral, but not Formally Administer MAID n = 21 (60%*)
Nurse Practitioner	6 (43%)	12 (57%)
Physician	8 (57%)	9 (43%)
Female	9 (64%)	14 (67%)
Male	5 (36%)	7 (33%)
Single/Never Married	1 (7%)	-
Married/Domestic Partnership	13 (93%)	17 (81%)
Divorced	-	4 (19%)
Age (years):		
• 25-34	3 (21%)	2 (10%)
• 35-44	4 (29%)	5 (24%)
• 45-54	2 (14%)	8 (38%)
• 55 and older	5 (36%)	6 (29%)
Years in Practice:		
• 1-9	6 (43%)	6 (29%)
• 10-19	3 (21%)	8 (38%)
• 20-29	4 (29%)	4 (19%)
• 30-39	1 (7%)	3 (14%)
Significance of faith, religions, spirituality:		
• Extremely Significant	7 (50%)	-
• Very Significant	3 (21%)	5 (24%)
• Significant	2 (14%)	2 (10%)
• Neutral	2 (14%)	11 (52%)
• Not Significant	-	3 (14%)
Belief system:		
• Protestant	4 (29%)	3 (14%)
• Non-denominational Christianity	3 (21%)	3 (14%)
• Agnostic/Atheist	-	4 (19%)
• Islam	1 (7%)	-
• Roman Catholic	5 (36%)	8 (38%)
• Did not disclose/Other	1 (7%)	3 (14%)
Location of Practice:**		
• Large Population Centre	5 (36%)	11 (52%)
• Medium Population Centre	1 (7%)	2 (10%)
• Small Population Centre	3 (21%)	6 (29%)
• Rural area	5 (36%)	2 (10%)
Primary Work Area:		
• Family Medicine/Primary Care	8 (57%)	13 (62%)
• Specialty Practice Areas***	6 (43%)	8 (38%)
Patients with Life-Limiting Illness (%):		
• 0-19%	8 (57%)	15 (71%)
• 20-39%	4 (29%)	4 (19%)
	2 (14%)	2 (10%)

• 40% or more		
Responses in the interview were informed by: • An actual patient request • A hypothetical request	4 (29%) 10 (71%)	5 (24%) 16 (76%)

* May equate 100% due to rounding.
** The Statistics Canada definitions were provided to the participants to support selection.
*** Including, but not limited to, emergency medicine, internal medicine, anesthesiology, surgery, critical care, psychiatry, and physical and rehabilitation medicine.

Table 5.1 Contextual Data of Participants (N=35)

In response to the vignettes, all HCPs stated they would refer the patient for continued care or direct the patient to speak with an alternative HCP. Fourteen HCPs anticipated this as their participation threshold, whereas the remaining HCPs anticipated alternative degrees of participation in the clinical care vignette. None of the HCPs stated that they would participate in the provision of MAID.

5.7.1 Factors Influencing Non-Participation

A spectrum of factors influenced HCPs' non-participation in formal MAID processes. While recognizing that decision-making is generally thought to be an intrinsic process, through the data interpretation, we identified some of the factors influencing non-participation originated external to the HCP. These were conceptualized as exogenous factors. The factors that influenced non-participation originating from within the HCP (conceptualized as the endogenous factors) were previously reported. These included their (1) previous personal and professional experiences, (2) level of comfort with death, (3) faith or spiritual beliefs, (4) preferred end-of-life care approaches, (5) self-accountability, (6) the consideration of emotional labour, (7) concern regarding the future emotional impact and (8) conceptualization of professional duty.[278]

5.7.2 Exogenous Factors and Decision-Making Considerations

Eight exogenous factors influenced HCPs' non-participation in formal MAID processes. These non-participation factors were identified as consistent themes across the demographic data and were related to (1) the healthcare *system* they work within, (2) the *communities* where they live, (3) their current *practice* context, (4) how their participation choices were *visible* to others, (5) the *risks* of participation to themselves and others, (6) *time* factors, (7) the impact of participation on the *patient's family*, and (8) *patient* relationship, and contextual factors. HCPs identified multiple decision-making considerations within each factor. Some of the decision-making considerations were nuanced to specific demographics, including the HCP's practice location and the HCP's professional group (Figure 5.1).

5.7.2.1 The healthcare system they work within. Some HCPs' identified their non-participation in formal MAID processes was influenced by their concern regarding gaps in EOL and chronic care. These HCPs explained that before they could consider participation in formal MAID processes, these system gaps required remediation. Specifically, these HCPs raised concerns about the limited access to palliative and chronic care support in outpatient, inpatient, and respite settings. Other HCPs identified that their non-participation was influenced by the "newness" of MAID and the associated evolving and uncertain practice landscape.

- **Concerns about lack of EOL resources:** *"I never want to suggest that conversations [about MAID] should never be on the table, so I am reluctant to make that argument. At the very least, could we be doing an impeccable job of chronic care support and disease management and palliative care first? Doing all of those things impeccably well, for every Canadian, and then if we still need it, well, maybe we could talk."*
- **Unknown and evolving practice landscape:** *"I just do not know if I could be the one to push the plunger [as a provider of MAID]...I know other countries have done it for years and, but Canada, we are kind of new to it."*

Simple referral processes and personal connections with existing MAID assessors and providers were considered "easy" referrals that facilitated HCPs' disengagement from participation. Some HCPs were frustrated that their non-participation was determined by institutional conscientious objection (CO), which occurred when MAID participation was prohibited by institutional policy directives. Other HCPs identified institutional CO meant they did not need to discuss their motivations or belief systems with others and could avoid participation.

- **Ease of referral:** *"So, it is easy for me to say to patients, 'We have to refer you [for formal MAID processes] through the centralized process to the next regional center.' It is easy for me to say that. So, it gives me a bit of an out."*
- **Institutional conscientious objection (CO):** *"It is kind of nice to hide behind the [employer's policy] and just be like, nope, I do not participate without having to explain my own emotions and thoughts. It is just very black and white. You cannot [participate] due to the policy.*

Practice limits influenced some NPs' non-participation in formal MAID processes. These practice limits impacted NPs ability to practice to their full-scope and included (1) absence of billing codes for remuneration, (2) agency job descriptions that limited care duties or excluded MAID participation, (3) an inability to roster patients in their practice resulting in episodic or singular care encounters, and (4) lack of admitting privileges resulting in patients with life-limiting illnesses transferring to physicians. Some NPs' non-participation was also influenced by their frustration regarding the culture of their practice. Specifically, some NPs described frustration at being overlooked during the early stages of MAID delivery as assessors and providers, expressed frustration that their participation only appeared to be considered when the availability of physicians was scarce, and articulated frustration by a perceived lack of respect as HCPs from colleagues and health system administrators.

- **Specific to NPs - practice limits:** *"The clinic I am working at does not allow me to roster my patients. And, nurse practitioners cannot admit to hospital, [and] they do not know how to pay you to do this, [and] there are hours of work limitations, and, we report to a manager, who is not a nurse practitioner and does not know what a nurse practitioner does. It is problematic, right?"*
- **Specific to NPs - professional respect and practice culture:** *"You know, the natural inclination is physicians should do this, physicians should do that, but the minute there is something that physicians do not want to do, let's just put nurse practitioners in there."*

5.7.2.2 The community where they live. Some HCPs stated that their non-participation in formal MAID processes was influenced by their perception of the community's conscience and used community cues to gauge participation's appropriateness. These community cues included (1) a lack of openness in other EOL conversations (i.e., "we don't even talk about DNRs here!"), (2) a lack of sexual health programs and services, which resulted in HCPs' hesitation to bring forward ethically complex conversations, (3) the communities' perceived dominant religious beliefs, (4) the historical relationship of HCPs and the community, and (5) the community's history with suicide and suicide prevention initiatives resulting in sensitivity or potential mixed messages in MAID conversations.

Some HCPs' non-participation was also influenced by the potentially adverse impact of competing demands. Specifically, participating in one individual's care (i.e., participating in formal MAID processes) relative to the greater community's care needs. These HCPs were ethically concerned about the prospect of declining, decreasing, or canceling service in an already limited setting, which they identified would be required to facilitate participation in formal MAID processes. Lastly, some HCPs’ non-participation in formal MAID processes was influenced by the adverse experiences of others in their professional or home community related to MAID participation.

- **Community conscience:** *"In our community, I do not think [MAID] would fit. It is a very strong Roman Catholic community. The community's religious beliefs, does it play a big role in the decisions I make? I think it does."*
- **Balancing of needs:** *"NPs work in small centers that get service two days a week. So, to take a half a day out of what is already limited service is very difficult and somewhat angst producing for the NPs who feel ethically and morally responsible for the lack of services in those areas.”*
- **Hearing from others:** *"I have sort of talked about it with one of the NPs that has [participated in formal MAID processes], and it has not done her any favours. She has struggled, and it is not something you can take back."*

Some HCPs identified their non-participation in MAID processes as influenced by the complexities of working within culturally diverse contexts. These HCPs were hesitant to participate in formal MAID processes as they were unsure *if* or *how* the community’s culture influenced the perception of MAID and if participation in MAID would alter the community’s trust in them. Some HCPs noted that using interpreters significantly complicated EOL conversations and discussed the anticipated exponential difficulties of using interpreters in formal MAID processes. These HCPs related situations when interpreters refused to translate or the interpreters filtered the HCPs' discussions. Additionally, they expressed concern regarding patient confidentiality, as translators were often family members or extended family members. In rural and remote areas, HCPs anticipated that if they did not support, facilitate, or participate in formal MAID processes, there would be “undue burdens” on patients and families, who would need to travel to another center and would experience increased costs. These HCPs also expressed concern that these considerations would add extra pressure to participate, which they factored into their participation perspectives.

- **Culture:** *"Within the [Indigenous] population that I work with, I want to make sure that I am not overstepping my boundaries of trust by being [involved with MAID], or that it would be seen as disrespectful. I do not ever want it to cause distress to the patient."*
- **Culture:** *"I am a big fan of discussing end-of-life care, but culturally, there is some pushback to that. The homecare department has even said, "Oh no, no, we are not going to have that conversation with the [elderly clients] it is culturally inappropriate." It is to the point where it is the home care staff or the family that says, "No, we are not going to let you talk to them about that." And sometimes, it becomes tough because they are the*

translators for us, and if I try to bring in a third-party translator, everybody here knows everybody, and so they will also just say, "No, no, no, don't, she won't like that conversation, don't do it."

- **Specific to rural/remote areas – location:** *"That would probably be the only, I mean, that would be one of the reasons I would consider participating [in MAID] is because I am the only healthcare provider in that small town. For them [the patient and family] to leave that small town and leave their support to have that done would seem unnecessarily cruel."*

5.7.2.3 Their current practice context. Some HCPs' non-participation in formal MAID processes was influenced by their lack of program and policy knowledge and their uncertainty about the optimal regional MAID model of care. Many HCPs questioned whether MAID was a component of family practice, an extension of existing EOL care programming, or a specialty practice area. The ambiguity of not knowing *if or how* MAID fit within their practice influenced their prioritization of MAID continuing education and their overall participation perspectives.

- **Program and policy uncertainties:** *"How do you pronounce death? What do you put on the certificate?" Like, those are huge issues. Regardless of what we think about MAID, you know, there are very real practical issues that you have to resolve regardless of your personal feelings [before considering participation]."*
- **Program and policy uncertainties:** *"I think we need a clear, local policy in our hospitals and with our pharmacies with how we are going to access medications. And, I feel like we do not really have that in place just yet."*
- **Model of care ambiguity:** *"I just do not know where putting that kind of specialized care and knowledge would go. I would rather hand that off to somebody that does do that more regularly."*

Some HCPs' non-participation in formal MAID processes was influenced by their self-assessed lack of skills, abilities, and competencies to safely participate in MAID processes. These HCPs expressed uncertainty about (1) how to apply the eligibility criteria to their patients, (2) the medication protocols, (3) navigating sensitive or challenging conversations, (4) understanding what competency in MAID encompassed, and (5) maintaining competency if infrequently participating. Other HCPs' non-participation was influenced by their clinical interests, their perceived practice strengths, as well as their belief it was unlikely that patients would approach them in MAID discussions. Some physicians' non-participation in the formal MAID process was influenced by their practice constraints, specifically the financial feasibility of participation in formal process relative to their operational overhead costs and the cost of malpractice insurance.

- **Competency:** *"I have very, very little knowledge or understanding whatsoever about any of the legislation around it. I would probably put mine on par with the general public."*
- **Lack of need and interest:** *"You know, I do not like doing stuff like that [presence and emotional support]. That is one of the reasons I do not deliver babies anymore. It is because just hanging out there for seven hours does not interest me."*
- **Specific to physicians – practice realities:** *"I know a few colleagues of mine said financially they cannot offer [MAID]. You can be out doing [MAID] for four hours, make $100, lose a half a day in clinic, and pay six, seven grand in overhead clinic costs. You are not making your ends meet doing that. Family practice right now is stretched financially."*

5.7.2.4 How participation was visible to others. How colleagues and clinic staff would view their participation or non-participation in formal MAID processes influenced HCPs. Some HCPs feared collegial disapproval if they did not participate, and some feared their non-participation would be viewed as shirking their professional duties or viewed as acting counter to patient autonomy. Other HCPs believed that if they participated in formal MAID processes, they would lose the clinic staff's respect or were concerned about how colleagues of the same faith would view them. Additionally, some HCPs expressed “surprise” when colleagues participated in MAID and that this changed their perceptions of their colleagues. They wondered how their colleagues could participate and discussed how they viewed their colleagues' practice approaches differently.

- **Colleagues:** *“I have also talked to physicians who get angry at the talk about conscientious objection. They feel that, you know, physicians are, not doing their job, that they are shirking their responsibility.”*
- **Colleagues:** *“My perceptions of my colleagues have changed a little bit because some of them are quite for [MAID]. One of them is quite interested in participating in it, which kind of took me by surprise. So, I kind of view their approach a little bit differently.”*

As patients and families are not obligated to maintain HCPs' privacy regarding their participation, HCPs considered how participating in formal MAID processes could influence how public members viewed them. Specifically, some HCPs were concerned that being known as participating would harm the relationship with patients and families who object to MAID, or that participation would be interpreted as “giving up” on patients, or that participation would complicate mental health and suicide prevention conversations. Lastly, some HCPs’ were concerned that the greater community or their faith community would view their participation unfavorably, which would impact the relationships with others therein.

- **Patients and families:** *"When you practice in a town of 1000 people, word [of my participation] would get around. I might not have a conscientious objection, but some of my patients might. I worry about how patients would feel about their practitioner being involved in this process."*
- **Patients and families:** *"I just could see some people who might have suicidal ideations saying to us, 'You are a hypocrite. How can you try to tell me [suicide] is wrong or that I should not do this when you are doing it? You did it to my granny.'"*
- **Greater community:** *"To put ourselves in that situation where we could potentially be seen as literally killing someone, I think would be very detrimental. Those perceptions in the community would be the biggest concern for me, the perception that the nurses are killing people."*
- **Greater community:** *"I would want to be confident in that decision [to participate in MAID processes]. There is always the consideration of how am I impacting other people's faith beliefs, and would our relationship be negatively impacted? Would it be worth it?"*

5.7.2.5 The risk of participation to themselves and others. HCPs' discussed how legal and professional risk and risk to themselves and their families influenced their non-participation. Specifically, some HCPs were concerned about the risk of litigation or professional discipline if family members or other HCPs disagreed with the patient's choice or the HCPs' eligibility assessments. Additionally, HCPs' considered the risk of personal physical harm or violence from extended family members or that their professional lives could be made "difficult" by colleagues. Lastly, some HCPs' identified their non-participation was influenced by a concern for their family's safety.

- **Legal and professional risk:** *"I think of the legality too. Like, if there was a family member completely against [MAID], will they come after you? You are always going to not please somebody. But in something like a death, you cannot go back and change it. So it is really high stakes."*
- **HCP risk:** *"If you piss off the wrong people, they can make life a little difficult. If you have a manager or a co-worker who is very respectful of your beliefs, you have no problem at all, but those are few and far between."*
- **HCP risk:** *"You know, when I have had to discuss death with a whole bunch of family members, I have seen people's responses go from very calm to very violent within a split second of me saying they died. It has never been towards me, but if I am the one who is pushing the injection, then it might be towards me."*

- **Risk to HCP's family:** *"I am more worried about my family then myself. We have already had some backlash in the community where lawyers were involved, and I am not willing to go that extra [step into MAID]. I had to take my kids out of town, and maybe this is worse case catastrophizing, but it happened. We have some very religious people, and we have people with lots of guns, and I would not take that risk with my kids."*

5.7.2.6 Time factors. HCPs' non-participation in formal MAID processes was influenced by time. Some explained that competing demands in time-limited appointments resulted in insufficient time for EOL conversations and participation in formal MAID processes. Further, HCPs identified that participation in formal MAID processes could not be rushed and should not be rushed, and the lack of time to participate in quality care limited their participation. Some HCPs' explained that their non-participation in MAID was relative to the time of their career. Some identified as not wanting to take on new "challenges" at the end of their careers, whereas others stated they would re-evaluate their future participation. Lastly, some HCPs' noted that time constraints also prohibited pursuing continuing education in MAID.

- **Competing demands/time to do well:** *"It is not that I would not have an interest in doing it, I just do not have time to do it. If I cannot do it well, I do not want to take it on."*
- **Point in career:** *"The only thing is my age and being close to retirement. I am 59 and might be pulling this [retirement] plug at the end of the year. So, to me, that is why I thought, well, I am not going to bother."*

5.7.2.7 The impact of participation on the patient's family. Numerous patient's family factors influenced HCPs' non-participation in formal MAID processes. Some HCPs explained they provided primary care to multiple other family members and were concerned that their participation would impact these relationships. For other HCPs', inter-family conflict and a lack of supports for family members before, during, and after MAID provision influenced their non-participation. Lastly, some HCPs were concerned that their MAID participation would have a lasting impact on internal family relationships and dynamics.

- **Family-HCP considerations:** *"I would prefer not to be seen as the one delivering the medication. Because then I think it kind of blurs the boundaries. You know, I am administering the medication, and then, on the other hand, I am going to be the person to console the family and, you know, be there for them after I have administered the lethal dose."*
- **Inter-family considerations:** *"I have had other patients that have brought the issue forward when they have had family members go through with the MAID process. They*

discussed the change in family dynamics because of the decision one family member made [to have or support another family member in MAID].”

5.7.2.8 Patient relationships and contexts. HCPs’ non-participation in formal MAID processes was influenced by the patient relationship. For some HCPs, a long-standing relationship with the patient would render participation “uncomfortable” and unlikely. Others identified that a long-standing relationship would facilitate open conversations regarding the reasons for the HCP’s need to disengage from formal MAID processes. Conversely, other HCPs identified that a sustained, deep relationship with the patient or family positively influenced their participation perspectives. Lastly, HCPs expressed a need to have a comprehensive understanding of the patient-family journey, including the clinical history and decision-making processes culminated in their MAID choice. These factors were considered important to the HCP’s perspectives on their participation.

- **Relationships:** *“That is what I would feel would be my biggest struggle, how well did I know this [patient]? How close was I to this person? How long had I been seeing this person as their primary care provider? I am not saying that would necessarily dissuade me; that may even push me more towards it, depending on what our relationship is, you know?”*
- **Understanding the why:** *It is like no different than if I am asking them why they are not taking their diabetes medications. I want to know, “okay, so I noticed that you are choosing not to take all of these medications. What is going on? Can you help me understand?” In the [MAID] regard, it would be, “Yes, I am happy that you brought up the topic, and I am happy to put you in contact with people who can provide you with this information. But I also want to clarify, you know, your thoughts behind that choice as opposed to other choices for end-of-life.”*

Figure 5.1 Exogenous Factors Influencing Non-Participation in Formal MAID Processes

5.8 Discussion

Our findings identified the exogenous factors that influence HCPs' non-participation in formal MAID processes were related to (1) the healthcare *system* they work within, (2) the *communities* where they live, (3) their current *practice* context, (4) how their participation choices were *visible* to others, (5) the *risks* of participation to themselves and others, (6) *time* factors, (7) the impact of participation on the *patient's family*, and (8) *patient* relationship, and contextual factors.

5.8.1 Intentional Contemplation

Intentional contemplation was identified as the process of considering the multiple, complex, and often inter-related exogenous factors that influenced HCP's non-participation in formal MAID processes. Intentional contemplation reflects the profound and purposeful HCP deliberation of how their current professional practice does not integrate with participation in formal MAID processes.

MAID has shifted the social contract of EOL care, and these factors and decision-making considerations are under intentional contemplation by HCPs. For the participants in our research, this culminated in non-participation in formal MAID processes. However, all participants would facilitate the social contract of care by referring to the MAID program (if they knew the MAID program referral pathway) or an alternative HCP (if they did not know the pathway). In this sense, the social contract of care is fulfilled. However, not all HCPs in our research study could identify the referral pathways. As such, referral pathways must be adequately communicated to all health care team members, patients, and families, *and* be attentive to HCPs' moral space to truly facilitate the social contract of care.[278]

Ruggerio explained that individuals choose actions that support their obligations, support their ideals, and have favorable consequences.[203] HCPs in this research study intentionally contemplated their professional ***obligations*** relative to (1) on-going care duties to the patient's family, (2) institutional CO, (3) role in an uncertain regional model of MAID care with a continually evolving MAID practice and legal landscape, (4) competency, (5) ease and ability to refer, (6) current time and place of their career, (7) practice limits and realities, (8) a lack of interest and belief of lack of need in their current practice, and, (9) concerns regarding the scarcity of non-MAID EOL care resources. In addition to their professional obligations, HCPs also intentionally contemplated their obligations to their families and communities. The intentional contemplation of ***moral ideals***, or concepts that assist in achieving respect for persons, was evident as HCPs intentionally contemplated (1) a lack of time to participate in what they would deem quality EOL care, (2) the need to contemplate and integrate what they hear from the experience of others, (3) the need to practice within the conscience of the greater community, (4) the cultural nuances in EOL care, (5) the need to understand the patient's care history and decision-making, (6) the importance of the patient relationship and, for NPs (7) need to achieve professional respect within the current practice culture. HCPs intentionally contemplated an extensive array of participation ***consequences,*** including (1) reduced available time to care for the patients in their practice in order to have adequate time to participate in MAID, (2) professional discipline, (3) litigation, (4) harm to themselves or their families, (5) being known or being visible as a care participator by their colleagues, other patients, and the greater community, (6) the impact on the patient's family unit after MAID provision, and (7) undue burdens on patients and families in rural areas.

5.8.2 Implications for Practice

There may be an opportunity to mitigate some of the exogenous factors that influenced HCPs' non-participation in formal MAID processes. These practice suggestions are not intended to compel nor convince HCPs to participate; however, they may support those HCPs who are considering formal participation but are reluctant or unable to do so. Specifically, we suggest clarifying the regional model of care, practice-focused MAID education and policy clarification, time, and practice enhancements.

5.8.2.1 Clarifying the regional model of care. Each province and territory is responsible for delivering health care services, and, not surprisingly, each has developed a distinct regional MAID model of care.[22,79] Some MAID models have a central access point and dedicated teams and resources, where others have incorporated MAID into the existing workload of the HCP. HCPs, in our research, expressed uncertainty about how MAID "fit" in their practice. Clarifying and communicating the regional MAID model of care is urgently required so that HCPs can accurately contemplate their obligations, ideals, and participation consequences, ensuring their perspectives are constructed on the regional practice model.

5.8.2.2 Practice-focused MAID education and policy clarification. Practice-focused education and policy clarification may also support HCPs who are intentionally contemplating formal participation but are reluctant or unable to do so. This includes pragmatic policy clarification (i.e., how to obtain the MAID provision medications, complete death certificates, and administrative practices) and education that moves beyond the legislative framework of MAID. MAID is a complex process[110] with a significant "learning curve."[109] This complexity and learning curve of MAID, in addition to our findings related to competency and lack of knowledge, signals that enhanced MAID education is required. Knowledge of the medical-legal and technical aspects of participation in MAID processes, communication skills, information on religion and MAID, explicit information on roles and responsibilities, and an opportunity to clarify personal feelings regarding MAID was desired by nursing and medical students.[280,281] As identified in this research, this same level of detailed and specific practice-focused information would support all HCPs as they intentionally contemplate their degree of participation in formal MAID processes.

5.8.2.3 Time. HCPs' non-participation in formal MAID processes was influenced by competing priorities in a timed clinic visit and their belief that participation in formal MAID processes required time beyond what they had available. Adequate time is a crucial foundational element in all patient-HCP relationships,[282] and relationships are critical in MAID processes.[110] To ensure the promotion of on-going excellent care, HCPs and patients need the time to have safe and satisfying clinical encounters. The need for adequate time to discuss EOL care with patients and families and, for those who desire to participate in formal MAID processes is acute as MAID deaths are increasing in Canada[22] and the Canadian population continues to increase and age.[238] System-wide action is required to ensure that HCPs (regardless of MAID participation) have adequate time to provide relational, holistic patient care and that practices (including rural and remote) have adequate HCPs to meet the populations needs.

5.8.2.4 Practice enhancements. Some non-participation considerations may be mitigated through practice enhancements such as fair remuneration, clear professional guidance, systems that respond to safety and risk concerns, and removal of practice barriers. Khoshnood et al. identified that MAID assessors and providers were concerned about remuneration, which is echoed in our research as remuneration influenced non-participation.[115] Given the practice, time, and relational investments of participation in formal MAID processes, reviewing remuneration policies for physicians and NPs is clearly warranted.

HCPs, in our research, considered the professional and legal risk of participation. This risk may stem from the often-polarized discourse surrounding the interpretation and application of the legislation. For example, HCPs can inform patients about MAID as an EOL care option, but cannot say anything that could be construed as counseling someone towards an assisted death.[12] Clear professional guidance regarding the legal and professional bounds of MAID may assist HCPs in assessing the risk of participation. Professional associations and employers must respond to concerns regarding the physical, emotional, and mental safety of the HCPs and their families, and provide both support and action such that risks are mitigated, and healthy workplaces are supported. Our data were collected approximately three years after MAID legalizations, and these considerations regarding risk may shift as the Canadian experience with MAID continues.

Lastly, NPs encounter many systemic barriers to their practices,[283] and NPs in our research identified practice limits or barriers that influenced their non-participation in formal MAID processes. A concerted review of NPs practice barriers is crucial to remove any hurdles that prohibit NPs from working to their full scope of practice in a respectful work environment. This would include (1) reviewing employer job descriptions to support those who may wish to participate in MAID, (2) ensuring remunerations structures support NPs formal participation in MAID processes, (3) ensuring NPs can roster patients in their practices to develop sustained relationships, (4) allowing NPs to admit patients to hospitals, and (5) actively counteracting outdated perceptions of what a full-scope NP practice entails.

Additional future research could explore if and how the factors and decision-making considerations vary by HCP sub-group, practice location, region, or over time. An inquiry into the perspectives of Canadians from diverse cultural backgrounds and faiths regarding MAID would contribute to improved working relationships with diverse patient populations. Finally, it is important to ascertain the efficacy of the proposed mitigations in positively supporting the HCPs who might have considered formal participation but were reluctant or unable to do so.

5.8.3 Limitations

We acknowledge that within our epistemology, additional data or variations within the data exist. Our qualitative interpretations are specific to the time (data collected approximately three years after MAID legalization in Canada), place, and participants of this research; as such, we have provided detailed accounts of the participants to support transferability. Despite the use of vignettes in the data production, it is possible that the participants' responses were hypothetical as only 27% of them had encountered an actual patient request for MAID. The research regarding HCPs' participation in MAID processes is emerging; thus, we utilized research from international jurisdictions to position our findings, which may differ from Canadian healthcare delivery approaches, culture, and laws.

5.9 Conclusion

Accounting for the reasoning of HCPs within their personal, patient, practice, and community contexts is vital to understand non-participation in ethically complex care. The factors and decision-making considerations influencing HCPs’ non-participation in formal MAID processes are extensive. Referral pathways that align with HCPs' moral space and are sufficiently known to all patients, family members, and health care team members will support the social contract between HCPs and patients at the EOL. Clarifying the regional MAID model of care, practice-focused education, policy clarification, time, and removal of practice barriers may support those HCPs who may consider formal participation in MAID processes but are reluctant or unable to do so. Supporting these HCPs may, in turn, foster sustainability in MAID programs and support the social contract of care by facilitating patients' access to MAID.

CHAPTER 6.0: DISCUSSION

The overall aim of the thesis was to foster an enhanced understanding of HCPs' non-participation in MAID. This chapter will provide an overview and integration of the scoping review and qualitative exploratory study results. The findings will be situated within the extant body of research, and the chosen theoretical frameworks will be used to interpret them. The resultant Model of Non-Participation in Formal MAID Processes and practice implications will be discussed, and future areas of research will be identified, and thesis strengths and limitations will be outlined.

6.1 Overview of Findings

This section will provide an overview of the scoping review and the qualitative exploratory study and summarize their results.

6.1.1 Factors Influencing Practitioners Who do not Participate in Ethically Complex, Legally Available Care: Scoping Review (Manuscript 1)

The scoping study determined what was known regarding the factors that influenced physicians and registered nurses who do not participate in the ethically complex, legally available care areas of EOL (including assisted death), reproductive health and technology, genetic testing, and organ or tissue donation. The goal was to identify, analyze, and synthesize the factors that influenced non-participation in the identified care areas.

In this scoping study, 10,664 articles were identified, and 172 articles were reviewed via full-text. The studies included registered nurses and physicians in their samples, were published between 2000 and 2019 and reported factors that influenced non-involvement within EOL care (including physician-assisted dying and medical assistance in dying) (n=3), genetic testing (n=1), reproductive health (n=10), and organ procurement (n=1). One article included two care areas; EOL and reproductive health. Five studies included registered nurses, and eleven studies included physicians in their samples. The studies originated in the United States (n=8), Australia (n=2), South Africa (n=1), Canada (n=1), Norway (n=1), Brazil (n=1), and Switzerland (n=1). One of the studies compared findings from the Netherlands and the United States. The studies were comprised of mixed (n=2), quantitative (n=7), and qualitative (n=7) methodologies.

HCPs' personal beliefs, HCPs' characteristics, HCPs' professional ethos, emotional labour, and system and clinical practice considerations (Figure 3.2) were themed as the factors that influenced HCPs who did not participate in ethically complex, legally available care. These findings aligned with a systematic review that explored midwives' and nurses' reasons for declining to participate in pregnancy termination.[159] The main finding from this scoping review was that, although conscientious objection (CO) is often the most prominent factor in non-participation care narratives, numerous factors beyond conscience also influenced non-participation.

The factors influencing non-participation are often distinct from one another and impact healthcare systems and HCPs' practices differently. Conscience-based factors influencing non-participation were noted in the results and were expressed as individual moral imperatives, religious tenets as well as belief that the practice is against normative conventions. Conscientious objection, or non-participation in care as the care is counter to a "particular important subset of an agent's ethical or religious beliefs,"[125] is complicated and often ambiguous as professional ethical codes fall short of capturing complex practice realities.[245] HCPs reporting CO described feeling stigmatized, uncertain, alone, and without support.[128]

Non-conscience-based factors that influenced non-participation in care were themed as HCPs' characteristics, professional ethos and system, clinical practice, and emotional labour considerations. Specifically noted in the scoping study were workload, time, and logistical concerns,[151,162,229] ambiguous policies,[164] workplaces that imposed practice limits,[162,225] HCPs' self-assessed inadequate concerns regarding competence,[151,162,164,225,229] and patient considerations.[163,222,224–226,232] HCPs, healthcare administrators, regulators, and leadership must engage in on-going dialogue to understand and mitigate these non-participation factors as HCPs' practice realities evolve.

6.1.2 A Qualitative Exploration of Non-Participation in Medical Assistance in Dying

The qualitative exploratory study identified the factors that influenced physicians' and nurse practitioners' (NPs') non-participation in the formal processes of determining a patients' eligibility for MAID and providing MAID. These results supported identifying the required supports for HCPs and the policy and practice gaps to support patients' access to MAID.

Two theoretical frameworks were chosen to support this study; Social Contract Theory and the Ruggerio approach to moral dilemmas and decision-making.[203] They were used in the conceptualization of the study, as noted in Figure 2.1.

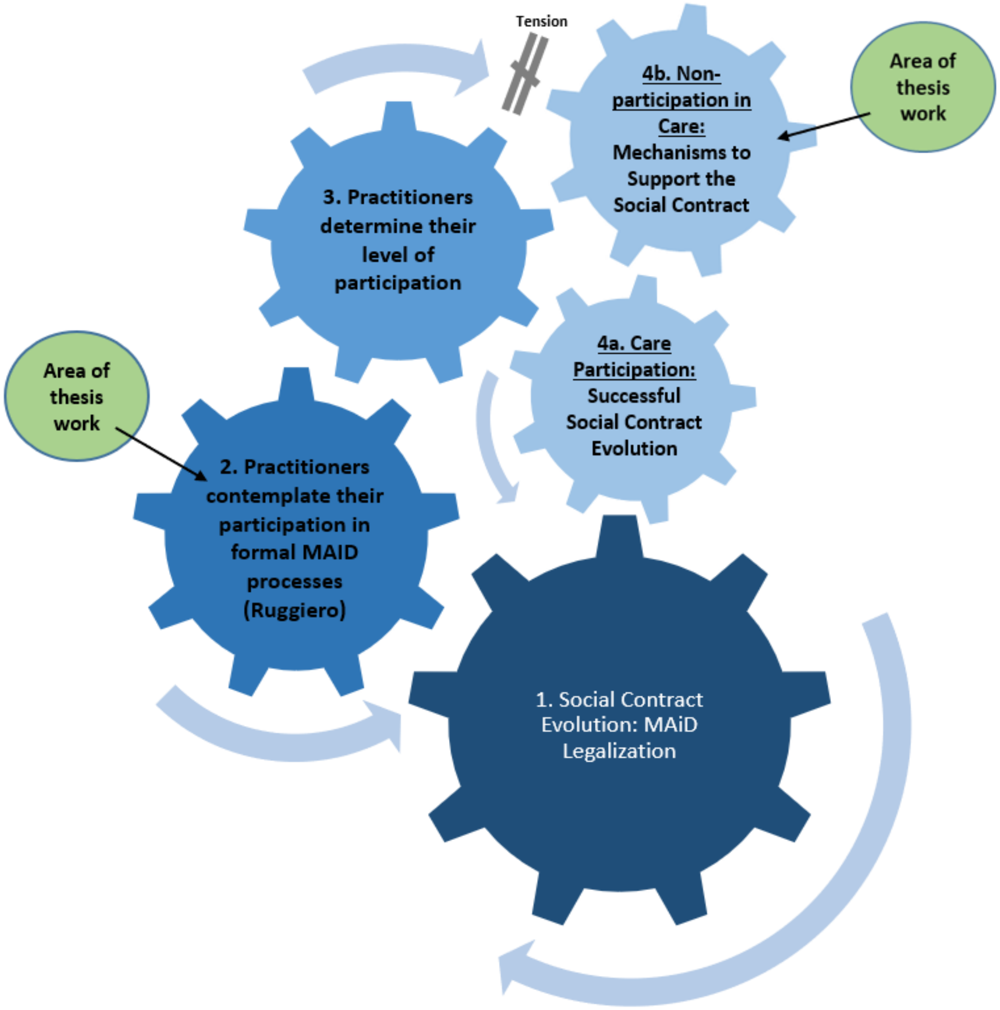

Figure 2.1: Integration of Theoretical Frameworks

As a new EOL care option, MAID changed the social contract of care between HCPs and patients. When HCPs consider their participation thresholds in this new EOL care area, they contemplate Ruggerio's standards of ideals, consequences, and obligations and determine their participation level. As noted in Figure 2.1, depending on the degree of HCP participation, the social contract either successfully evolves, or alternative mechanisms are required to support the social contract of care. Ruggerio's standards of consequences, obligations, and ideals informed the interview guide and vignette development (Appendix I) with the standards noted in the question areas.

Thirty-five HCPs who self-identified as non-participators in formal MAID processes in the province of Saskatchewan were interviewed. There was robust representation across the collected demographic and contextual data. While being open to emerging data patterns, Ruggerio's standards and Social Contract Theory were considered in the data interpretation as inductive coding occurred across the entire data set. Participants described a range of non-participation thresholds, which varied according to the individual participant's circumstances and clinical context. When considering the MAID clinical care vignette, fourteen HCPs anticipated that they would not participate beyond the facilitation of a referral, whereas twenty-one foresaw varying levels of participation. Consequently, non-participation in formal MAID processes should be viewed as a continuum, ranging from no participation to participation that varied according to the individual participant's circumstances and clinical context.

Numerous factors contemporaneously influenced these individual-specific degrees of non-participation. All participants stated they would refer the patient for continued care. In this sense, the social contract of care was fulfilled. However, very few of the participants could articulate the specifics of the current referral pathways. As such, the tension of a disconnected HCP/patient social contract expectation may still exist. Additionally, as some HCPs' consider complicity in and shared responsibility for referrals in morally objectionable practices, ensuring multiple referral pathways (including patient, family and other provider-initiated referrals) are in place may also support the continuation of care. view referrals as being morally complicated. Some factors originated from within the individual HCP, which were conceptualized as endogenous factors ("endo" word-forming element means within, and the "genesis" word-forming element means origin[284,285]). And factors that originated external to the individuals were conceptualized as exogenous ("exo" word-forming element means outside[286]).

6.1.2.1 "What is right for me is not necessarily right for you" endogenous factors (manuscript 2). This paper highlighted the endogenous factors that influenced HCPs' non-participation in formal MAID processes. These endogenous factors were identified as HCPs' (1) previous personal and professional experiences, (2) comfort with death, (3) conceptualization of duty, (4) preferred end-of-life care approaches, (5) faith or spirituality beliefs, (6) self-accountability, (7) consideration of emotional labour, and (8) future emotional impact.

These HCPs also discussed their professional needs relative to non-participation in formal MAID processes. These were themed as (1) safe passage and (2) clear care pathways. The theme of safe passage was conceptualized as the need for HCP's to work within their moral space in safe and satisfying work environments. Specifically, this encompassed (1) the ability to discuss non-participation with patients, families, colleagues, managers, and regulators without fear of reprisal, (2) respectful, transparent processes to support their disengagement from MAID, and (3) a recognition that their non-participation perspectives were valued. The theme of clear care pathways emerged as although referral pathways existed in our province at the time of this study, many HCPs expressed they did not know the referral pathways that existed or the referral processes. The integration of the Ruggiero standards of consequences, obligations, and ideals relative to the data interpretation and the resultant factors are outlined in table 6.1.

Ruggiero's Standards:[203]	**Endogenous Factors**
Consequences: Outcomes that affect all	• Consideration of emotional labour • Future emotional impact
Obligations: Professional, friendship, colleagueship, employment relations	• Preferred EOL care approaches • Conceptualization of duty
Ideals: Promote harmony with self and others	• Self-accountability • Faith and/or spirituality beliefs • Comfort with death • Previous personal and professional experiences

Table 6.1 Integration of Ruggiero's Standards with the Endogenous Factors

The process of contemplating the endogenous factors relative to HCPs' clinical practice is conceptualized as reconciliation. Reconciliation was not an acceptance of MAID as an EOL care option, nor a willingness to participate. Reconciliation is the process of harmonizing the endogenous factors with the HCPs' participation threshold within their current practice. Reconciliation is a fluid process. As the HCPs integrate new personal and professional experiences, the factors influencing their non-participation may also shift. The consideration of consequences was evident as HCPs reconciled the emotional labour and the future emotional impact of participation.

6.1.2.2 "I am okay with it, but I am not going to do it" exogenous factors (manuscript 3). This paper highlighted the exogenous factors and identified specific decision-making considerations within each factor that influenced HCPs' non-participation in formal MAID processes. These non-participation factors were related to (1) the healthcare *system* they work within, (2) the *communities* where they live, (3) their current *practice* context, (4) how their participation choices were *visible* to others, (5) the *risks* of participation to themselves and others, (6) *time* factors, (7) the impact of participation on the *patient's family*, and (8) *patient* relationship, and contextual factors. Additional profession and geographic-specific decision-making considerations were described. The integration of the Ruggiero standards of consequences, obligations, and ideals relative to the data interpretation and the resultant factors and decision-making considerations are outlined in table 6.2.

Ruggiero's Standards:[203]	**Exogenous Decision-Making Considerations/Factors**
Consequences: Outcomes that affect all	• Balancing of needs (community factor) • Rural/remote areas (location community factor) • Colleague visibility (visibility factor) • Patient and family visibility (visibility factor) • Greater community visibility (visibility factor) • Legal and professional risk (risk factor) • Risk to HCP (risk factor) • Risk to HCP's family (risk factor) • Inter-family considerations (patient's family factors)
Obligations: Professional, friendship, colleagueship, employment relations	• Family and HCP relationships (patient's family factor) • Unknown/evolving practice landscape (system factor) • Ease of referral (system factor) • Institutional CO (system factor) • Practice limits (NP system factor) • Program and policy uncertainties (practice factor) • Model of care ambiguity (practice factor) • Competency (practice factor) • Practice realities (physician practice factor) • Point in career (time factor) • Lack of interest or need (practice factor) • Lack of EOL resources (system factor)
Ideals: Promote harmony with self and others	• Professional respect and practice culture (NP system factor) • Community conscience (community factor) • Hearing from others (community factor) • Culture (community factor) • Competing demands/time to do well (time factor) • Relationship (patient factor) • Understanding the why (patient factor)

Table 6.2 Integration of Ruggiero's Standards with the Exogenous Factors and Decision-Making Considerations

The theme of intentional contemplation emerged. This was the profound and purposeful deliberation of these multiple, complex, and often inter-related factors and decision-making considerations relative to HCPs and their practices. This paper further noted that some of the exogenous factors might be modifiable, and practice implications were provided. These suggestions were not provided to compel HCPs to participate but to support the HCPs who were reluctant or unable to participate. Discussion included clarification of the regional model of care, policy, time and practice enhancements, and practice-focused MAID education.

6.2 Integration of Study 2: Manuscripts 2 and 3

This section will merge the qualitative exploratory study findings presented in chapter four and chapter five. Professional and geographical variations will be discussed, and Social Contract Theory and Ruggerio's approach to moral dilemmas and decision making will be used to interpret the study's findings.

6.2.1 Unique Considerations in Non-Participation in MAID

The study sample included NPs and physicians who self-identified as non-participants in the formal processes of MAID assessment and provision. The participants identified various degrees of non-participation that were influenced by diverse and often interwoven factors. The endogenous factors that influenced non-participation were strikingly similar within the demographic and contextual data sub-groups. However, unique considerations specific to practice location and the professional groups were identified with the exogenous factors.

6.2.1.1 Professional differences in the exogenous non-participation factors. Two exogenous factors had profession-specific decision-making considerations. There were profession-specific decision-making considerations that limited NP participation in formal MAID processes. These included NP (1) practice limits (i.e., inability to roster patients, remuneration structures, hours of work limitations), and (2) professional respect and practice culture (i.e., lack of appreciation for the full scope of NP practice). Physicians' practice realities (i.e., remuneration relative to overhead practice costs) were identified as particular factors influencing their non-participation in the formal MAID processes.

6.2.1.2 Geographical differences in the exogenous non-participation factors. HCPs in rural and remote areas were particularly concerned about the consequences of their non-participation on their patients and families. They specifically expressed concern that their non-participation would cause travel, costs, and in some cases, physical discomfort to patients as they would be required to leave their home location for MAID assessments and care. These additional considerations resulted in the sense of pressure and distress.

6.2.2 Application of Theoretical Frameworks

6.2.2.1 Social Contract Theory. Nursing and medicine contend they have social contracts with patients/society with mutual expectations (table 2.1).[197,199,200,287] If we apply the patient's social contract expectations (noted in table 2.1) to MAID it is reasonable to posit that interested and eligible MAID patients expect HCPs to support their access to MAID, be transparent in their participation choices, provide objective advice, and ensure patients' needs at the EOL are met. At the same time, HCPs contemplate these patient expectations, their responses to these changed expectations, and subsequent actions. Consequently, tensions exist when the care desired and the care provided are disconnected.[201] This tension may be mitigated by having mechanisms to support the social contract of care that meet both patients' and HCPs' needs.

In alignment with the qualitative study's eligibility criteria, all interviewed HCPs identified as non-participators in the formal MAID processes. However, all participants indicated they would refer to the MAID program or an alternative HCP, which would honour the social contract of care. In this sense, the social contract of care (specifically, the patient's expectations of HCPs to facilitate MAID access, support patient choice, and ensure the patient's needs are met) would be fulfilled. However, potential deficiencies in meeting the social contract of care via referrals became apparent. Not all study participants could identify the Saskatchewan referral pathways for provider-initiated and for patient-initiated referrals to the MAID program. If the non-participation HCP does not know of the referral pathway, the social contract cannot be honoured. An additional consideration is that practitioner-initiated referrals may conflict with the moral needs of HCPs as some HCPs consider a referral as participation in a morally objectionable practice. Lastly, patient-initiated referral options to continue the social contract of care are based on patients (and their families) knowing this care pathway and navigating this pathway during one of their most vulnerable periods at the end of life.

6.2.2.2 Ruggiero Approach to Moral Dilemmas and Decision-Making. When contemplating their participation in the evolved social contract, HCPs weigh their obligations and ideals and the consequences of their participation.

Endogenously, HCPs' previous personal and professional experiences and comfort with death influenced the reconciliation of their moral ideals (i.e., self-accountability, faith/spirituality beliefs) and obligations (i.e., preferred EOL care approaches and conceptualization of duty). As HCPs integrate new professional and personal experiences, there *may* be a subsequent shift in their conceptualization of duty, end-of-life care approaches, and spirituality or faith beliefs relative to MAID. Ruggerio believed highly ethical people viewed their ideals as obligations they expect themselves to uphold,[203] which may be particularly applicable to HCPs who are anchored by their professional code of ethics. This was evident in the study results, which demonstrated how the conceptualization of professional duty and preferred approaches to EOL care intertwined and demonstrated how the factors overlapped and influenced one another. The contemplation of consequences was evident as HCPs identified the emotional labour of participation and the future emotional impact of participation as limiters to their participation in formal MAID processes.

Ruggerio further explained that individuals ultimately choose the action that supported their ideals, obligations, and favorable consequences. This was evident as the HCPs intentionally contemplated numerous exogenous factors and decision-making considerations. HCPs intentionally contemplated the *consequences* of MAID participation relative to (1) litigation, (2) professional discipline, (3) harm to themselves or their families, (4) reduced available time to care for the patients in their practice in order to have adequate time to participate in MAID, (5) being known or being visible as a care participator by their colleagues, other patients, and the greater community, (6) the impact on the patient’s family after MAID provision, and (7) undue burdens on patients and families in rural areas.

HCPs intentionally contemplated *obligations* relative to their (1) role in an uncertain regional model of MAID care with a continually evolving MAID practice and legal landscape, (2) on-going care duties to the patient’s family, (3) ease and ability to refer, (4) institutional CO, (5) practice limits and realities, (6) competency, (7) current time and place in their career, (8) a lack of interest and belief of lack of need in their current practice, and (9) concerns regarding the scarcity of non-MAID EOL care resources.

Lastly, the participants intentionally contemplated their *moral ideas* as they identified (1) the cultural nuances in EOL care, (2) the importance of the patient relationship, (3) the need to understand the patient’s care history and decision-making, (4) the need to practice within the conscience of the greater community, (5) a lack of time to participate in what they would deem quality EOL care (6) the need to contemplate and integrate what they hear from the experience of others, and (7) specific to NPs, the need to achieve professional respect within the current practice culture. Individuals will choose actions that have favorable consequences (or to avoid negative consequences) while honouring their obligations and ideals.[203] In our research project, in alignment with our sampling inclusion criteria, these choices resulted in all participants avoiding all participation in formal MAID processes beyond the facilitation of a referral.

6.3 Integration of Study 1 and 2

This section will merge the results of study one and study two and highlight how the study results extend the knowledge regarding factors influencing non-participation in the ethically complex, legally available care area of MAID.

Both studies found that numerous factors influenced HCPs' non-participation in ethically complex, legally available care (including MAID). It was also evident that both conscience-based and factors not solely related to conscience influenced non-participation. The scoping study identified that HCPs' personal beliefs, professional ethos, emotional labour considerations, system, and clinical practice considerations influenced non-participation. The endogenous and exogenous non-participation factors identified through the qualitative exploratory study aligned with the scoping study, as noted in figure 6.1.

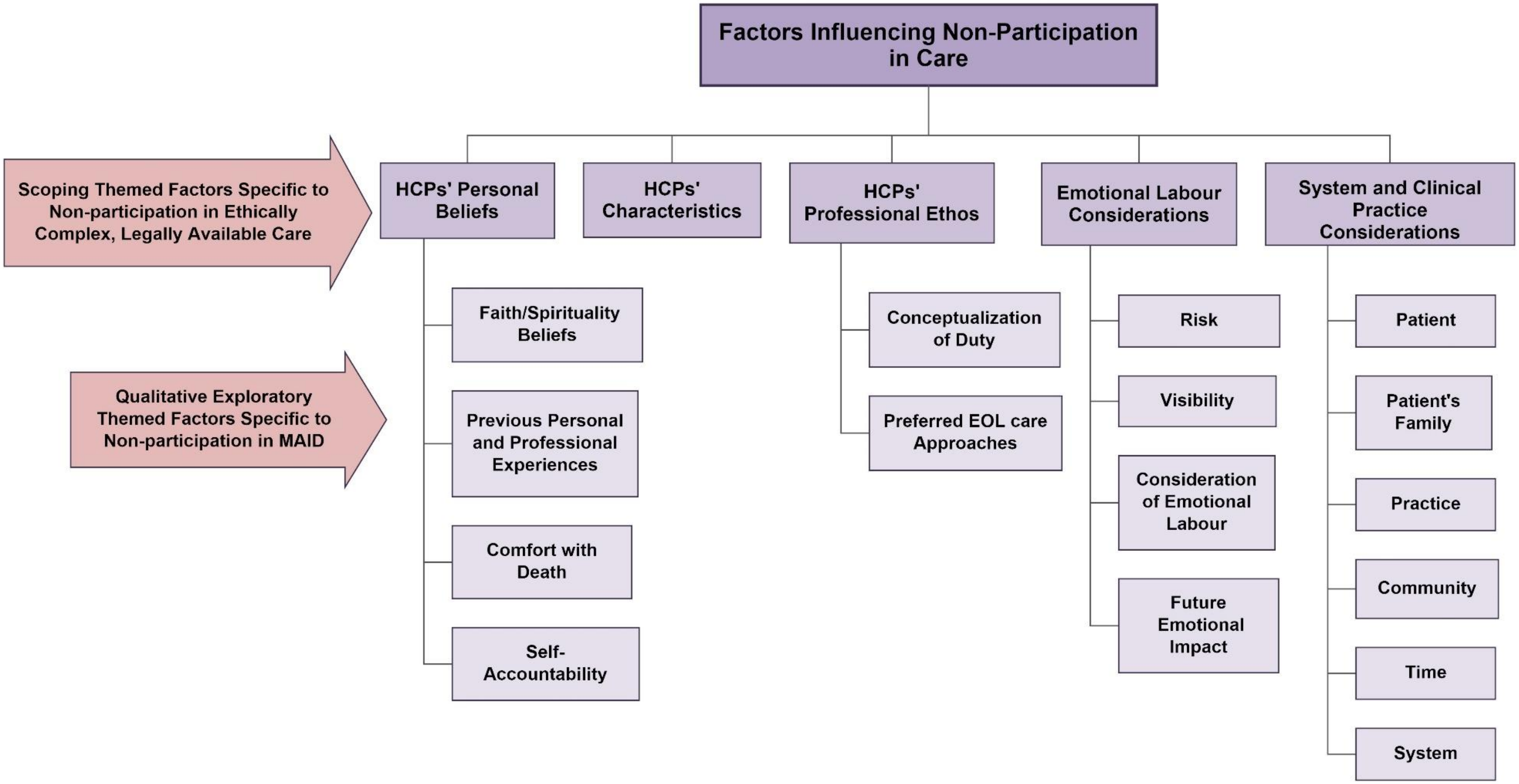

Figure 6.1 Scoping Project Results Relative to Qualitative Exploratory Results

The scoping theme *HCPs' personal beliefs* aligned with the endogenous factors influencing non-participation in formal MAID processes and included faith/spirituality beliefs, previous personal and professional experiences, comfort with death, and self-accountability. Within the scoping study results, non-participation in ethically complex, legally available care was identified as more likely for male HCPs, rural practitioners, and those within private and religiously affiliated practices. Because the qualitative exploratory study sample was limited to those who self-identified as non-participators in formal MAID processes, a comparison of the *characteristics of HCPs* associated with participation in MAID in Saskatchewan was not undertaken. As such, there are no results to align with the scoping results in this theme.

The scoping theme *HCPs' professional ethos* aligned with the endogenous factor theme of HCPs' conceptualization of duty and preferred EOL care approaches; whereas the scoping theme of *HCPs' emotional labour considerations* aligned with the non-participation factors (1) concerns about future emotional impact, (2) concerns about the emotional labour of participation, (3) risk and (4) visibility. The processes of reconciliation (endogenous factors) and intentional contemplation (exogenous factors) are intensive processes that inherently result in emotional labour, which also corresponded to the scoping study results. Furthermore, the scoping finding of *HCP's system and clinical practice considerations* aligned with the patient, patient's family, practice, community, time, and system non-participation factors.

The professional groups included in the scoping study are different from the qualitative exploratory study sample. The scoping study included registered nurses, one of the largest practicing healthcare provider groups in article inclusion criteria, whereas the qualitative exploratory study included NPs because of their ability to participate in formal MAID processes of assessment and provision under the legislation.

Having the qualitative exploratory results align with what was known regarding non-participation in other ethically complex, legally available care areas lends strength to the thesis findings. However, the qualitative exploratory study, with its extensive rich data set, also provided unique knowledge. The unique contributions of the thesis include (1) the differentiation of endogenous and exogenous factors influencing non-participation in formal MAID processes and, (2) a detailed accounting of decision-making considerations within the exogenous factors (Table 6.3).

Exogenous Factor Influencing Non-Participation	**Decision-Making Consideration**
The Healthcare ***System*** the HCP Works Within	• Concerns about a lack of EOL resources • Unknown and evolving practice landscapes • Ease of referral • Institutional conscientious objection • Practice limits (specific to NPs) • Professional respect and practice culture (specific to NPs)
The **Community** Where the HCP Lives	• Community conscience • Balancing of needs • Hearing from others • Culture • Location (specific to rural and remote areas)
The **Practice** Context of the HCP	• Program and policy uncertainties • Model of care ambiguity • Competency • Lack of need and interest • Practice realities (specific to Physicians)
How Participation was **Visible** by Others	• Colleagues • Patients and families • Greater community
The **Risk** of HCP Participation	• Legal and professional risk • HCP risk • Risk to HCP's family
Time Factors	• Competing demands and time to do well • Point in career
The Impact of Participation on the **Patient's Family**	• Family-HCP considerations • Inter-family considerations
The **Patient** Relationship and Contextual Factors	• Relationships • Understanding the "why"

Table 6.3 Exogenous Factors and Decision-Making Considerations

With the identification of endogenous and exogenous factors and the detailed exogenous decision-making considerations, the Model of Non-Participation in Formal MAID Processes was developed.

6.4 Model of Non-Participation in Formal MAID Processes

My findings culminated in the development of the Model of Factors Influencing Non-Participation in Formal MAID Processes. The model illustrates the complex, fluid, and interrelated endogenous and exogenous factors and decision-making considerations that influenced non-participation in the formal MAID processes of assessment and provision. The model was grounded in the data from individual HCPs as they discussed the consequences of participation, their moral ideals, and their obligations in the changing social contract of EOL care relative to their non-participation threshold.

When the endogenous factors, and exogenous factors, and the unique considerations are integrated, a detailed understanding of non-participation in formal MAID processes emerges (figure 6.2).

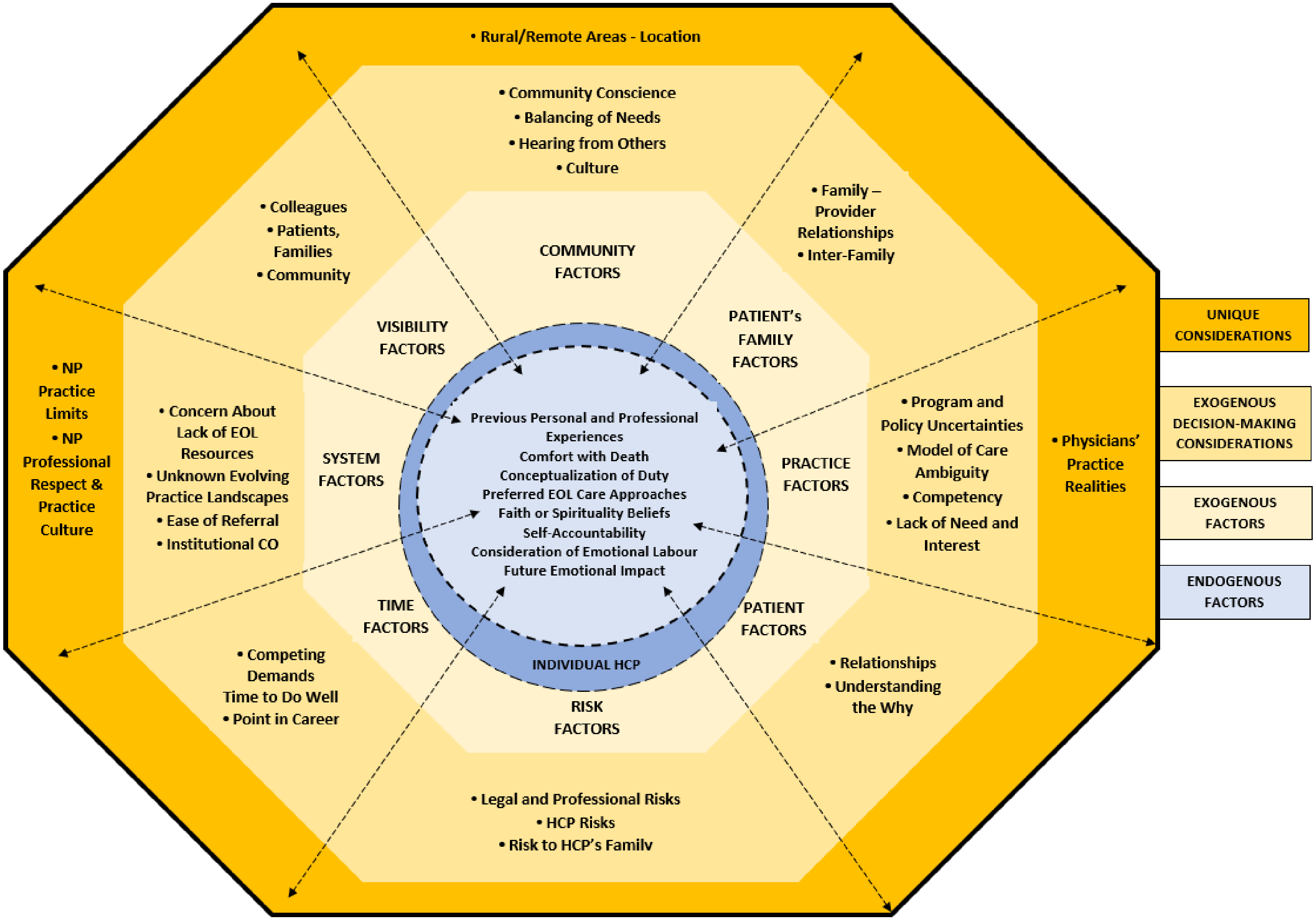

Figure 6.2 Model of Factors Influencing Non-Participation in Formal MAID Processes

Within the model of non-participation, HCPs contemporaneously undergo the endogenous process of reconciliation and the exogenous process of intentional contemplation and are influenced by numerous factors and decision-making considerations in the determination of their non-participation threshold. The dashed lines and dual head arrows indicate these factors interact, allowing the factors to evolve. For example, as HCPs' personal and professional experiences change, there may be a corresponding shift in the influence of the factors relative to their participation thresholds. Additionally, participation thresholds may shift or change as some of the factors influencing non-participation may be mitigated. These mitigations are not intended to compel HCPs to participate in formal MAID processes but may support those HCPs who are reluctant or unable to do so.

As factors shift, evolve, and interplay, HCPs may continue as non-participators in formal MAID processes. Consequently, alternative mechanisms are needed to support patients' and HCPs' mutual expectations in the social contract of EOL care. However, for some HCPs, the shifting or evolving factors may culminate in their participation in formal MAID processes. Should the resultant participation threshold be MAID provision, then the social contract expectations between the requesting patient and the participating HCP are met.

6.5 Implications for Policy and Practice

As noted in the resultant Model of Factors Influencing Non-Participation in Formal MAID Processes, some non-participation factors and decision-making considerations align with non-conscience-based non-participation (e.g., ambiguity in the regional model of care, risk of litigation, HCPs' point in career). In contrast, other factors do align with conscience-based non-participation (i.e., faith/spirituality beliefs). I suggest several healthcare practice implications and recommendations in light of this for both CO to MAID and non-participation in MAID. These system-level practice recommendations are offered to support patients' access to care, cultivate safe and satisfying workplaces, and foster sustainable MAID programming. I believe these outcomes are symbiotic in that safe and satisfying workplaces will provide the moral space to support HCPs' decision-making, which will foster HCP well-being, which will impact the sustainability of MAID programming and patient's access to care.

6.5.1 Conscientious Objection to Participation in Formal MAID Processes

As healthcare practice evolves and the roles and responsibilities of HCPs shift,[147] the complexity of enacting a CO in healthcare is anticipated to continue. HCPs require a "moral space" to practice without compromising their moral integrity.[125] Compromising moral integrity harms individual HCPs, impacts job retention,[256] and impacts the social contract of care. As such, healthcare systems must actively clarify and remediate the disconnect surrounding the protection of conscience, workplace policies, and practice realities. To support HCPs as they practice within their moral space, I propose 1) safe passage grounded in respect, 2) attention to referral pathways, and 3) the consideration of emotional labour.

6.5.1.1 Safe passage grounded in respect. Healthcare delivery teams and administrators must engage in authentic conversations without fear of reprisal or disdain, have transparent processes to support disengagement from care, and recognize that divergent views are important. I conceptualized this as safe passage, or the ability to work within one's moral space in satisfying work environments. As Weinstock[136] noted, these discussions support HCPs' reflections on the practice demands and laws and policies that impact their practice. I believe this to be a high priority as it respects the moral agency of all and supports the examination of differing viewpoints.

6.5.1.2 Attention to referral pathways. To support the social contract of care, options to optimize and expedite the MAID referral processes should be considered. As some HCPs consider a MAID referral to be counter to their conscience, HCP-initiated referrals may be problematic.[257] The balance then is to find a means to support the patient's unencumbered and timely access to care while respecting the conscience concerns of HCPs. HCP-initiated and patient-initiated referral options must be known by all care delivery team members, patient advocates, and patients and families to support patients' access to care. However, given the traditional "gatekeeping" role of HCPs,[40] patients may not know of the ability to self-refer to the provincial MAID program, and EOL patients are vulnerable as they live with their fears, insecurities, loneliness, the prospect of facing death, their care burdens, and their restricted activities.[259] Therefore, patient-initiated referrals may shift an undue burden to patients as they navigate the healthcare system. Patient-initiated referrals do, however, provide choices and options to both HCPs and patients.

6.5.1.3 Consideration of emotional labour. Emotional labour includes the management of emotions that arise from working with others[288] or the management of one's emotional display as part of work duties.[234] Emotional labour in EOL care is often overlooked.[262] Within the MAID research, conscientious participators in formal MAID processes noted feelings related to strained relationships with colleagues, loss of personal time, isolation, lack of team support, the impact of denying patient's MAID requests, working with non-participating institutions, and working with families in their grief.[16,109,115] Thus, I believe it is vital to acknowledge emotional labour in EOL care, which includes participation in formal MAID processes. I emphasize the need to integrate meaningful supports for HCPS as they manage these emotions and reconcile what MAID means to their professional practice.

6.5.2 Non-participation in Formal MAID Processes due to Factors Other Than CO

Elucidation of non-conscience-based factors requires dialogue among HCPs, healthcare administrators, and professional regulators. I suggest that there may be an opportunity to mitigate some of these factors to support HCPs who are hesitant to participate in formal MAID processes, which may positively support participation and patient access to care.

6.5.2.1 Clarifying the regional model of care. There are numerous national and provincial professional guidance documents, yet there is little national uniformity in MAID programming.[77] Because provinces and territories retain the responsibility for health care delivery, it is not surprising that provincial, territorial, and even regional differences exist.[46,78,79] Clarifying the regional model of care is not meant to compel HCPs to participate; however, I believe that HCPs must be able to consider their practice obligations, ideals, and participation consequences within the current Saskatchewan practice model to support informed practice choices. For some HCPs, this may lessen their reluctance to participate in formal MAID processes.

6.5.2.2 Practice-focused MAID education and policy clarification. Participants in the qualitative exploratory study discussed their lack of knowledge and competency to participate in the formal MAID processes. HCPs who participate in MAID identified that MAID is a complex care area[110] with a significant "learning curve."[109] Health sciences students identified a desire to know MAID's technical and legal aspects, understand the roles of the various healthcare team members, and have an opportunity to explore their feelings regarding MAID.[281,289,290] These findings indicate that enhanced MAID education is required for HCPs. As such, practice-focused education and policy clarification will support HCPs as they reconcile and contemplate their ideals, obligations, and the consequences of participation in formal MAID processes.

6.5.2.3 Adequate time. Adequate time is required for honest and open patient-HCP relationships,[282] holistic and safe clinical encounters, and healthcare excellence. The need for adequate clinical time to build relationships and discuss EOL care with patients and families is acute as the Canadian population continues to age[238] and the number of MAID deaths increases.[22] I bring forward the need to evaluate HCPs' allotted clinical practice time in rural and remote care areas so that HCP clinical practice time in the community adequately meets the population's needs.

6.5.2.4 Practice enhancements. Some non-participation issues may be mitigated through practice enhancements to support HCPs who are reluctant to engage in formal MAID processes of assessment and provision. Practice enhancements such as systems that respond to risk and safety concerns, fair remuneration, clear professional guidance, and removal of NP practice barriers must be explored.

Professional statements that clarify the legal and professional MAID boundaries will help HCPs understand the current MAID context and accurately assess participation risks and consequences. Employers and professional associations must swiftly respond to concerns expressed by HCPs regarding their individual and their families' physical, emotional, and mental safety. Reviewing remuneration policies for NPs and physicians is warranted given the relational, time, and practice investments in care participation and HCP-patient-family encounters.

As NP participation in assisted dying is internationally unique,[11] it is especially crucial to eliminate the systematic impediments that hinder NP participation in this area. These barriers included (1) an inability of NPs to roster patients in physician-led clinics (which resulted in NPs tending to the "walk-in" patient which were frequently singular patient encounters), (2) the inability of NPs to admit patients to hospitals (resulting in EOL or complex patients transferred to physicians for admission), (3) NPs remuneration structures, (4) job descriptions that limited NP practice, and (5) outdated perceptions of what a full-scope NP practice entails.

6.5.2 Intersection of CO to MAID and Non-participation in MAID

There are complex situations in which CO, non-participation for reasons other than conscience, and HCP's duty of care and patient abandonment interact. Clarifying the duty of care within the constructs of CO and non-participation in care by professional regulators is important for HCPs, patients, and healthcare administrators. This clarification is acutely required in practice areas (such as single-provider practices and practices in rural and remote settings) to support seamless patient access to care.

6.6 Strengths and Limitations

There are strengths and limitations to the two thesis studies. Scoping study strengths included physicians' and nurses' inclusion as the two largest healthcare professional groups across multiple legally available, ethically complex care areas and the inclusion of research articles from jurisdictions where the care was legally available. The inclusion of jurisdictions where the care was legal removed anticipated or hypothetical non-participation factors.

Specific to the scoping study, there may have been non-participation factors that were not captured due to our selection and inclusion criteria. Notably, we included nurses and physicians, included studies in English, and utilized specific research databases to identify the scoping studies for inclusion. In identifying care areas for the scoping study, we may have excluded other care areas where non-participation also occurs. Lastly, as the included scoping literature was from eight different countries, it was impossible to account for cultural diversity and cultural influence in the themed findings.

The qualitative exploratory study's strength was that we extensively accounted for the first author and team's positionality and reflexivity. We had a deep, rich data set with robust participant demographic and contextual data from large, medium, small, and rural areas. The use of vignettes across multiple aspects of possible MAID participation was a strength as this data production method supported the exploration of decision-making processes, attitudes, perceptions, and beliefs. These vignettes were vetted by two physicians and two NP field experts for suitability, and after four interviews were conducted, the research team reviewed the resultant interview data to ensure the vignettes answered the research objective. We established rigor by using multiple data sources, using a single transcriptionist and primary coder, cross-checking the codes by the co-authors, sharing the aggregate findings with participants for member checking, and using the expertise of the doctoral committee as part of the analysis review. We provided multiple participant quotations within the manuscripts to support the analysis and presented the demographic and contextual data to frame the results.

Within the qualitative exploratory study, limitations exist relative to the research paradigm, methodology, and sampling. The primary author, the co-supervisors, and the doctoral committee interpreted 35 specific participants' perspectives in a specific geographic location (Saskatchewan) collected within a narrow frame of time (May to September 2019) approximately three years after MAID legalization in Canada. Despite drawing our interpretations from a robust data set, variations in non-participation factors may also exist within and beyond this data. Because some participants were included as a result of snowball sampling, it is possible that like-minded individuals were overrepresented. However, the resultant wide range of demographic and contextual data obtained demonstrated the diversity of personal and practice contexts, making this potential bias less likely. We were also aware of the possibility of social desirability bias in the participant responses, which occurs when participants share themselves and their views in a manner perceived to be socially acceptable and not reflective of their true opinions.[291] However, as the interviewer deliberately took a neutral stance to MAID in the interviews and was not in a position of authority over the participants, we did not believe that this was a significant concern. As only 27% of participants had encountered a patient inquiry regarding MAID, the other participants' responses were hypothetical. The influence of this on the findings is unknown.

6.7 Future Research

In considering non-participation in ethically complex, legally available care, there are several future areas of inquiry. As identified in the scoping project, although CO is widely discussed in the literature, research into the specific factors influencing non-participation in legally available care is limited. This focus is even further limited as 14 of the 16 included studies were in the reproductive health and EOL care areas. This suggests other ethically complex, legally available care areas such as reproductive technology, organ procurement, and genetic testing are underexplored. Additionally, future inquiry could contrast the factors influencing non-participation in jurisdictions where the care is legal and where the care is not legally available. This would illuminate if there is a difference between anticipated and actual non-participation.

Future research in the factors influencing non-participation in formal MAID processes could explore possible regional variation. A follow-up study would also provide insight into the evolution of factors influencing non-participation in MAID after being legally available for a longer time, and more HCPS are familiar with the processes. As patient and family-initiated referrals are increasingly utilized in care pathways, research to understand the patient and families' perspective regarding their use would further clarify their contribution to the social contract of care. Given the patient and the patient's family's influence on HCPs' non-participation, research into the care needs and preferences from diverse Canadian cultures and backgrounds may support improved professional relationships with diverse populations. Because of the influence of emotional labour, examining the efficacy of practice supports and the long-term emotional impact on HCPs who participate in the formal MAID processes on HCPs' holistic health is also required.

MAID is influenced by possible legislative changes, court challenges, and evolving best practices. Research into how these influence non-participation factors is required. As several practice considerations were discussed to support participators and non-participators in the formal MAID process, research into the efficacy of the proposed mitigations would ascertain if HCPs feel supported in this new care area, if patient's access to care meets the anticipated demands, and if the current MAID programming is sustainable. A review specific to NPs practice barriers and the system limits to practice may also support NPs working to their full scope of practice.

6.8 Conclusion

This thesis aimed to foster an enhanced understanding of HCPs' non-participation in MAID. These understandings were intended to inform the necessary support for HCPs in this emerging practice area, identify possible policy and practice implications, facilitate safe and satisfying workplaces, and support patient access to care. As patient MAID requests are anticipated to increase,[22,97,238] understanding the factors influencing HCPs' non-participation and, when possible and appropriate, mitigating the factors to support HCPs who are reluctant or unable to participate are essential to ensure equal and timely patient access to MAID.

The factors and decision-making considerations influencing HCPs' non-participation in formal MAID processes are interwoven, complex, and diverse, and non-participation in the formal MAID processes is viewed along a continuum with various HCP thresholds. The Model of Non-participation in Formal MAID Processes identified the contemporaneous influence of endogenous and exogenous factors and decision-making considerations as well as several unique professional and geographic considerations. The model reflected the interaction among the factors and decision-making considerations and allowed factors such as HCPs' comfort with death, personal and professional experiences, time, practice, or systems factors to evolve. The evolution of these factors and decision-making considerations may result in HCPs' continued non-participation in formal MAID processes, or it may result in some HCPs altering their participation threshold.

Identifying the overlapping constructs of CO and non-participation for reasons other than conscience is critical as the HCPs' needs, the practice supports, and policy clarifications are different within each construct. The identified practice implications include safe passage grounded in respect, attention to referral pathways, consideration of emotional labour, clarifying the regional model of care, practice-focused MAID education and policy clarification, adequate time, and practice enhancements. These practice-focused suggestions will support HCPs as they build safe and satisfying practices within their moral space while supporting the social contract of care by facilitating patient's access to legally available EOL care.

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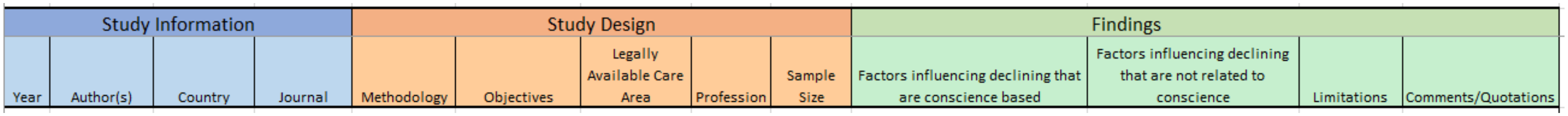
APPENDIX A

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>Search Strategy

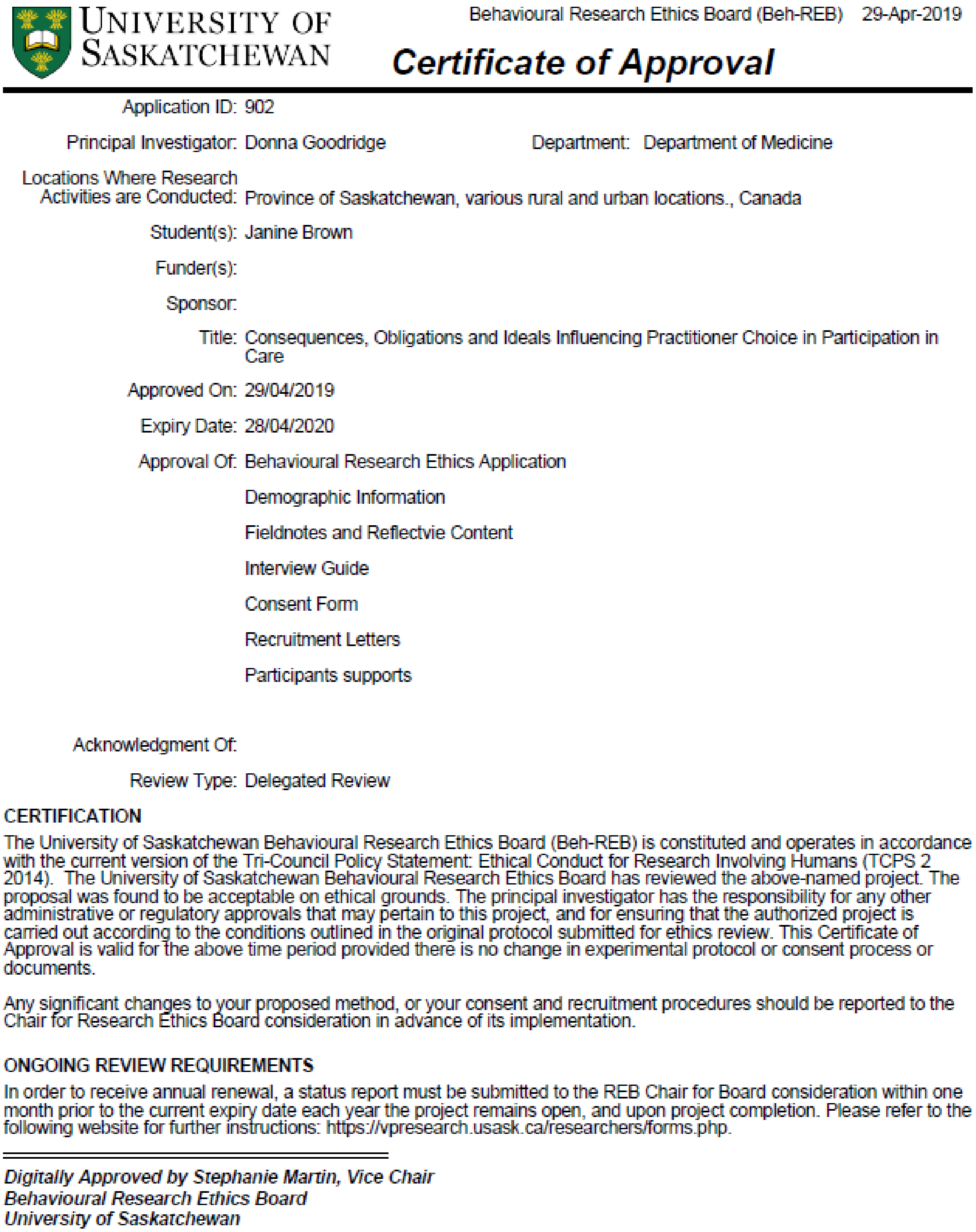
1 conscientious objection.mp.
2 Refusal to Treat.mp. or Refusal to Treat/
3 Conscience/
4 Ethical Relativism/ or ethical relativism.mp.
5 objector.mp.
6 objection.mp.
7 moral obligations.mp. or Moral Obligations/
8 personal autonomy.mp. or Personal Autonomy/
9 PROFESSIONAL AUTONOMY.mp. or Professional Autonomy/
10 LEGISLATION, MEDICAL/es [Ethics]
11 Attitude of Health Personnel.mp. or "Attitude of Health Personnel"/
12 exp NURSES/
13 exp PHYSICIANS/
14 exp Health Personnel/
15 1 or 2 or 3 or 4 or 5 or 6 or 7
16 11 or 12 or 13 or 14
17 7 or 8 or 9 or 10
18 15 and 16
19 17 and 18
20 limit 19 to (english language and yr="1998 -Current")

APPENDIX B



Study Information				Study Design					Findings				
Year	Author(s)	Country	Journal	Methodology	Objectives	Legally Available Care Area	Profession	Sample Size	Factors influencing declining that are conscience based	Factors influencing declining that are not related to conscience	Limitations	Comments/Quotations	

APPENDIX C



UNIVERSITY OF SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB) 29-Apr-2019

Certificate of Approval

Application ID: 902

Principal Investigator: Donna Goodridge

Department: Department of Medicine

Locations Where Research Activities are Conducted: Province of Saskatchewan, various rural and urban locations., Canada

Student(s): Janine Brown

Funder(s):

Sponsor:

Title: Consequences, Obligations and Ideals Influencing Practitioner Choice in Participation in Care

Approved On: 29/04/2019

Expiry Date: 28/04/2020

Approval Of: Behavioural Research Ethics Application
Demographic Information
Fieldnotes and Reflectvie Content
Interview Guide
Consent Form
Recruitment Letters
Participants supports

Acknowledgment Of:

Review Type: Delegated Review

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board (Beh-REB) is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2 2014). The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this project, and for ensuring that the authorized project is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month prior to the current expiry date each year the project remains open, and upon project completion. Please refer to the following website for further instructions: https://vpresearch.usask.ca/researchers/forms.php.

Digitally Approved by Stephanie Martin, Vice Chair
Behavioural Research Ethics Board
University of Saskatchewan

APPENDIX D

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Email: donna.goodridge@usask.ca
Web: https://medicine.usask.ca/respiratoryresearch/

Project Title: Consequences, obligations, and ideals influencing practitioner choice in participation in medical assistance in dying (MAID) care

Researcher(s):

Janine Brown, Primary Contact, Graduate Student, University of Saskatchewan, Jma401@mail.usask.ca

Donna Goodridge (PI), Co-Supervisor University of Saskatchewan 306-966-4209

Lilian Thorpe, Co-Supervisor, University of Saskatchewan, 306-655-7997

Purpose(s) and Objective(s) of the Research:

- To identify the factors considered by physicians and nurse practitioners (who currently do not participate in MAID related care) when contemplating MAID participation.

Procedures:

- A mutually agreeable time and means for the interview will be determined. If required, the interview may occur via WebEx or telephone at no cost to you.
- If the interview is done via telephone, the interviewer will be in a private office on a landline, and the participant may choose a location/time and phone number that meets their privacy needs. If the interview is done via WebEx, the interviewer will be in a private office, using the University of Saskatchewan video conferencing method. The participant may choose a location and time that meets their individual privacy requirements. All information obtained from the WebEx session will be retained and hosted on the University of Saskatchewan password-protected networks.
- At the time of the meeting, the participant information sheet/consent form will be reviewed; you will have the opportunity to ask questions. You will keep a copy of the information sheet/consent form, and the signed form will be kept by primary contact Brown.
- You will be provided a tablet with a short (approximate 12-15 question) demographic/context questions hosted on SurveyMonkey. A statement of consent will be the opening question. If the interview is occurring via WebEx or telephone, the survey link will be provided to you, and you can complete these questions during the interview time.
- Once the recorded interview commences, you will record your consent via reading the statement below. The interview is expected to last a maximum of 60 minutes.

- The interview will include open-ended, exploratory questions, and vignettes. The questions will explore your current practice context, your feelings regarding potential participation in MAID, reflection on potential situations, and the factors influencing your MAID care participation choices. As part of the data collection process, the interviewer will collect descriptive field notes and reflective interviewer content at the interview conclusion. You will not be identified in this data.
- After data analysis, aggregate preliminary findings will be shared back with you via your email. You will then be invited to provide final reflection and comment (via email response return). Email responses and follow-up comments will be considered data and included in data analysis after your identifying information has been removed.

Funded by: Unfunded.

Potential Risks:

- Some individuals may experience a minor emotional reaction (potential discomfort, stress, or distress) due to the process of reflection in the individual interview. The nature of the research question and data collection approaches requests introspective personal reflection but not confidential information.
- The Saskatchewan Medical Association physician health program and nurse practitioner employee health programs are available to participants who require personal and professional support at the interview's conclusion. Contact information for post-interview supports will be provided to you at the conclusion of the interview.

Potential Benefits:

- This study will provide new insight into practitioners' decision making within a new clinical context. Enhanced elucidation will steer practitioners' continuing education programs and remediate gaps in supportive care fostering quality, safe workplaces, and satisfying work environments.
- Project results may be used to support MAID programming and health delivery organization policy design, supporting quality care for those at end-of-life.
- Exploring the realities of MAID implementation in relation to practitioner choice inform future iterations of practice statements, identify policy and education needs, and illuminate possible professional association and legal supports.

Compensation:

- No compensation will be provided.

Confidentiality:

- No email addresses, IP addresses, or other identifying information will be part of the study data.
- Email communication and the demographic/context questions will utilize online technology. Email communication will be with a University password-protected account, and SurveyMonkey, the University of Saskatchewan's official online survey system, will be used. All survey information will be hosted on the Survey Monkey server in Canada and is protected by SSL encryption.

- Your email responses and follow-up comments that are considered data will be scanned and anonymized and saved as part of the interview data.

- After study closure, all other corresponding emails will be deleted (and deleted from the trash). All email communication will occur with you from the University of Saskatchewan email addresses on a password protected accounts/computers.

Data Privacy:

- Dr. Donna Goodridge will be responsible for data storage.
- Your interview will be transcribed by a transcriptionist who has signed a confidentiality contract. The transcriptionist will remove any identifying information from the transcripts. The project information/consent form will be kept separate from your transcripts and demographic data.
- Transcripts will be password protected on password-protected computers in locked offices. Data will be kept for five years.
- Researchers will only present de-identifying data. De-identified participant quotations may be utilized in the presentation of the findings.

Right to Withdraw:

- Your participation in the interview is voluntary, and you answer only the questions you are comfortable with or stop the interview at any time.
- After you have completed the interview, your interview data cannot be withdrawn as data collection and analysis will occur concurrently.

Follow up:

- Please forward the project information through your respective professional channels (if you see fit) as part of a robust recruitment initiative.
- Data is intended to be used as part of a doctoral thesis and journal articles, conference presentations, and executive summary documents and may be shared with professional associations, educational bodies, and academic research forums. You may contact the research team to obtain a summary of the research results and copies of any publications.

Questions or Concerns:

- Contact the researcher(s) using the information at the top of page 1.
- This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on April 29, 2019 (REB# 902). Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town, participants may call toll free (888) 966-2975.

A copy of this consent will be left with you, and the signed copy will be taken by the researcher.

For the researcher: "I reviewed this information and consent form with the participant, and the participant had knowledge of its consent and appeared to understand it. The participant was provided the opportunity to ask and have their questions answered prior participation in the project. The participant was made aware the interview was being recorded before consent being obtained on the tape.”

Name of Participant	*Researcher’s Signature*	*Date*

For the participant to read on the recording: “I have had an opportunity to review the project information sheet and ask questions. I understand I will participate in an interview, and the preliminary findings will be sent to me via email for follow-up comment and reflection. My questions have been answered, and I freely provide informed consent to participate in this research project. A copy of this participant information sheet/consent form has been given to me for my records. Todays’ date is_________.”

https://www.surveymonkey.ca/r/MAIDinSK

For physicians:

Thank you for your participation in this project. During participation in this interview, you may have discussed sensitive topics relevant to your practice. It is important for you to know you have the option to seek after-care if you require support or follow-up.

The Physician Health Program provides assistance to colleagues, physicians in training, and their families who may be struggling with various issues, including mental health, relationship issues (professional and personal), substance abuse/addiction, physical health, work, and family concerns. Support is available to physicians throughout the spectrum of their careers, from medical school and residency, through active practice and into retirement. Referral sources and those accessing service can be reassured that all information remains strictly confidential.

Physician Health Program committee members are from various backgrounds and expertise, the common denominator being a dedication to the provision of non-judgmental and confidential assistance and support. Compassionate and knowledgeable in the field of physician health and well-being, they assist struggling physicians and their families in whatever way necessary to access the necessary education, rehabilitation, support, and maximize the potential for physicians to continue in effective medical practice.

To access: Contact Brenda Senger (306-244-2196, 1-800-667-3781 or brenda.senger@sma.sk.ca), Director of Physician Support Programs for assistance. If you require immediate medical assistance, visit your local hospital emergency room.

Source: http://www.sma.sk.ca/programs/44/physician-health-program.html

For nurse practitioners:

Thank you for your participation in this project. During participation in this interview, you may have discussed sensitive topics relevant to your practice. It is important for you to know you have the option to seek after-care if you require support or follow-up.

As a Saskatchewan Health Authority employee, you and your dependent family members have access to various professional support resources and tools under the Employee and Family Assistance Program (EFAP) from Shepell. Shepell is a leading EFAP service provider and offers a wide range of confidential and voluntary support services to help you and your family resolve everyday challenges, complex issues, and everything in-between. You and your immediate family have access to the EFAP at **no cost** to you. The EFAP is completely confidential within the limits of the law. No one, including your employer, will ever know that you have used the service unless you choose to tell them.

To access: Call the Shepell Care Access Centre toll free at 1-844-336-3136 or online access (Canada only) via workhealthlife.com. For crises requiring immediate attention, call 911 or the Shepell Client Care Access Centre at 1-844-336-3136.

APPENDIX E

UNIVERSITY OF SASKATCHEWAN

Donna Goodridge, RN, PhD
Room B523, Health Sciences Building, 107 Wiggins Road
Saskatoon SK S7N 5E5
Telephone: 306-966-4209
Email: donna.goodridge@usask.ca
Web: https://medicine.usask.ca/respiratoryresearch/

Dear Physician/Nurse Practitioner;

I am excited to share a participation opportunity for Saskatchewan licensed physicians and nurse practitioners. I am undertaking a project to understand better the decision-making factors considered by practitioners who currently do not participate in medical assistance in dying. Participation in this project will provide insight into practitioners' decision making within a new clinical context and may be used to support continuing education programs and remediate gaps in employee supportive care, fostering quality, safe workplaces, and satisfying work environments. Additionally, project results may be used to support MAID programming and health delivery organization policy design, supporting quality care for those at the end-of-life. Exploring the realities of MAID implementation in relation to practitioner choice inform future iterations of practice statements, identify policy and education needs, and illuminate possible professional association and legal supports.

I wish to connect with physicians and nurse practitioners who may have thought the following:

1) "I do not know what I would do if I were approached by a patient for MAID related care,"

2) "I might be interested in participating, but have not been approached by a patient,"

3) "I do not think I would participate in MAID related care," or

4) "I would not participate if approach by a patient."

If you relate to these, I would like to meet with you. Please email me at jma401@mail.usask.ca, and I will confirm your participation eligibility and send you a complete participant information/consent form. I will work with you to determine a time, place, and modality for an interview (in-person, telephone, or WebEx). At the time of the meeting, full informed consent will be obtained; you will be asked to complete a brief context/demographic questionnaire and participate in an interview, including questions and vignettes. The interview will be recorded and subsequently transcribed. The questions will explore your current practice context, your feelings regarding potential participation in MAID, reflection on potential situations, and the factors influencing your choices in MAID care participation. It is anticipated that the discussion will take a maximum of 60 minutes. After preliminary data analysis, I will share aggregate findings via email to see if you have any further comments, reflections, or insight.

This project's information and results will support my doctoral project and be shared via multiple knowledge translation venues. Information may be submitted for publication and shared in professional conferences via abstract, poster presentations, or presentations. Information may also be shared with professional associations, employers, and educational bodies. If you wish to have a copy of the publications or documents, please connect me via email. Please feel free to share this letter of invitation to participate through your networks with your colleagues as are you are comfortable.

To arrange participation or to have any of your questions answered, please email me at jma401@mail.usask.ca**.** This email account is only accessed by myself and is password protected. This project was reviewed by the University of Saskatchewan Behavioural Research Ethics Board on April 29, 2019 (REB # 902).

On behalf of myself and the research team, thank you for your consideration.

Janine Brown, RN CCNE Ph.D. (c)

Lilian Thorpe	Donna Goodridge (PI)
Co-Supervisor	Co-Supervisor

APPENDIX F

Social Media (Facebook):

We are looking for Saskatchewan Physicians and Nurse Practitioners to take part in a study to understand better the decision-making factors considered by practitioners who currently **do not** participate in medical assistance in dying. You would participate in an interview and complete a short questionnaire. Interviews can be in person or via phone or WebEx. For more information or to participate, contact Janine at jma401@mail.usask.ca

This study has been reviewed by and received approval through the Research Ethics Office, the University of Saskatchewan, on April 29, 2019 (REB#902). Share this post!

Social Media (Twitter thread)

Retweets Welcome! We are looking for Saskatchewan Physicians and Nurse Practitioners to take part in a study to understand better the decision-making factors considered by practitioners who currently **do not** participate in medical assistance in dying. *1/3*

You would participate in an interview and complete a short questionnaire. Interviews can be in person or via phone or WebEx. 2/3

For more information or to participate, contact Janine at jma401@mail.usask.ca This study has been reviewed by and received approval through the Research Ethics Office, the University of Saskatchewan, on April 29, 2019 (REB#902). 3/3

College of Medicine, Health Sciences Program
University of Saskatchewan

PARTICIPANTS NEEDED FOR
RESEARCH IN MEDICAL ASSISTANCE IN DYING (MAiD)

I am looking for physicians and nurse practitioners to take part in a study to better understand the decision making factors considered by practitioners who do not participate in medical assistance in dying.

As a participant in this study you will be asked to participate in an interview and complete a short demographic questionnaire.

Your participation would involve one session, of which is approximately 60 minutes. Interviews may be in person, or via telephone/WebEx.

For more information about this study, or to participate,
please contact:
Janine Brown, College of Medicine, Health Sciences Program
Email: jma401@mail.usask.ca

(This email account is only accessed by myself and is password protected)

This study has been reviewed by, and received approval through, the Research Ethics Office, University of Saskatchewan on April 29, 2019 (REB #902).

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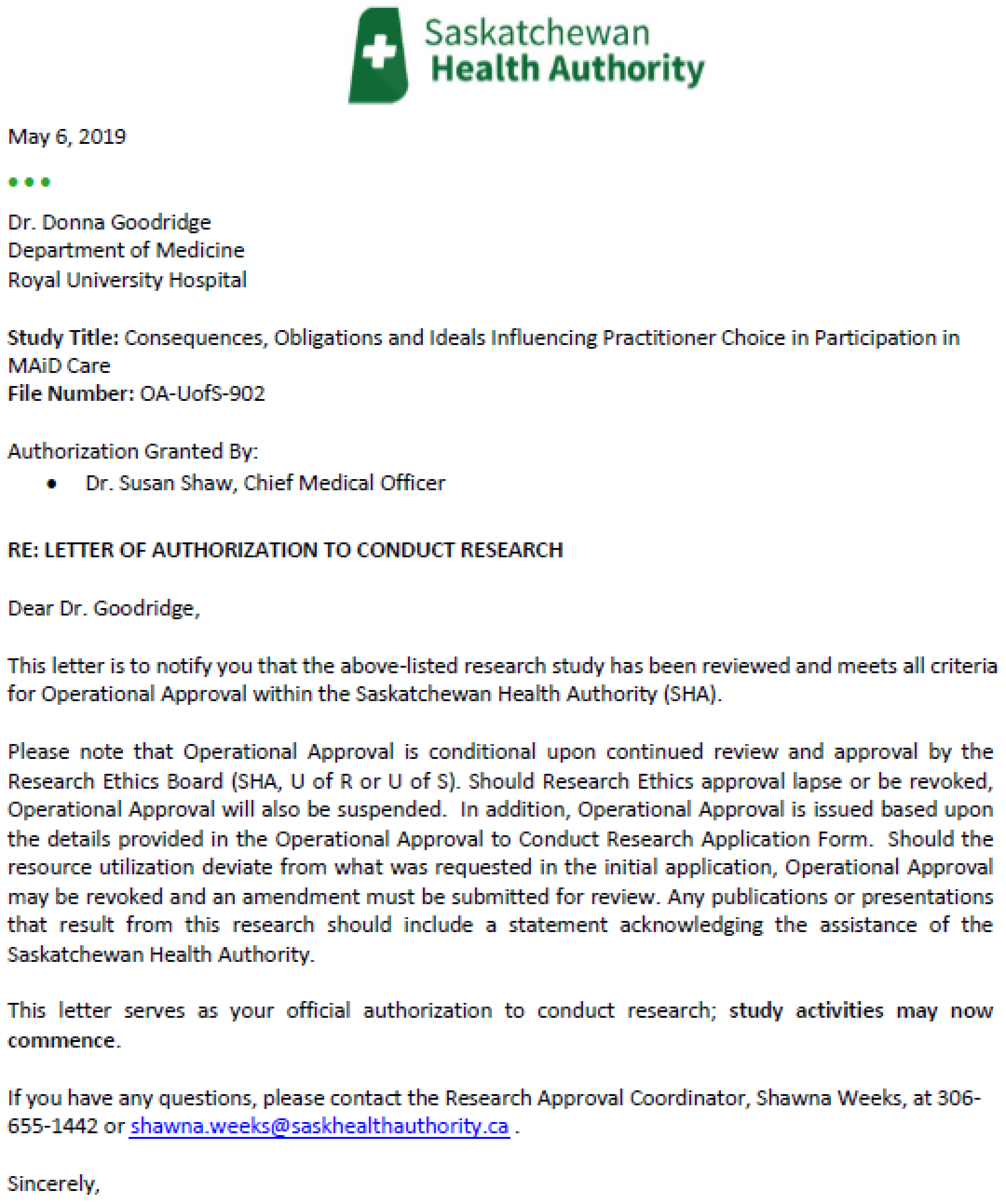
APPENDIX G



Saskatchewan
Health Authority

May 6, 2019

* * *

Dr. Donna Goodridge
Department of Medicine
Royal University Hospital

Study Title: Consequences, Obligations and Ideals Influencing Practitioner Choice in Participation in MAiD Care
File Number: OA-UofS-902

Authorization Granted By:

- Dr. Susan Shaw, Chief Medical Officer

RE: LETTER OF AUTHORIZATION TO CONDUCT RESEARCH

Dear Dr. Goodridge,

This letter is to notify you that the above-listed research study has been reviewed and meets all criteria for Operational Approval within the Saskatchewan Health Authority (SHA).

Please note that Operational Approval is conditional upon continued review and approval by the Research Ethics Board (SHA, U of R or U of S). Should Research Ethics approval lapse or be revoked, Operational Approval will also be suspended. In addition, Operational Approval is issued based upon the details provided in the Operational Approval to Conduct Research Application Form. Should the resource utilization deviate from what was requested in the initial application, Operational Approval may be revoked and an amendment must be submitted for review. Any publications or presentations that result from this research should include a statement acknowledging the assistance of the Saskatchewan Health Authority.

This letter serves as your official authorization to conduct research; **study activities may now commence.**

If you have any questions, please contact the Research Approval Coordinator, Shawna Weeks, at 306-655-1442 or shawna.weeks@saskhealthauthority.ca .

Sincerely,

APPENDIX H

1. By answering yes to the question below, YOUR FREE AND INFORMED CONSENT IS GIVEN for the use of your responses (both on the interview and this demographic collection questionnaire) for research purposes. You also indicate that you understand the conditions of participation in this study, as described, in the written materials provided to you.

Do you consent for your responses to be used for research purposes?

- Yes
- No

2. Which of the below best describes your professional affiliation?

- Family Physician
- Nurse Practitioner
- Medical Specialist

3. How do you describe your gender?

- Female
- Male
- Other
- Prefer not to disclose

4. What best describes your martial status?

- Single/never married
- Married/domestic partnership
- Widowed
- Divorced
- Separated
- Other (please specify) (open text response)

5. What is your age (open text response)

6. How many years have your been in practice (open text response)

7. Where is the location of your practice?

- Large population centre (population between 100,000 or more)
- Medium population centre (population between 30,000-99,0000)
- Small population centre (1,000-29,000)
- Rural area (less than 1,000)

8. What is your primary work area?

- Family medicine
- Physical medicine and rehabilitation
- Surgery (general and specialties)
- Internal medicine (general, geriatric and other specialties)
- Oncology

- Palliative care
- Critical care medicine
- Psychiatry/mental health
- Anesthesiology
- Emergency medicine
- Other (please specify) (open text response)

9. How significant is faith, religion, or spirituality to you?
   - Extremely significant
   - Very significant
   - Significant
   - Neutral
   - Not significant

10. Which of the following best describes your belief system?
    - Buddhism
    - Hinduism
    - Islam
    - Judaism
    - Non-denominational Christianity
    - Protestant
    - Roman Catholic
    - Sikh
    - Agnostic/Atheist
    - Other (please specify) (open text response)

11. What percentage (%) of your patients have life-limiting illness?
    - 0-19%
    - 20-39%
    - 40-59%
    - 60-79%
    - 80 or more

12. How many of your patients (with life-limiting illness) have died over the previous month? (provide approximate number) (open text response)

13. How many of your patients (with life-limiting illness) have died over the previous year? (provide approximate number) (open text response)

14. Are your responses today informed by:
    - An actual patient care request (i.e. I have had a patient wish to discuss MAID with me)
    - A hypothetical patient care request (i.e. I have not had a patient wish to discuss MAID with me)

APPENDIX I

Opening Questions:

Questions and their relation to Ruggiero:	Rationale and Plan:
1) Tell me about your current practice. **(Obligations)** Related questions: ● How many years have you been in practice? ● What is the age-range of patients typically cared for? What proportion of patients have life-limiting illnesses and what types of life limiting illnesses do you typically see? ● How many of your patients have died over the previous month? In the last year? ● Tell me about your understanding of the MAID legislation.	Opening questions to facilitate building of an open and comfortable dialogue. Obtain understanding of practitioners practice context. Obtain a baseline understanding of participant’s knowledge regarding MAID.

Exploratory Questions:

Questions and their relation to Ruggiero:	Rationale and Plan:
2) In your current practice, do you routinely participate in end-of-life care discussions? ● If yes, ○ Are these discussions patient or practitioner initiated? **(Obligations)** ○ How have end of life care discussions (with your patients, your colleagues, your own families) changed since MAID legalization. **(Obligations, Consequences, Ideals)** ● If yes or no, ○ What is it like to work in your practice setting since MAID legalization? **(Obligations, Consequences)**	Exploratory question to facilitate understanding of practitioner care context (patients and colleagues) and within the criteria of obligations and consequences. Also through exploration of end of life care discussions with their own family, reflection will occur around individual ideals.
3) Which one of the statements best reflects your feelings regarding participation in MAID related care: (**Obligations, Ideals, Consequences)**	Broad exploratory questions with options for follow-up.

A) *“I don’t know what I would do if approached by a patient for MAID.”* B) “*I don’t think I would participate in MAID.”* C) *“I might be interested in participating.”* D) *“I would not participate.”* ● If answered A, B or C, ○ Tell me about your hesitations. ○ How could colleagues, patients, regulators, and/or health system leadership support you in working through your hesitations or uncertainty? ● If answered D, ○ Tell me about your thoughts that brought you to your choice. ○ Are there any circumstances when you would consider participation? If so, what would they be?	Statements will be provided on cards for participant consider the wording choices prior to/during discussion. This question will be used to start the conversation regarding the factors practitioners are considering when approached by a patient for MAID related care. Follow-up questions exist to explore with those who are sure they would not participate and for those who are less certain of their degree of participation.
4) The health authority, in partnership with your professional regulator, is considering offering a continuing education opportunity to support practitioners in relation to MAID care provision. Question: How likely is it you participate in this training? Tell me about your choice. **(Obligations, Consequences, Ideals)** Question: What is hold you back from participating? **(Consequences, Obligations, Ideals)** Question: How do you view this training and education in relation to your current practice? **(Obligations, Ideals)**	Questions to explore participant participation in training/education events. A hypothetical conference invitation/flyer may be presented for the participant’s reference.

Vignettes:

Questions and their relation to Ruggiero:	Rationale and Plan:
5) “You are the care provider for a 67-year old patient diagnosed with stage 4 metastatic breast cancer four years ago. At that time, the patient underwent a bilateral mastectomy and follow-up oncology care. The patient currently presents with headaches, drowsiness and vision changes. A significant malignant frontal lobe brain lesion	Introduction vignette by stating “I will read you a short scenario and then ask you to share your reflections and responses in relation to the different levels of care provision.” Scenario will be provided on a card for the participant to refer back to.

was discovered on an MRI. Specialists believe it may be partially resected and reduced further with subsequent treatment. The patient, after consulting with her adult child and spouse, request palliative care. This has been arranged.” **(Obligations, Consequences, Ideals)** a) On follow-up appointment, the patient states she is very pleased with palliative care and her symptom control but continues to rapidly lose her vision. She also asks you for information on MAID, including eligibility and how to access care. <u>Question:</u> Do you provide information regarding MAID to your patient? Tell me about your choice. <u>Question:</u> If not, do you consider referring the patient to another practitioner? <u>Question:</u> What factors are particularly difficult to consider? b) This patient presents for a follow-up appointment and arrives with MAID information and assessment forms. She asks you for a formal assessment to determine if she would qualify for MAID. <u>Question:</u> Do you provide an assessment? Tell me about your choice. <u>Question:</u> What factors are particularly difficult to consider? c) This patient has been deemed eligible for MAID through the assessment process. As one of her care providers, she asks you to be present on the day of her chosen death to provide emotional support to her and her family. <u>Question:</u> Do you agree to be there? Tell me about your choice. <u>Question:</u> What factors are particularly difficult to consider?	Content and characteristics of this vignette are controlled and variables will not be changed or manipulated across participants. The patient represented in this vignette is one with a substantial life-limiting illness, symptoms and access/utilization of palliative care services/approaches. This unfolding vignette will encourage the participants to consider MAID participation at various levels, each exploring a greater depth of participation with each unfolding layer. The aim will be to explore the decision-making factors as the level of MAID involvement progresses. Scenario is generic to be applicable to all within the inclusion criteria.

d) The patient asks you to be her MAID provider and administer the medications. <u>Question:</u> Do you administer? Tell me about your choice. <u>Question:</u> What factors are particularly difficult to consider?	
6) **For physicians:** a) You are at a professional development conference and part of a physician panel of experts discussing the Canadian Medical Association Code of Ethics in relation to emerging practice areas. Your group is discussing the physician's responsibility to 'consider first the well-being of the patient' when a patient request MAID. <u>Question:</u> How do you explain the Code of Ethics in relation to MAID? **(Obligations, Ideals)** b) During the question/answer section of the panel discussion, a conference participant asks "how do physicians' practice professionally when their personal beliefs do not align with the care a patient requests?" <u>Question:</u> How do you respond? **(Obligations, Ideals)** <u>Question:</u> What factors are particularly difficult to consider? c) During the conference nutrition break, the discussion continues at your table. One colleagues states "physicians have a duty to respect patient choice." Another colleague states "physicians can choose what care they provide." They turn to you and ask you your thoughts. <u>Question:</u> How do you respond to your colleagues? <u>Question:</u> How easy or difficult is it for you to participate in this conversation with your colleagues? <u>Question:</u> How does conscientious objection fit within this discussion? **For nurse practitioners:**	Introduction vignette by stating "I will read you a short scenario and then ask you to share your reflections and responses in relation to your profession, your beliefs and MAID." Scenario will be provided on a card for the participant to refer back to. This vignette is contextual and will be altered to the practitioner type (NP or Physician). However, the questions will be the same for each practitioner group. This vignette was designed to explore the participant's reconciliation of their professional Code of Ethics and current understanding of obligations to the MAID practice context. Secondary goals of this vignette are to explore the ethical considerations of practitioners in relation to what they think and believe, what their professional code says and what their patients may request. Question is guided by the CO spectrum (moral absolutism versus professional absolutism). The goal of this question is to explore the perceptions of practitioners with regards to the application of CO.

a) You are at a professional development conference and part of a nurse practitioner panel of experts discussing the Canadian Nurses Association Code of Ethics in relation to emerging practice areas. Your group is discussing nurse practitioner's responsibility to "promote health and well-being' when a patient requests MAID. Question: How do you explain the Code of Ethics in relation to MAID? **(Obligations, Ideals)** b) During the question/answer section of the panel discussion a conference participant asks "how do nurse practitioners practice professionally when their personal beliefs do not align with the care a patient requests?" Question: How do you respond? **(Ideals)** Question: What factors are particularly difficult to consider? c) During the conference break, the discussion continues at your table. One colleagues states "nurse practitioners have a duty to respect patient choice". Another colleague states nurse practitioners can choose what care they provide." They turn to you and ask you your thoughts. Question: How do you respond to your colleagues? Question: How easy or difficult is it for you to participate in this conversation with your colleagues? Question: How does conscientious objection fit within this discussion?	

Wrap-up:

Question:	Rationale and Plan:
7) Is there anything else you would like to tell me that I have not thought to ask?	Participants have the opportunity to add any information or clarify any discussions before concluding.

APPENDIX J

Descriptive Field Notes: Who, What, When, and Where and How

Interview Date: ________________________ (When)

Participant ID (code or initials): _________________________ (Who)

1) Observations of physical environment (Where)
2) Participant appearance, behaviour, mannerisms (Who)
3) Specific words, phrases or insider language used (What)
4) Significant interview events and statements (What)
5) Description of the encounter/interview (How)

APPENDIX K

Analytical and Reflective Content:

Interview Date: __________________________

Participant ID (code or initials):__________________________

Date of Reflection: _______________________

1) What would might you follow-up or clarify with this contact?
2) What would you ask differently?
3) What were the main issues or themes that struck you in this interview?
4) Summarize the information you obtained or failed to obtain on within the interview guide.
5) Is there anything that stuck you as salient, interesting, illuminating or important?
6) What new questions did this bring forward?
7) How did you feel through this interview process?

APPENDIX L

Dear Participant,

We are sharing with you the preliminary findings from the project you participated in during the summer and fall of 2019. In this document are some visual graphics and a narrative of the preliminary project findings capturing the range of factors and decision-making considerations heard during the interviews. The data is a representation of the conversations as a whole so you might not see your interview reflected in every detail, but you will recognize *elements* of your interview. Additionally, you can see what others are experiencing.

A total of 35 individuals were interviewed from across Saskatchewan, 18 nurse practitioners (NPs) and 17 physicians. In this sample:

- 12 of you identified as male and 23 identified as female;
- 16 were from large population centres, 3 from a medium population centre, 9 from a small population centre, and 7 from a rural population centre;
- 21 worked in family medicine or primary care, and 14 worked in specialty practice areas;
- 19 rated spirituality/faith beliefs as significant to extremely significant, 13 were neutral on the significance of faith/spirituality beliefs, and 3 stated faith/spirituality beliefs were not significant;
- Approximately 25% of you stated responses were informed by an actual request by a patient for MAID;
- Approximately 40% stated there would be no participation in MAID related care beyond the facilitation of the referral.

Interviews were transcribed and any potentially identifiable information was removed. The transcripts and the reflective interviewer content were uploaded into NVivo12 and with this program, the data was coded and categorized into themes formulating the eventual factors and decision-making considerations. Many codes repeatedly rose through the transcripts while others were less frequent but compelling and all were added to the spectrum of considerations from the interviews. Dr. Donna Goodridge and Dr. Lilian Thorpe reviewed the data, resultant themes and visuals. We desired to represent all of your voices within the constellation of factors influencing choice and decision-making considerations.

In this project, we sought to identify the factors considered by physicians and NPs (who currently do not participate in MAiD related care) when contemplating MAiD participation. Decision making is an inherently individual and internal choice. We conceptualized that some of the factors and decision-making considerations originated from within the individual (endogenously), and other factors and decision-making considerations originated external to (exogenously) the individual.

Endogenous Factors and Decision-Making Considerations

The overarching theme within the endogenous factors and decision-making considerations is *reconciliation* (Figure 1). This harmony or compatibility is not necessarily an endorsement of MAID, but an expression of your care choices being consistent with your intrinsic selves. Self-reconciliation and aligning the endogenous factors and decision-making considerations with your intrinsic selves was unique to each of you. For some of you this was knowing definitively when participation in MAID related care was not possible, and for others it was knowing that care participation may be further considered. For those of you who knew care participation was not possible, there was a desire for care options (mechanisms for referral), safe passage (ability to speak with direct reports, colleagues, professional bodies, patients and families without fear of reprisal or disdain), respectful, satisfying systems to support your choices, and recognition that your perspectives were important.

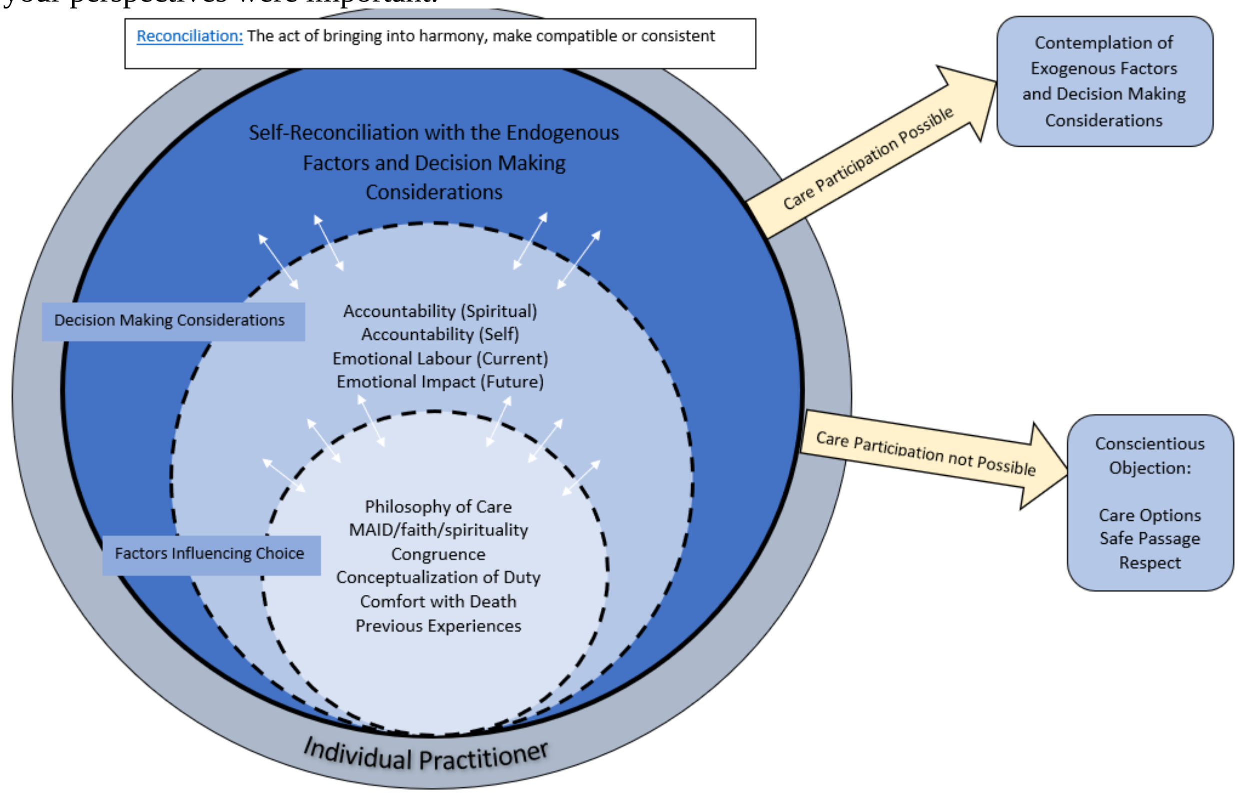


Figure 1: Endogenous factors influencing choice, decision-making considerations and needs

The range of factors influencing or underpinning individual choice are:

Factors Influencing Choice:	**Articulation:**
Philosophy of Care:	Many of you were considering how MAID fits into existing philosophy and approach to end-of-life (EOL) care, for some of you, this included how MAID did not fit into your palliative approaches and included articulations of the benefits of palliative approaches. Others conceptualized how palliative care and MAID were not mutually exclusive EOL options.
MAID and Faith/Spirituality Congruence:	Many of you were reflecting how MAID resonated with your faith or spiritual beliefs. Some of you shared how MAID did not align with your core spiritual beliefs, and some of you discussed how MAID was internally aligned to your faith or spiritual beliefs. Some discussed the importance of spirituality and faith aligning with your core beliefs as it provided you an inner strength.

Conceptualization of Duty:	Many of you were considering how MAID aligned with your conceptualization of professional duty and you reflected on how MAID fit into your professional practice and obligations to your patients, on how you viewed your potential participation in this practice area, and how MAID aligned or did not align with the tenets of your profession. Some of you articulated MAID was a privilege and it would be an honour to accompany the patient to "close the loop in the care being provided" as a "completion of duty." Some of you were clear that MAID was counter to your professional duty. Others were still working through the alignment of MAID and professional duty.
Comfort with Death:	Some of you were recognizing the varying degrees of healthcare provider comfort when participating in end-of-life care and that care participation choices were influenced by your comfort with end-of-life care.
Previous Experiences:	In reflecting how personal and professional previous experiences affected your thoughts regarding MAID, you shared personal experiences about yourselves including living with advancing illness, having a close family member die, or having a family member with advancing illness or disability. You also shared your previous professional experiences and articulated how these informed your perspectives on end-of-life care and MAID.

The endogenous decision-making areas under considerations are:

Decision-Making Consideration:	**Articulation:**
Spiritual Accountability:	You were considering your accountability to a higher power.
Accountability to Self:	You were articulating the need to feel at peace about your individual choices and to self-account for your actions.
Emotional Labour (Current):	You were considering the costly and complex emotional expenditures that care participation may involve. Emotions included guilt of participation in any way, fear of the impact of an assessment error on the patient or family, "second guessing" during the assessment and decision-making process, sadness and grief in the death of an individual, and how potential moral distress would compound work environments already fraught with emotional and ethical distress.
Emotional Impact (Future):	You were considering how participation in MAID care would impact your emotional future. These concerns included PTSD, burnout, losing the sense of significance and its potential impact on family interaction and future quality of care, and feeling isolated and feeling a lack of sustained connection between those engaging in MAID.

Exogenous Factors and Decision-Making Considerations

After self-reconciliation and considering if care participation may be possible, some of you are further undergoing a process of intentional contemplation (overarching theme) with MAID and the exogenous factors and decision-making considerations (Figure 2). The factors and decision-making considerations are extensive, complex, and sometimes interrelated. Not all the exogenous factors and decision-making considerations were noted by all of you as this is a representation of the data set as a whole. Those of you at this level of intentional contemplation need care options (mechanisms for referral), time, trust, model of care clarity, removal of practice barriers, open conversations, enhanced, practical, education opportunities, and research to support evidence informed practice.

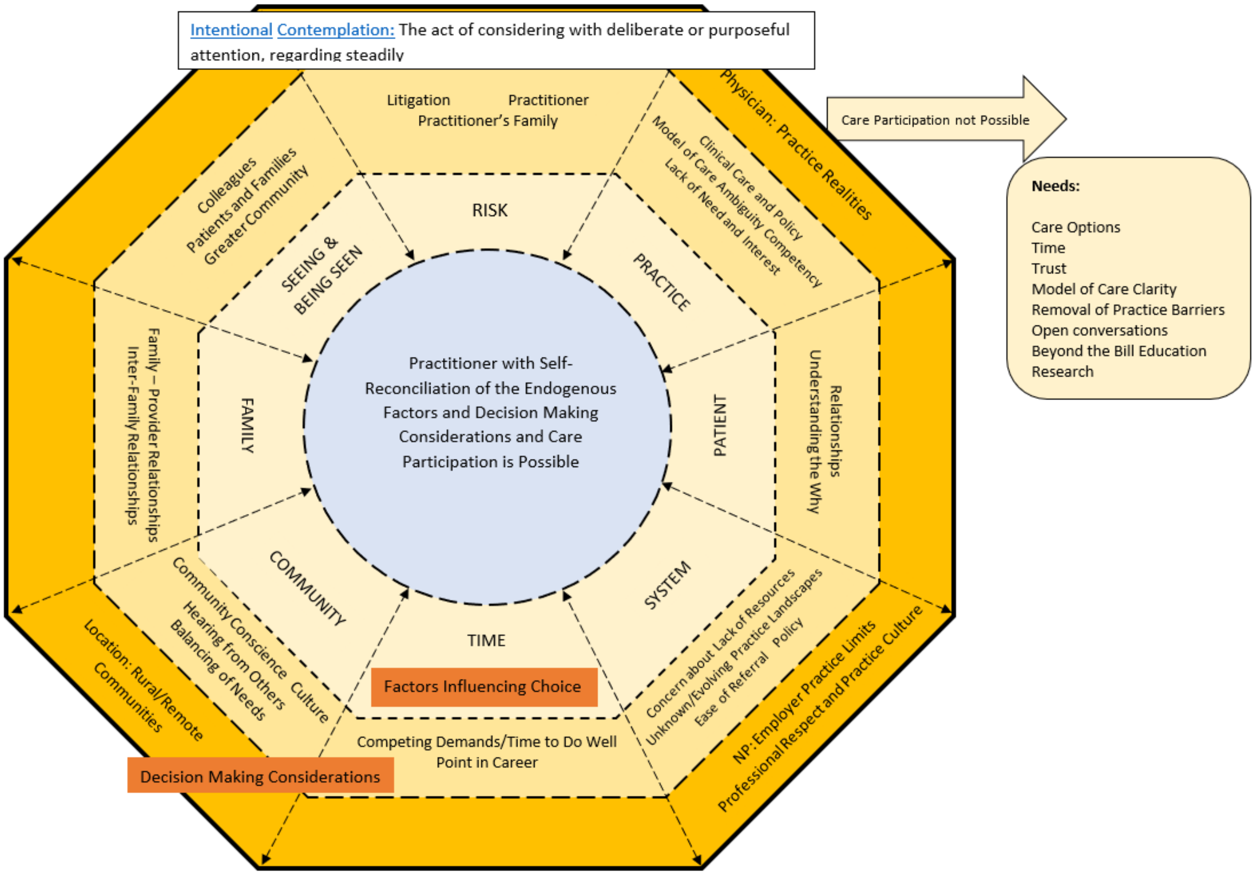


Figure 2: Exogenous factors influencing practitioner choice and practitioner decision-making considerations

Factor:	**Decision-Making Consideration:**	**Articulation:**
The Influence of Time	***Competing Demands/ Time to do it***	Some of you were expressing that while there are tools to assist in caring for those with chronic illnesses end-of-life care conversations may not be the highest priority given patient/provider time and competing priorities in chronic care management and the clinic time available. Many of you recognize that to provide MAID related care, the patient and family deserve the time to have it done 'well' and time constraints in a robust practice are prohibitive to that.

		Time constraints and competing demands were also noted as prohibitive to continuing education concerning MAID.
	Point in Career	Some of you were considering your participation in MAID in relation to your overall career trajectory. Some were identifying as being close to your career end and didn’t want to take on new challenges. Some of you were identifying as being in the prime of your career, but may consider participation in MAID closer to the “slowing down” of your career. MAID was perceived to natural fit when there was significant clinical experience as opposed to newer care providers.
The Influence of Your Practice Realities	***Clinical Care and Policy***	Some of you were expressing substantial questions regarding clinical care practicalities in your location. Others of you who were primarily involved with patients in episodic care and identified constraints of place appropriateness of MAID conversations.
	Model of Care Ambiguity	You were considering how MAID fits into your practice. There was uncertainty if MAID “belonged” as an extension of palliative care, or within family practice, or as a specialty practice area with interested individuals from a variety of practice backgrounds. There was a feeling of not knowing “where” and “how” the care would be best delivered or how it would fit with your context. This impacted your interest and ability to partake in education events regarding assessor or provider level of MAID involvement.
	Competency	Many of you identified competency, skills, and abilities as a limiter to your potential participation. This included knowledge of assessment criteria, forms and paperwork, medications, timing, navigation of patient conversations and managing challenging conversations, mentorship and peer support, understanding what competency encompasses, and how to maintain competency when done infrequently. Desire to attain competency was strongly impacted by how you envisioned MAID in relation to your current practice setting.
	Lack of Need and Interest	Some of you noted that MAID did not align with your areas of practice interest or perceived practice strengths and this limited the need to consider participation in a more formal manner. Some of you perceived that within your practice context, it would be unlikely that a patient would bring the MAID

		discussions forward, which underpinned the perceived lack of need to be involved.
	Practice Realties (specific to physicians)	Regarding physicians, some of you noted you had substantial questions and extremely limited knowledge of practice practicalities in your various locations. This included how it would be financially feasible or practical given clinic costs and other considerations such as malpractice insurance.
The Influence of Risk	***Litigation Risk***	Some of you identified concerns regarding legal risk when contemplating participation. You discussed the need to document your non-involvement and referral (to avoid claims of abandonment), concerns about your assessments being called into question, risk of losing your practice license, the need to have neutral witnesses at the MAID death to confirm independence and non-coercion, and risk if the family is not in unanimous agreement with patient choice.
	Practitioner Risk	Some of you were considering your safety and well-being concerning MAID involvement. This included your professional life ‘being made difficult’ by colleagues, or, risk of physical harm or violence from extended family members.
	Risk to Practitioner Family	Some of you were considering your own family’s safety (physical and other) when contemplating MAID involvement.
The Influence of Seeing and Being Seen	***Colleagues***	Some of you were considering how colleagues would see you if you participated in MAID. Some of you noted concern regarding how colleagues of the same faith group may judge you if you participated in MAID. Some of you talked about not having to “stick your neck out” because other practitioners were assessors and providers already. Some of you expressed a need to keep potential MAID participation private and confidential out of concern that the clinic staff would think less of you as clinicians. Some of you were considering how colleagues would see you if you were **not** participating in MAID. This included the fear that if you were not participating in MAID or supporting client choice that you were shirking your care responsibilities and thus you should not practice medicine. Some were feeling colleagues would not be happy with the choice of not “going along” with the norm. Some of you were reflecting on how your perceptions might change of your colleagues that participated in MAID, including surprise by your

		colleague's practice choices, and, while noting colleagues good intensions wondering “how” they could practice in such an area or viewing their practice approach differently.
	Patients and Families	You were considering how other patients in your practice or how patient’s family members may view you if you participated in MAID. Some were noting this concerning mental health and suicide prevention discussions (i.e., you helped another patient die, why will you not allow me to die), that it may look like a healthcare practitioner “gave up” on a patient, and, that participation in MAID related discussions may give the impression of being supportive of MAID. Concern was expressed that even if you didn’t conscientiously object, that your participation or facilitation of care could impact your patient/provider relationships for patients who would never consider MAID.
	Greater Community	Community was noted to be either a community of residence or a faith community. Some of you discussed how your greater community may view you if it was known that you participated in MAID (i.e., the perception that healthcare providers are killing people). There was concern that while healthcare providers are bound by confidentiality, there is a chance your participation could be communicated to the greater community by patient or family members themselves. There was concern about how you may be viewed within your faith communities and if your participation in MAID would impact or alter other individual’s faith beliefs, or harm your relationship with others.
The Influence of The Patient	***Relationships***	The patient relationship was a highly significant decision-making factor. Some of you noted that you would feel potentially more comfortable in MAID care provision without the personal connection to the patient (and wondered if the patient/family would be more comfortable without the relationship). Others stated a sustained, deep relationship with the patient and family would positively influence your likelihood of participation. Additionally, it was viewed that a trusting, long-term, open relationship would facilitate end-of-life (including MAID) conversations for patients and healthcare providers. Without this open trusting relationship, conversations about MAID care would not proceed. In an established, mutually

		respectful, patient/provider relationship, non-participation can be communicated and respected. You noted that disengaging from the patient/provider relationship when there was conscientious objection was fairest to both the practitioner and the patient.
	Understanding the Why	Some of you were expressing the great importance of understanding the patient and family journey that brought the patient to the point of considering MAID. This was not out of judgement, but out of a need to understand. The process of understanding the patient's decision-making was as important as honouring the decision itself.
The Influence of The Family	***Family-Provider Relationships***	You often considered not just the patient, but your relationship with the family when contemplating MAID participation. Many of you stated you would take time to know the patient's family as much as the patient. Others of you were considering how MAID participation would impact the ongoing patient/provider relationships with the family members after the MAID death occurred (i.e., how participating in MAID would impact the therapeutic relationships with family members going forward). You were considering how you would provide support (i.e., the juggling or balancing of needs) to the family members in advance of MAID, during the MAID death, and post-MAID. You were considering what resources you would have, or what interdisciplinary team members you would have (or wish to have) to support this.
	Inter-Family Relationships	You were considering inter-family dynamics when contemplating MAID participation. Familial discord was a significant consideration negatively impacting participation. Conversely, when family members were supportive of the patient's MAID request, this was viewed as not hindering MAID participation. You were considering how a MAID death would impact inter-family relationships in the present, as well as, going forward and into the future.
The Influence of The Community	***Community Conscience***	Some of you were considering the greater communities' sensitivities concerning MAID and identified challenges in balancing the perceived conscience of the community. You identified cues such as openness of other EOL conversation (i.e., DNRs, advanced directives), availability of sexual health clinics, assessing the predominant age of your patients (i.e., older being more conservative and

	religious), perceived communities’ dominant religious beliefs, providers’ relationship with the community, communities’ history with suicide, and the impact of MAID on other residents in a care home or assisted living.
Culture	You expressed uncertainty on how the patient’s culture might influence assisted dying and what the cultural perspectives of MAID may be. Further you considered how MAID may impact the fragile trust between professions and some cultural groups. Some of you highlighted the ongoing complexities of using interpreters (i.e., barriers in moving the conversations forward, gatekeeping or refusing to bring up provider’s questions to patients, breaching confidentiality when family members or extended family are interpreters). Working within diverse populations was perceived to amplify the challenge of participation significantly.
Hearing from Others	Some of you were sharing what you had heard from families, friends or colleagues with regards to the current state of MAID programming. This ranged from favourable impressions of MAID encounters to negative encounters and emotional impacts on staff and family members. In the early stages of MAID program development, care providers were “watching” and “listening” to the experiences of others which influenced your degree of interest and participation.
Balancing of Needs	You were considering how to juggle the “needs of many” versus the “needs of one” and how care the care for other patients may have to be sacrificed in order to participate in MAID. This included concern of limited practice time allotted to rural clinics and how to provide adequate care to other patients and families in large practice contexts.
Location (specific to rural/remote communities)	Some of you in rural and remote areas were expressing an extra sense of obligation to participate. You were concerned that if you did not support, facilitate, or participate in MAID care, there would be unfair consequences to the patient. Those of you in rural and remote areas were conflicted with this, as referral may mean travel costs or “burdens” to the patient and family to access MAID related care in other centres. Those of you in a single healthcare provider practice area may feel pressure to provide MAID to support patient access.

The Influence of the Greater Care Delivery System	***Concern about Lack of Resources***	You discussed concerns about the scarcity of EOL resources including palliative education for nurses and physicians and limited availability of non-MAID options (i.e., lack of palliative homecare or limited homecare hours, lack of respite, lack of palliative care inpatient units, lack of inpatient space to admit a patient for pain control). In areas of insufficient homecare, it was noted family frequently provided care which may be burdensome and unsafe. You expressed concern that patients were aware and even fearful of the impact of the scarcity of EOL resources on patient's EOL choices. There was concern that MAID was more available than palliative care or adequate chronic care support. You were concerned about the availability of post-MAID resources and appropriate after-care options for family. You were wanting the system gaps in EOL care to be addressed.
	Unknown/evolving practice landscapes	Some of you were highlighting that "newness" of the practice and rapidly evolving the practice landscape were areas that hindered your participation. You felt there was not enough Canadian experience with models of practice or research to support evidence-based clinical care.
	Ease of Referral	You were considering the ease or challenge of referral for a patient requesting MAID related care. In situations when the referral process was well known, or the MAID assessors and providers were known, referral was thought to be easy and the most likely option to support patient choice without directly participating. For others, having a known and relatively easy referral meant you could readily align your discussions with patients and families with your chosen level of participation.
	Policy	For some of you, the limits of policies were a source of comfort. In these situations, you did not have to explain your intrinsic selves as non-participation was determined at the policy level. Others expressed frustration by the limitation of your practice by faith-influenced policies.
	Employer Practice Limits (specific to Nurse Practitioners)	Some NPs were explaining your employer practice limits were barriers to participation. This included remuneration structures, limiting job descriptions, divisions between care teams (i.e., palliative care versus homecare), managerial discretion for time to participate, ability to roster patients, and ability to admit patients to a hospital.

	Professional Respect and Practice Culture (specific to Nurse Practitioners)	Some NPs expressed you felt marginalized at the onset of conceptualizing the MAID program resulting in resentment and frustration. Some noted a perception that NPs were not brought into the conversation as MAID assessors and providers until there was a scarcity of physicians, which you attributed to an overall lack of appreciation and respect for the NP practice. You cited examples of not being included in health authority communications regarding MAID, non-responses to volunteering to provide MAID care, NPs scope of practice increasing or decreasing based on other physician availability and "first choices," and, in some circles, NPs not being part of the physician's circle.

We invite your reflections and comments via email on these preliminary findings (Janine Brown at jma401@mail.usask.ca). We will consider all feedback in the final data analysis. As noted in the participation information/consent, your email will be anonymized and included as part of the final data set.

It has been an honour to do this research, and we hope we have accurately represented your experiences. We sincerely thank you for sharing yourselves, your time, and your experiences.

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