Witness to Medically-Assisted Dying in Canada

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Abstract

The central objective of this study is the elicitation of the lived experience of individuals surrounding medically-assisted dying (MAiD) in Canada. An introductory analysis of the current place of MAiD in Canada forms the philosophical basis for the contribution of individual participants. Participants considered their experiencing of the 2016 introduction to medical assistance in dying in Canada, considered how that experience evolved over the subsequent three to four years, and considered the experiential impact of medically-assisted dying at the level of meaning, belief, or spirituality. Three groupings of participants are included: medical professionals; those who provide care for the bereaved; and community actors. Participants from within each of the three groupings went on to consider their singular experience. This study contributes to understanding, through these early experiences of the new MAiD regime in Canada, the ethics surrounding dying in the first quarter of the 21st century. How does Canadian society now assign value to life? Not merely the exclusive purview of elderly patients in rapid decline, the new way of dying through MAiD informs our living together throughout the lifespan. Delineating gradations of acceptance of assisted dying enhances the status-based rights foundation for ongoing dialogue concerning MAiD in Canada and beyond. The aim of capturing the essence of participants' lived experience before the five-year governmental review superseded the desire to build a larger sample, with more comprehensive representation. Despite a modest sample, the study provides a broad range of experiences rather than highlighting one specific group's involvement with MAiD. Far from providing a clearly defined dichotomous break down, various nuances of the ethics surrounding MAiD's application were discerned and form the basis for ongoing dialogue, identifying changing values, and future public policy development.

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Abbreviations

Acronym or Initialism	Meaning	Page
AMA	American Medical Association	20
CHPCA	Canadian Hospice and Palliative Care Association	10
CMA	Canadian Medical Association	38
CSPCP	Canadian Society of Palliative Care Physicians	10
CEJA	Council on Ethical and Judicial Affairs	24
DWDA	Death with Dignity Act	4
MAiD	Medical Assistance in Dying	ii
PAD	Physician-Assisted Dying	4
PSW	Personal Support Worker	110
SCC	Supreme Court of Canada	3

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Introduction

During the entire length of this research project, from inception to completion, several prominent Canadian's died. Some of those deaths reverberate through songs, and the melodies within. The project began around the time of Gord Downie's agonizing primal scream – *Lemme out!* – as the Tragically Hip's final concert came to a close in August 2016, an event broadcast live across Canada on the CBC, viewed by one-third of the population (CBC, 2016). Fourteen months later, the anticipated news of Downie's death sounded across the country like an unmuted cymbal. Three months after that final Hip show, news came of Leonard Cohen's death. Then in August 2017, another Montrealer and famous piano teacher Daisy Peterson-Sweeney died. In 2018, it was country music star Ronnie Prophet. Fifty-seven-year-old John Mann of North Vancouver's Spirit of the West died far too soon in November 2019. To bookend this project, 2020 began with news of the death of Canadian music legend Neil Peart, drummer and lyricist of the iconic rock band Rush. Salome Bey, "Canada's First Lady of the Blues," died as the summer of 2020 waned – the COVID-19 summer. Of course, many more less prominent, less musical, Canadians died during the span of this research project, around 275,000 per year according to Statistics Canada, and a small percentage of those thousands chose to end life through medical assistance in dying, the first ever to do so in Canada (Statistics Canada, 2020).

We are all going to die, at least as it stands in 2021, and along the way we will suffer, often profoundly. The very realization of death coming as it does at an early age provokes suffering, something incumbent on every person to internalize and ultimately accept, though many do not. Try as we might, attempting to avoid the reality of death does not seem to alleviate attendant suffering, and it likely enhances it in the long run. Many hold to live authentically we must come to embrace our mortality and the understanding that reaching a level of acceptance

concerning our death invites and even necessitates suffering, suffering as a means not an end. As much as we may strive to avoid suffering and the concomitant reality of death, the two, one inviting the other, remain inextricable from the human experience. We are left either attempting to shield ourselves from it or moving toward accepting it. Suffering validates the depth of that human experience we all share.

What role might government play in accessing the relief of suffering along the road toward eventual death? If at the heart of compassion lies the relief of suffering, does government have a responsibility to pursue compassion in its governing? The consensus seems to affirm, at least since the Great Depression of the 1930s, and more specifically in Canada since the limited, initial iteration of universal health coverage in the province of Saskatchewan, two years following the ending of World War II, government should maintain a role in the relieving of suffering, generally through social welfare programs, and especially access to healthcare. In Canada, the mandating of "reasonable access to health services without financial or other barriers" serves as the most obvious stated expression of compassion, even when the delivery does not seem to match the stated intention (Canada Health Act, 1985, p. 5). If assisting someone in hastening death is, under prescribed circumstances, an act anchored in compassion, it makes sense for volunteering members of the Canadian medical community to provide the provision of that assistance. If assisting the hastening of death is not a compassionate response, because the elimination of suffering is not always primarily compassionate, though approaching and reducing suffering regularly displays compassion, then it fails to follow accordingly the medical community, Canada's purported centerpiece of shared compassion, has an appropriate role in hastening the death of a human being. If the hastening of death can under prescribed circumstances be considered compassionate (and in fact it remains vital the two are inextricably

linked, lest patients become nameless) the question remains: Under what parameters in Canada is assisting in death an act of compassion?

Gauging the place of medically-assisted dying in Canada remains a challenging proposition. To a certain degree its standing remains in flux, even following the landmark 2015 Supreme Court of Canada (SCC) decision in *Carter v. Canada (Attorney General)*, and the 2016 royal assent of Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*. The intervening years saw occasionally jarring and intermittently manoeuvrable integration of medically-assisted dying in the provinces and territories. There was the 2017 *A.B. v. the Attorney General of Canada and the Attorney General for Ontario* decision, which further clarified the parameters around a physician's interpretation of the "reasonably foreseeable" clause found in Bill C-14, and the Quebec Superior Court ruling in *Truchon v. Procureur Général Du Canada* (2019), which moved the federal government toward still further clarification surrounding what defines "reasonably foreseeable," challenged the requirement for imminent death, and provided the impetus for ongoing consideration of amendments to the existing federal legislation. Consideration of the inclusion of requests by mature minors, advance requests, and requests where a mental disorder is the sole underlying medical condition rounded out the intervening years. Despite considerable support among Canadians for the capacity of autonomous individuals, under prescribed circumstances, to legally decide to end life – as it has turned out, almost always with a physician or nurse practitioner carrying out the procedure (euthanasia), rather than individuals carrying out the procedure

independently, at the time and place of one's choosing (physician-assisted dying) – there remain gradations of how that support translates, and that too likely remains in flux.[1]

Considering the place of assisted dying in various jurisdictions throughout the United States, helps in understanding the broader context for medical assistance in dying in Canada. Whether or not an individual determines to carry out a physician-assisted death (PAD), which is currently the established protocol in 10 jurisdictions within the United States, or receives a medically-assisted death in Canada, significantly impacts the number of individuals pursuing an assisted death overall. Looking at 2018 for example, the Canadian province of British Columbia recorded 773 medically-assisted deaths during the first 10 months of that year, from January 1, 2018 through October 31, 2018 (Government of Canada, 2019, April, p. 9). The population of Canada's westernmost province stood at around 5 million in 2018. Comparatively, the adjacent U.S. jurisdiction, the State of Washington's population in 2018 stood at approximately 7.5 million. In that year, the State of Washington recorded 267 participants of the *Death with Dignity Act* (*DWDA*). Of the 267 participants, 251 died in 2018, while 16 were left with status pending (Washington State Department of Health, 2019, p. 5). If British Columbia continued to record approximately 77 deaths in each of the remaining two months of 2018, the total MAiD deaths for the year comes in at around 927. The Government of Canada's *First Annual Report on Medical Assistance in Dying in Canada, 2019*, lists the number at 951 (Government of Canada, 2020, p. 19).

The Canadian province of Alberta's population in 2018 stood at around 4.3 million, while the State of Oregon's population was nearly 4.2 million, convenient numbers for comparison. In

[1] A January 2020 Canadian national survey conducted by Ipsos and commissioned by Dying with Dignity Canada affirmed the ongoing support (86 percent) for medical assistance in dying, to varying degrees, going back to the Supreme Court of Canada *Carter v. Canada (Attorney General)* decision in February 2015.

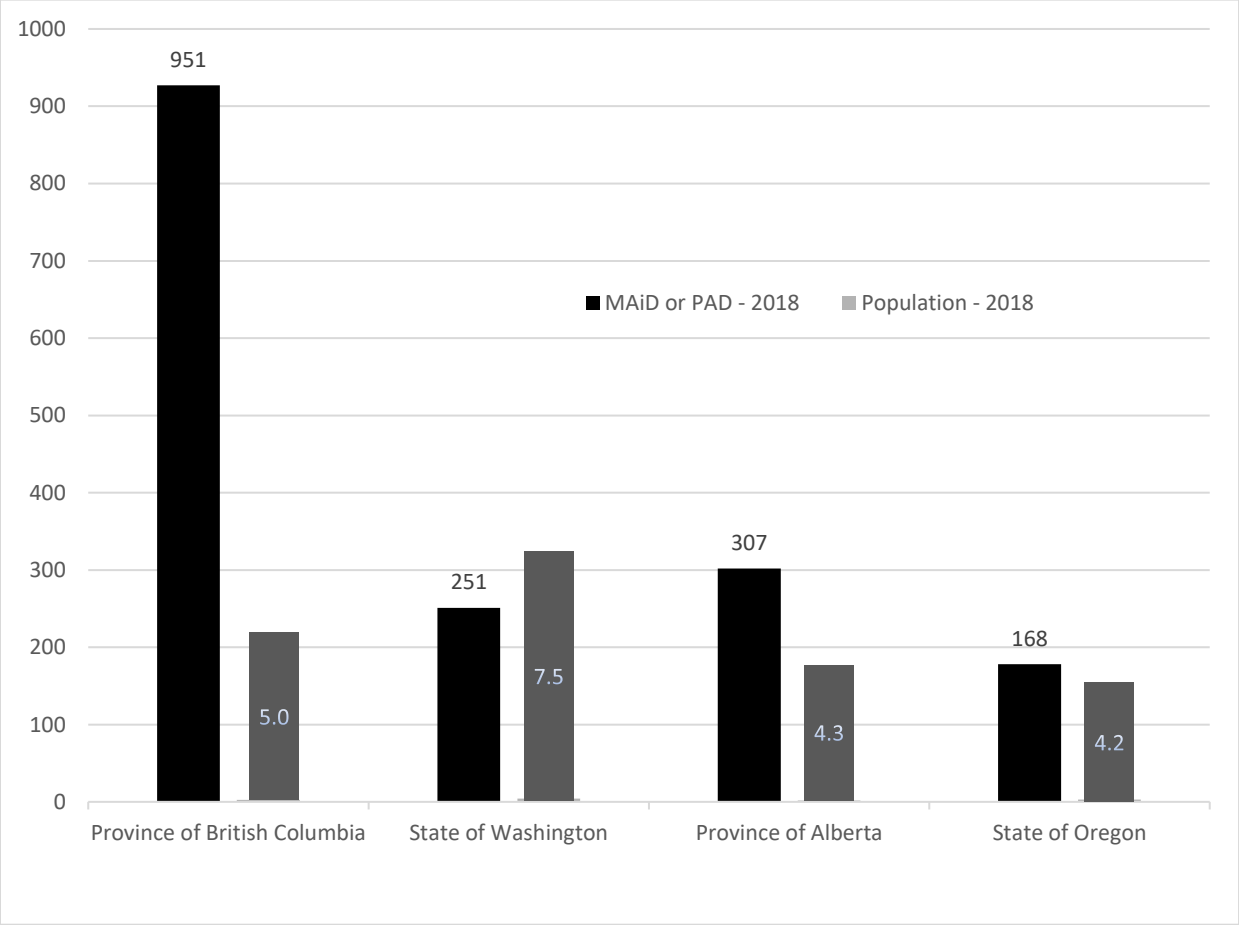
the first ten months of 2018, January 1st through October 31st, the province of Alberta recorded 252 deaths resulting from medically-assisted dying (Government of Canada, 2019, p. 9). If Alberta continued to record approximately 25 deaths in each of the remaining two months of 2018, the province's total MAiD deaths for the year comes in at 302. The Government of Canada's *First Annual Report on Medical Assistance in Dying in Canada, 2019*, lists the number at 307 (Government of Canada, 2020, p. 19). In 2018, the State of Oregon recorded 249 prescription recipients through the *DWDA* (Oregon, p. 14). Of the 249 *DWDA* prescription recipients in 2018, 168 reportedly died.

Oregon's *Death with Dignity Act* took effect in 1997, the second world-wide jurisdiction to legalize any form of assisted dying, following the Northern Territory of Australia.[2] From 1998 through 2018, Oregon averaged 69 deaths per year, as a result of physician-assisted dying. During the 10-year period 2009 through 2018, Oregon averaged 106 deaths per year resulting from physician-assisted dying (Oregon, p. 14). Washington's *Death with Dignity Act* went into effect in March 2009, more than 10 years following Oregon's legalization of the *DWDA* and 7 years before medical assistance in dying received royal assent in Canada and represents the second U.S. jurisdiction to legalize physician-assisted dying. During the 10-year period 2009 through 2018, the State of Washington averaged 153.5 deaths per year resulting from physician-assisted dying (Washington State Department of Health: Annual Reports, 2020). The first 20 years of physician assisted dying in the United States, exclusively in the States of Oregon and Washington through the *DWDA*, remained relatively consistent year over year and remained a small percentage of overall annual deaths recorded in either jurisdiction.

[2] The Northern Territory of Australia passed the *Rights of the Terminally Ill Act 1995*, which permitted euthanasia beginning in 1996, within the Northern Territory. The law was nullified in 1997 by the Parliament of Australia when in 1997 it passed the *Euthanasia Laws Act 1997*. Northern Territory Government. (2020). *Northern Territory Legislation*. https://legislation.nt.gov.au/en/Legislation/RIGHTS-OF-THE-TERMINALLY-ILL-ACT-1995

Figure 1

Comparison of MAiD to PAD Deaths in 2018, With Approximate Population



In Canada, Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, represents the 2016, initial legislative iteration of assisted dying. Medical assistance in dying in Canada has emerged as substantially different from the PAD regime in the United States and more closely aligned with its European counterparts. United States jurisdictions with PAD require the death criteria go beyond the strictures of the "reasonably foreseeable" clause found in Bill C-14. More stringent than

Canada's legislation, Oregon's *Death with Dignity Act* (the boilerplate for U.S. jurisdictions that have adopted physician-assisted dying) requires the patient have a diagnosed terminal illness and fall within six-months of their death, as determined by a physician (Death with Dignity Acts, 2020b).

In Canada the standard for qualification has been much less stringent, with a patient's death needing only to fall into the "reasonably foreseeable" category, whether or not it likely falls within a six-month timeframe. Ensuring a death falls within a six-month time frame severely restricts a physician's capacity for gauging the imminence of a patient's death. "Reasonably foreseeable," though often considered restrictive within Canada, and regularly referred to as a betrayal of both the letter and spirit of the 2015 Supreme Court of Canada decision in *Carter*, alone provides a greater degree of latitude for a participating Canadian physician over against a physician from Oregon or the State of Washington or one of the other U.S. States and the District of Columbia, permitting physician-assisted dying. In Canada, the interpretation of "reasonably foreseeable" opened up more broadly as a result of both the 2017 *A.B. v. The Attorney General of Canada and the Attorney General for Ontario* decision, where Judge Paul Perell wrote: "natural death need not be imminent and that what is a reasonably foreseeable death is a person-specific medical question to be made without necessarily making, but not necessarily precluding, a prognosis of the remaining lifespan" (as cited in Downie, 2017, July 28), and the 2019 Quebec Superior Court decision in *Truchon v. Procureur Général Du Canada*, which held the SCC *Carter* ruling did not "impose a temporal restriction on the availability of MAiD," (Washington et al., 2019, p. 6.1.11) or "medical aid in dying," as it was originally referred to in Quebec's *Act Respecting End-of-Life Care* (2013).[3] Additionally

[3] In keeping with the ruling, the "end of life" criterion no longer applied as of March 12, 2020, while the "natural death has become reasonably foreseeable" criterion from the *Criminal Code* continued through July 11, 2020, due to

instructive in transforming the Canadian understanding of natural death being reasonably foreseeable came within one week of the *Truchon* decision. Julia Lamb from Chilliwack, British Columbia learned the Attorney General of Canada, David Lametti, submitted expert evidence to the Supreme Court of British Columbia, which showed Lamb did in fact qualify for MAiD should she determine to stop the daily care she requires as a sufferer of spinal muscular atrophy. Lamb subsequently dropped the challenge she and the B.C. Civil Liberties Association brought in 2016 over the constitutionality of the "reasonably foreseeable" clause found in Bill C-14 (Grant, 2019, September 18).

In a different way, the 2018 case of Saskatchewan couple Cecilia Chumura and her husband David Dunn challenged the federal medically-assisted dying legislation on the issue of a death being reasonably foreseeable, and physician assisted-dying, or self-administered deaths. Dunn argued his wife was pushed to the point of taking her own life, by overdosing on her prescribed medication, after being refused a medically-assisted death on the basis her death was not deemed foreseeable. The case points to a largely unforeseen consequence of restricting medically-assisted dying, and in particular physician-assisted dying. If physicians refuse to prescribe the medication to end life, a patient can attempt to self-administer a fatal dose of their own medication at the time of the patient's choosing, without the involvement of the medical community. Saskatoon, Saskatchewan police reported there were no charges pending against Dunn for refusing to interfere in his wife's suicide by providing life-saving assistance, though he lay beside her as she died and remained conscious of his wife's actions (McKenna, 2018).

Before exploring those shifting gradations emerging in Canada since 2016, it must first be noted a significant number of staunch opponents of any form of medically-assisted dying

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the extension obtained by the federal government. Government of Quebec. (2020). *Medical aid in dying*. https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/medical-aid-in-dying/

remains. This segment of the Canadian population found shelter for twenty-two years behind the Supreme Court of Canada 1993 decision in *Rodriguez v. British Columbia (Attorney General)*, though the five-four decision upholding the *Criminal Code* prohibition against assisting in a suicide proved less than decisive and acted as a harbinger of what was to come in a handful of international jurisdictions, and eventually in Canada itself. Former Chief Justice of the SCC Beverley McLachlin, who in 2015 presided as chief justice over the unanimous opinion in *Carter*, was one of four justices dissenting in the 1993 *Rodriguez* decision. McLachlin and L'Heureux-Dubé found:

> Parliament has put into force a legislative scheme which makes suicide lawful but assisted suicide unlawful. The effect of this distinction is to deny to some people the choice of ending their lives solely because they are physically unable to do so, preventing them from exercising the autonomy over their bodies available to other people. (*Rodriguez v. British Columbia*, 1993, pp. 523-524)

For the staunch opponents of any form of assisted dying, here referred to as the *Never Compatible Group* (meaning assisted dying is under no circumstances compatible with a compassionate response to suffering), any administration of medical assistance in dying lacks compassion because MAiD's primary objective is not principally the relief of suffering. Accordingly, if assisted dying cannot be described as compassionate it is by definition excluded from medical practice. The only role of the state in medicine must be to enable the relief of suffering. For the *Never Compatible Group*, MAiD's primary focus is not compassion through the relief of suffering, but rather the facilitation of autonomous personal decision making. Fulfilling the desire for ultimate autonomy falls outside the scope of acceptable state-sanctioned medical practice. The *Never Compatible Group* looks at how the unanimous ruling in *Carter*

focused almost exclusively on the patient contemplating medically-assisted dying, without accompanying consideration for the societal impact of the new regime, on familial impact, on various non-dominant cultural considerations within Canada, on the inability of some patients to offer informed consent and the potential for coercion, and on the likelihood of unforeseen consequences.

The *Never Compatible Group* continues to find its most strident, coordinated representation within Canadian medicine from the palliative care community. In its October 2015, *Key messages: Physician-Hastened Death*, *Anticipating the Federal Legislation Following Carter*, the Canadian Society of Palliative Care Physicians (CSPCP) made it clear in a bald message: "Palliative care does not include physician-hastened death" (Canadian Society, 2015, October). Lest any confusion might have arisen over intervening years, a joint statement by the Canadian Hospice and Palliative Care Association (CHPCA) and the CSPCP dated November 27, 2019 intended to erase any misconception. Executive director of CHPCA Sharon Baxter, and president of CSPCP Leonie Herx wrote:

> Due to ongoing confusion amongst the general public regarding Hospice Palliative Care (HPC) and Medical Assistance in Dying (MAiD), the Canadian Hospice Palliative Care Association (CHPCA) and the Canadian Society of Palliative Care Physicians (CSPCP) would like to clarify the relationship of hospice palliative care and MAiD. Healthcare articles and the general media continue to conflate and thus misrepresent these two fundamentally different practices. MAiD is not part of hospice palliative care; it is not an "extension" of palliative care nor is it one of the tools "in the palliative care basket". National and international hospice palliative care organizations are unified in

the position that MAiD is not part of the practice of hospice palliative care. (S. Baxter, & L. Herx, personal communication, November 27, 2019)

The Canadian implementation of medically-assisted dying, coming as it did more than two decades after initially proposed in *Rodriguez*, and as seen in a larger international context, encouraged a relatively broad implementation (conceived in *Carter*) as compared to other U.S. jurisdictions, and as the legislation trended in 2020, yet a less permissive implementation than within the Benelux Union, the European countries of the Netherlands (where implementation came in 2002), Belgium (where legalization and implementation came in 2002), and Luxembourg (where assisted dying came into force in 2009). In each of the three European jurisdictions euthanasia is permissible (in Belgium without age restrictions, and in the Netherlands to minors age 12 and older), and in Belgium and the Netherlands is permitted in cases where mental illness is the sole consideration. Colombia is the lone South American country which permits any form of assisted dying. In 2015, Colombia became the fourth international jurisdiction to permit euthanasia, along with the previously mentioned European nations (My Death, 2018). In Colombia the implementation proved unique. The constitutional court in Colombia ruled in favour of euthanasia back in 1997, but willing doctors were reluctant to implement the ruling until 2015, due to a separate law which punished participation by doctors with up to three years in prison (Tegel, 2015).

Canada became the first national North American jurisdiction and the fifth worldwide to permit euthanasia, beginning in 2016. Canada's medically-assisted dying, from June 2016 through the end of October 2018, took place largely in hospitals (about 44 percent of the time), in patient's homes (about 40 percent of the time), in long-term care facilities or nursing homes (about six percent of the time), in a hospice (about two percent of the time), and about seven

percent of the time in an unknown location or in a remote location where the identity of the patient is protected (Government of Canada, Fourth, p. 5).[4] MAiD is delivered intravenously. Though included in the legislation as one of the two MAiD options, it remains unfeasible for Canadian patients to fill a prescription with a pharmacist, from an assisting physician or nurse practitioner, to end life at home (i.e. physician-assisted dying).

The Government of Canada's first interim update, *Interim Update on Medical Assistance in Dying in Canada June 17 to December 31, 2016* (2017, May 31), on medical assistance in dying in Canada captured the initial six months following implementation. Of the medically-assisted deaths in Canada during the initial six months, 504 of 507, or 99 per cent, were under the category "voluntary euthanasia." It must be noted here that well before the Supreme Court of Canada's 2015 *Carter* decision and well before the consequent royal assent of Bill C-14 in June 2016, Canada recognized (in large part as a way of easing the minds of physicians concerned over nefarious accusation) that what is known as palliative sedation (or continuous palliative sedation therapy), which results in the death of a patient who is palliative, is generally accepted medical practice in Canada.

In palliative sedation, as noted by McIntyre (2014), the principle of double effect is invoked to explain the permissibility of an action that causes a serious harm, such as the death of a human being, as a side effect of promoting some good end, such as relieving pain. Morphine, for example, may hasten death but relieves unbearable pain. Thomas Aquinas is credited with the principle of double effect in his discussion of the permissibility of self-defense, part of his just war theory. Contradicting Augustine, killing one's assailant is justified, argued Aquinas, provided one does not intend to kill. According to Aquinas, "Nothing hinders one act from

[4] Importantly, the data excludes: Quebec, Northwest Territories, Yukon, and Nunavut (4th Interim Report, p. 5).

having two effects, only one of which is intended, while the other is beside the intention." (Summa Theologica; II-II, Qu. 64, Art.7). Continuous palliative sedation therapy, formerly known as terminal sedation, is used when all other attempts to relieve a patient's excessive suffering have failed, and the only option is to reduce a patient's level of consciousness. This is considered a therapy when all others have failed, since the sedation continues until death. Although there are no laws in Canada outlining the use of continuous palliative sedation therapy, many doctors refer to the recommendations of the Canadian Society of Palliative Care Physicians Taskforce, which outlines the guidelines for physicians in this highly sensitive treatment, at end of life (Glauser et al., 2015).

The Government of Canada's *2nd Interim Report on Medical Assistance in Dying in Canada* was released in October 2017. The *2nd Interim Report* included an added feature, "Number of Medically Assisted Deaths by Provider." Within the period January 1, 2017 to June 30, 2017, 837 (or 95.7 percent of medically-assisted dying) were carried out by physicians and 38 (or 4.3 percent) were carried out by nurse practitioners. As in the first *Interim Report*, Quebec was excluded, which is no small omission in terms of numbers. The territories were omitted over privacy concerns. The most striking feature of the implementation of medically-assisted dying in Canada, thus far, is the relative absence of controversy over the dominance of euthanasia as the means of administering medically-assisted dying. The trend continued according to the Government of Canada's *Third Interim Report on Medical Assistance in Dying in Canada* (2018, June 21). Of the 1086 medically-assisted deaths recorded from July 1, 2017 to December 31, 2017, all of the deaths were administered by a clinician, either a physician (95 percent) or a nurse practitioner (5 percent).

In Switzerland, where in 2010 Kay Carter travelled with her daughter Lee (a plaintiff in *Carter v. Canada*) to receive assisted dying, the law is more relaxed than in Germany. The Swiss allow assisted dying as long as there are no "self-seeking motives" involved. Switzerland has allowed for the creation of organizations such as Dignitas and Exit, which provide assisted-dying services for a fee. Kay Carter was the tenth Canadian to seek assistance in ending her life in Switzerland at the Dignitas clinic, but the first to make known her plan. In Germany, Switzerland's northern neighbour, potential for the commercialization of assisted dying is of paramount concern (Todd, 2015). With physicians in Germany spearheading the medicalization of Nazi ideology throughout the 1930s and into the Second World War, an ideology of "racial hygiene," an ongoing reluctance to involve the medical community in assisted dying remains (Grodin et al., 2018, p. 53). In 2020, Germany's Federal Court of Justice overturned a ban on physician-assisted dying, which before 2015 was accepted practice, while continuing to forbid euthanasia. The Australian state of Victoria became the first to legalize assisted dying in 2017, under its new regime. The legislation, which took effect from June 2019, applies to terminally ill patients of sound mind and a life expectancy of less than six months (similar to the U.S. state of Oregon's *Death with Dignity Act*, which profoundly influenced subsequent U.S. legislation).

Jocelyn Downie of Dalhousie University, a prominent member of the Council of Canadian Academies expert panel on medically-assisted dying, deemed the initial federal legislation too restrictive and out of step with the 2015 *Carter* decision. The clause in Bill C-14 stating, "natural death must be reasonably foreseeable," is for Downie particularly disconcerting. Downie is committed to seeing the initiative through. That is, realizing the full breadth of the expansiveness she finds inherent in *Carter*. Downie believes Canada can achieve the best system in the world for end-of-life care, where patients' wishes are respected, whether through

access to aggressive treatment, palliative pain management, or medical assistance in dying (Downie, 2017, July 27). Downie's approach highlights the most significant aspect of the transformation of Canadian society that now permits medically-assisted dying, the increased focus on the individual and individual autonomy.

Patients' rights, among civil rights, emerged forcefully beginning in the 1960s, and eventually superseded the paternalistic model in medicine. This transition toward patient autonomy is seen prominently in transformations in bioethics and additionally in medicine, where treatments, devices, and therapies are prolonging and redefining the experiencing of life's ending. Informed consent remains the centerpiece of transformation toward greater patient autonomy. Though the connections may in places be circuitous, it is difficult to conceive of the incorporation of medically-assisted dying, in Canada, or assisted dying in any worldwide jurisdiction, without these monolithic transformations in bioethics and medicine.

Palliative Care and Transformation in Bioethics

The palliative care model, imbued as it is by a distinct philosophy of caring, has emerged alongside, and in some cases in concert with, developments in bioethics and life-prolonging medicine, not entirely independent of these developments, yet maintaining a philosophical perspective purportedly providing a corrective to the excesses of curative hubris in medicine. The approach remains holistic. Both the patient and those close to the patient receive consideration. Currently, though a formal consensus exists in Canada concerning the place of medically-assisted dying firmly outside the context of the palliative care philosophy and model of care, as noted above, informally some advocate for the inclusion of MAiD into the palliative care offering. The chronic care model stands apart from both the acute and palliative care models of care. Whereas acute and palliative care "share similar outlooks on patient autonomy,"

chronic care patients often go unrecognized when "executive autonomy is assumed to be unimpeded" (Lanoix, 2013, pp. 692-693). This translates into chronic care patients regularly missing out when the proper time to transition to palliative care emerges (Lanoix, 2013). The 2019 *Truchon* decision and its transforming of MAiD in Canada through Bill C-7 may further complicate the timing of this transition for chronic care patients. Some may come to bypass the transition altogether and pursue MAiD.

The palliative care movement in the United States gained prominence through secular and legal developments that began with the push toward patients' rights in the 1960s and culminated in the debate over assisted suicide in the 1990s. Prominent medical ethicist, Joseph Fins (2006) wrote: "The relationship between physician-assisted suicide and palliative care in the U.S. medical community remains complicated – although palliative care should be judged on its own merits, it is often seen through the prism of an ideological stance about PAS [physician-assisted suicide]," (p. 14) even though palliative care emerged decades before any form of assisted-dying proposal. That is to say, palliative care is often and unwittingly set up as the ideological opponent of assisted dying, first in the United States, and since 2016 in Canada.

Palliative care was slow to take root. The first hospital palliative care unit in Canada opened in 1974, begun at Saint Boniface Hospital in Winnipeg, Manitoba. Nearly fifty-years later, challenges to the integration of the palliative philosophy in Canada remain. Consider Private Members Bill C-277, which received royal assent on December 12, 2017. The Summary of the bill reads: "This enactment provides for the development of a framework designed to support improved access for Canadians to palliative care." Member of Parliament Marilyn Gladu of Petrolia, Ontario, the bill's sponsor, spoke in the House of Commons at the third reading of her private member's bill on May 9, 2017. Gladu said: "Canadians need palliative

care services now more than ever. Less than 30% of Canadians have access to this vital service, which allows them to choose to live as well as they can for as long as they can." Gladu went on: "The bill is timely, since the special committee that studied the *Carter* decision on medically-assisted dying legislation said that without good quality palliative care there would be no true choice. We want Canadians to have a choice." If by 2017 less than 30 percent of Canadians had access to palliative care services, as MP Gladu reported, the division between the medical mainstream model over against a palliative model (half a century from its inception) for end-of-life care seems overwhelmingly evident, leaving medically-assisted dying open to filling the considerable vacuum.

Patient autonomy provides the necessary foundation for conceiving of lawfully assisting a person in hastening their death through assisted dying. In this evolution, no longer sanctity of life, but the autonomous patient is deemed sacrosanct. Free of coercion, the informed, consenting individual achieves mastery over life's ending. The issue of adult patients first articulating the right to consent to treatments emerged in the 1950s and into the 1960s, when cancer patients in particular began to express a desire to know the full extent of their diagnosis, challenging the near sacred paternalistic model in medicine. In the 1961 often-cited study of physicians at Chicago's Michael Reese Hospital (which closed in 2009), 90 percent of physicians reported withholding the diagnosis when their patient had cancer. In a clear indication of the dramatic change toward patients' rights, when the same study of physicians at Michael Reese Hospital was repeated in 1979, 97 percent of physicians indicated a preference for telling a cancer patient the diagnosis (Fins, 2006). By the end of two decades, the dynamic entirely reversed, seemingly following the trendline of unrelenting change and self-focus characterizing the decades following World War II in North America.

More than any single factor in developing patients' rights, judicial activity altered the clinical landscape, with decisions advancing informed consent and patient autonomy. The legal system provided the means of overturning the old paternalism and replaced it with laws sensitive to patient self-determination. Two cases stand out in significantly impacting arguments surrounding informed consent and patient autonomy in end-of-life decision making. Though both cases were adjudicated in the United States, they significantly altered the medical landscape across North America, and served as a platform for consideration of assisted dying in the 1990s (Fins, 2006).

The first is the well-known case of Karen Ann Quinlan, and the negative right to be left alone, as part of the larger right-to-die movement. In 1975, Karen Ann Quinlan, age 21, fell into a coma following an evening with friends which included tranquilizers and alcohol. Quinlan ultimately lapsed into a persistent vegetative state. The Quinlan case became the basis for U.S. state laws that allow for natural death and orders to forgo resuscitation through do-not-resuscitate orders, extensions of the doctrine of informed consent. In Canada, orders are similar to those in the United States. In 1995, the *Joint Statement on Resuscitative Interventions* provided guidelines to determine when and how do-not-resuscitate orders are assigned (Joint Statement, 1995).

The next major marker in the development of bioethics and the right-to-die movement was the case of Nancy Beth Cruzan, whose car overturned in 1983 as she drove home from work in Carthage, Missouri. Cruzan suffered severe brain damage as a result (Steinbrook, 1990). Like Quinlan, the Cruzan case involved a woman in a persistent vegetative state. Unlike Quinlan, the Cruzan case hinged on the removal of artificial nutrition and hydration, and not extraordinary measures like a ventilator. The case went to the U.S. Supreme Court, its first right-to-die case.

The Rehnquist Court's 1990 ruling recognized the Constitutional right of a competent person to refuse life-sustaining therapy. Crucially, the Court did not distinguish life-sustaining therapies, such as ventilators, from interventions considered ordinary, such as artificial nutrition and hydration (Fins, 2006).

Coming out of the U.S. Supreme Court Cruzan decision, *Cruzan v. Director, Missouri Department of Health* (1990), there was much greater emphasis placed on the role of advance directives. The *Patient Self-Determination Act* became law in the United States at the end of 1991, a year following the death of Nancy Beth Cruzan in a Missouri hospital at the age of 33. She did not go without considerable resistance to the removal of the feeding tube. One leading protester remarked, "Even a dog in Missouri cannot be legally starved to death" (Lewin, 1990). Following the *Patient Self-Determination Act's* passage, debate followed as to whether the right to die and right to refuse life-sustaining therapies extended as well to interventions that would hasten death. If a patient had the right to refuse life-sustaining therapy, they also should be allowed to hasten their death through assisted dying, went the argument. Yet many saw extending patients' rights from refusing life-sustaining therapy to a right to physician-assisted dying taking patient self-determination too far, arguing physician-assisted dying was a distortion of the principle of autonomy.

This debate played out in the United States throughout much of the 1990s, while, as mentioned above, in Canada the issue had been decided by the Supreme Court of Canada's 1993 decision in *Rodriguez v. British Columbia (AG)* – no hastening of death. In the U.S. the temporary calm achieved by the 1991 *Patient Self-Determination Act*, and the dramatic rise in the use of advance directives by patients, became eclipsed by physician-assisted suicide, and a particular physician assisting (or often more than assisting) in the suicides of over 100

individuals. Jack Kevorkian became a prominent face of the debate over the legalization of physician-assisted suicide. Keith Schneider, in his 2011 *New York Times* obituary for Kevorkian, noted that in 1995, the American Medical Association (AMA) called Kevorkian "a reckless instrument of death" who "poses a great threat to the public." In an unforeseen turn, Kevorkian's "stubborn and often intemperate advocacy of assisted suicide helped spur the growth of hospice care" (Schneider, 2011, June 3).

As the foundational value put forward in support of the right to request medically-assisted dying, autonomy demands attention. After all, it is autonomous individuals who are deemed capable of medical decision making, derived from informed consent. The emphasis on the principle of autonomy was part of the development of a framework of universal principles that emerged as part of a burgeoning biomedical ethics during the 1970s and into the early 1980s and included psychiatric ethics. A central impetus for developing the set of principles was the ending of the Tuskegee Institute syphilis study in 1972. This exploitive research on human participants alerted researchers and informed the National Commission for the Protection of Human Subjects, which produced its findings in *The Belmont Report*, in 1978. Both *The Belmont Report* and Beauchamp and Childress' *Principles of Biomedical Ethics*, spoke to the need for an elevated research standard, one identifying the danger of allowing participants in research to become mere instruments. Beauchamp and Childress identify that respect for the autonomous choices of persons runs as deep in common morality as any principle, and that virtually all theories of autonomy view two conditions essential: liberty (independence from controlling influences) and agency (capacity for intentional action). Simply put, if you've got liberty and you've got agency, you've got autonomy. For Beauchamp and Childress, the obligation to respect autonomy does not extend to persons who cannot act in a sufficiently

autonomous manner, and who cannot be rendered autonomous because they are: immature, incapacitated, ignorant, coerced, or exploited. Infants, irrationally suicidal individuals, and drug-dependent patients are examples of those unable to act autonomously (Beauchamp & Childress, 2001).

All of the principles in the framework of Beauchamp and Childress's theory of *Principlism* are in some contexts justifiably over-ridden by other moral principles with which they conflict. None of the principles is morally weighted or placed in a hierarchical order of importance. Questions of weight and priority must be assessed in specific contexts. The framework of four clusters of principles, defended by Beauchamp, falls into four categories: (1) respect for autonomy; (2) nonmaleficence; (3) beneficence; and (4) justice. Nonmaleficence and beneficence have played a role throughout the history of medical ethics, whereas respect for autonomy was largely neglected or not considered, and only since approximately 1980 began its march to the prominent position it now holds (Beauchamp, 2015). The recent rise to prominence of the principle of autonomy, as the cornerstone of medical ethics, corresponds with the acceptance of assisted dying in a growing number of worldwide jurisdictions.

Canadian philosopher Susan Sherwin provides what may be described as a corrective or a refining of the view of autonomy put forward by Beauchamp and Childress, through a specific feminist analysis. Sherwin's feminist analysis of autonomy reveals both attraction to and distrust of the dominant interpretation of the concept of autonomy. In response to difficulties, an alternative conception of autonomy labelled "relational" was brought forward by Sherwin. According to Sherwin, despite broad consensus about the value of the principle of respect for patient autonomy in health care, there are problems with interpretation and application in health care ethics. We need to question how much control individual patients have over the

determination of their treatment within the stressful world of health care services. For Sherwin, "The paradigm offered for informed consent is built on a model of intelligent, articulate patients accustomed to making decisions about the course of their lives" (Sherwin, 1998, p. 25). The concern raised by Sherwin provides a check on the application of assisted dying without proper consideration of the context of the broader patient experience.

The 2014 *Canadian Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* seeks to balance the differing emphases articulated by Beauchamp and Childress on the one hand and Susan Sherwin on the other. Under the Core Principles of Respect for Persons is the following statement: "Respect for Persons incorporates the dual moral obligations to respect autonomy and to protect those with developing, impaired or diminished autonomy" (Canadian Institutes, p. 8). The wording remains the same in the 2018 iteration of the *Tri-Council Policy Statement*, which like the 2014 version includes three principles under its Core Principles section: Respect for Persons; Concern for Welfare; and Justice.[5]

Physician-Assisted Dying and Euthanasia

In way of clarification, physician-assisted dying (also referred to as physician-assisted suicide, the two denoting an identical procedure) occurs when a physician knowingly provides a competent patient with the prescription for medication to end life, and the patient makes a voluntary request for this assistance. The patient self-administers the lethal dose of medication obtained from a participating pharmacist. In contrast, euthanasia occurs when a physician provides and administers intravenously a lethal dose of medication to a patient who makes a voluntary request for the procedure. Although physician-assisted dying and voluntary euthanasia

[5] The use of the term "Respect for Persons" in the *TCPS* corresponds with autonomy in Beauchamp and Childress' *Principles of Biomedical Ethics*, while use of the term "Concern for Welfare" corresponds with beneficence in *Principles*. The principle of nonmaleficence does not appear as a core principle in the *TCPS*.

are voluntary requests, advocates for physician-assisted dying argue the patient maintains less control when they do not administer the lethal dose of medication. Concern remains, particularly in the U.S., euthanasia is more open to becoming coerced precisely because the physician controls the medication administration.

As noted above, in Canada, as of 2016, the distinction between physician-assisted dying and euthanasia has been subsumed under the umbrella term "medically-assisted dying." The semantics here are important. The elimination of the term "euthanasia" from Canadian deliberation may well have made its implementation more palatable to the Canadian public. The term "euthanasia" appeared 12 times in the February 2016 Canadian Parliament's *Report of the Special Joint Committee on Physician-Assisted Dying*, while the terms "physician-assisted dying" and "medical assistance in dying" appeared 74 and 67 times respectively. The title of the *Report* indicates the government continued to refine its terminology as the pressure mounted to deliver legislation by the 16-month mandate issued by the SCC. As it turned out, neither the *Report* nor Bill C-14 dealt squarely with physician-assisted dying and remained focused almost exclusively on euthanasia. Bill C-14 (2016) and Bill C-7 (2020) drop the term "euthanasia" entirely. It has largely disappeared from Canadian discourse surrounding assisted dying. The term "euthanasia" appears in the *First Annual Report on Medical Assistance in Dying in Canada 2019* in an explanatory footnote: "Criminal Code provisions on MAID do not employ specific…terms, but refers only to medical assistance in dying. However, assisted suicide in other jurisdictions is commonly termed self-administration in Canada, and voluntary euthanasia is commonly termed practitioner administration" (p. 11). No explanation for substituting new terms is provided.

In the United States the clear distinction between euthanasia and physician-assisted dying remains. More particularly, the debate taking place within the AMA from 2016 through 2019 largely revolved around whether to distinguish the terms "physician-assisted suicide" and the softer sounding "aid in dying." The AMA's Council on Ethical and Judicial Affairs (CEJA) reiterated its opposition to altering the existing use of the term "physician-assisted suicide" in favour of the inclusion of "aid in dying," and upheld their previous statement: "In the council's view, despite its negative connotations, the term 'physician assisted suicide' describes the practice with the greatest precision. Most importantly, it clearly distinguishes the practice from euthanasia" (Smith, 2018). In 2019, CEJA formally recommended the AMA *Code of Medical Ethics* not be amended to accommodate a distinction between the two terms (Sabin, 2019). Speaking in favour of adopting the CEJA report at the AMA House of Delegates meeting in June 2019, physician Shane Macaulay of Kirkland, Washington expressed grave concern physician-assisted suicide could expand in U.S. jurisdictions to include euthanasia:

> Last month, the Oregon state House of Representatives approved a bill to allow patient death by lethal injection, showing the inevitable progression from assisted suicide to euthanasia once physicians have accepted the idea that taking a patient's life is permissible. (Frieden, 2019, June 11)

Macaulay went on, sounding the alarm on creeping euthanasia and the distinct possibility of progression toward something favouring the Canadian regime:

> In Canada, assisted suicide and euthanasia were legalized only three years ago, and in the three years we've debated this topic here, euthanasia has become a runaway contagion in Canada, with over 4,000 deaths last year. These alarming developments show us that the wheels are coming off [the] bus on assisted suicide. We do not have the luxury of time to

> continue to fail to act on the CEJA report while the real-world situation deteriorates. Unless we're willing to embrace widespread euthanasia, we must accept the CEJA report and reaffirm this policy now as a firewall against what is [happening in] Canada. (Frieden, 2019, June 11)

The Canadian adoption of both euthanasia and physician-assisted dying under the umbrella term "medical assistance in dying," eliminated the debate the U.S. medical community found itself embroiled in over the last several years. The introduction of MAiD in Canada corresponds with increasing calls for amending the term "physician-assisted suicide" in various U.S. jurisdictions. In this study, the term "assisted dying" captures all its manifestations, throughout every participating international jurisdiction, while the term "medical assistance in dying" refers specifically to the Canadian version of assisted dying, which in Canada includes both euthanasia and physician-assisted dying.

The term medical assistance in dying became the preferred nomenclature in Canada in 2016, largely emanating from the *Report of the Special Joint Committee on Physician-Assisted Dying* (2016, February) and from Bill C-14 itself (2016, June), and not from the Supreme Court of Canada's decision in *Carter* (2015, February).[6] Notably, the *Expert Panel Report* (2015, December), published two months before the *Report of the Special Joint Committee*, does not use the term one time. The *Expert Panel Report* represented nearly the final act for the term "euthanasia," where it is referred to 147 times. The word euthanasia did emerge in the *Report of the Special Joint Committee* 12 times, did not appear in Bill C-14 and did not appear at first reading of Bill C-7 (2020, February). The *Carter* decision referred to the term "medical

[6] Quebec's National Assembly began debating Bill-52, *An Act Respecting End-of-life Care* in 2013. The provisions of Bill-52 came into force in December 2015, permitting medically-assisted dying in Quebec seven months before the Canadian federal legislation, Bill C-14, took effect.

assistance in dying" one time. The emphasis in *Carter* remained on broadly distinguishing "physician-assisted suicide," or "assisted suicide" (as noted above, what is often referred to in the United States as physician-assisted dying) from "physician-assisted dying" (by which is meant euthanasia and not physician-assisted dying), and that reserved "for competent adults who seek such assistance as a result of a grievous and irremediable medical condition" (Bill C-14, p. 1). The Supreme Court of Canada in *Carter* recognized the legitimacy of prohibiting assisting in a suicide under existing federal law, while recognizing exceptions when specified medical conditions represent the motivating factor in pursuing the assistance of someone in dying. The term "medical aid in dying" was referenced twice in *Carter*, once in reference to the Quebec National Assembly's *Select Committee on Dying with Dignity 2012* report, and in reference to the State of Oregon's 1994 passage of the *Oregon Death with Dignity Act*. Within Canada, the term "medical aid in dying" is largely confined to use in Quebec.

Between the February 2015 Supreme Court of Canada decision in *Carter* and the royal assent of Bill C-14 in June 2016, a significant transformation of terminology occurred. The wording of Bill C-14 streamlines the language surrounding assisted dying, with the term medical assistance in dying appearing 76 times. The terms "physician-assisted dying" and "euthanasia" do not appear in the bill. The term "medical aid in dying" is also absent from Bill C-14, as are the terms "assisted suicide" and "physician-assisted suicide," which appear throughout the *Carter* decision.

The term euthanasia is used sparingly yet impactfully in the Supreme Court of Canada's *Carter* decision. The Court referred to euthanasia in its support of the trial judge's findings of fact, rejecting Belgian bioethics professor Etienne Montero's concern over a slippery slope in the Belgian implementation of euthanasia. The Supreme Court of Canada's dismissal of a potential

connection between the Belgian and Canadian contexts smoothed the path toward the inclusion of euthanasia through Bill C-14, under the banner "medical assistance in dying." For the purposes of this research, the term "medical assistance in dying," or "medically-assisted dying," denotes the current implementation of assisted dying in Canada, which to date falls almost exclusively under the purview of the medical community to deliver. In the Government of Canada's four *Interim Reports on Medical Assistance in Dying*, published in 2017 (2), 2018 and 2019, the two constituent parts of medical assistance in dying are identified initially as "clinician-administered" deaths (for euthanasia), which by the *First Annual Report on Medical Assistance in Dying in Canada 2019* (2020) became identified as "practitioner administered," and "self-administered" deaths (for physician-assisted deaths).

Table 1

Use of Various Terms in Notable Assisted-Dying Decisions, Reports, or Legislation in Canada

Decision, Report, or Legislation	Euthanasia	Medical Aid in Dying	Suicide / Physician Assisted Suicide / Assisted Suicide	Physician Assisted Dying or Assisted Dying	Medical Assistance in Dying / Medically-Assisted Dying
Rodriguez v. British Columbia (September 1993)	26	0	297	0	0
Act Respecting End-of-Life Care (2014)	0	26	0	0	0
Carter v. Canada (February 2015)	18	0	45	61	1

Expert Panel Report (December 2015)	147	0	217	597	0
Report of the Special Joint Committee on Physician-Assisted Dying (February 2016)	12	0	9	74	67
Bill C-14 (June 2016)	0	0	7	0	76
Bill C-7 At first reading (February 2020)	0	0	1	0	65

The *Fourth Interim Report on Medical Assistance in Dying in Canada* (2019) reported seven deaths in Canada fell into the self-administered category, from 2016 to October 31, 2018 (p. 8). Despite the potential for underreporting in this category, there is no apparent indication this extremely low percentage of overall MAiD deaths in Canada has changed in any substantial way since 2018. The *First Annual Report* (2020) states plainly: "Almost all cases of MAID reported in 2019 were administered by a practitioner. There were fewer than 7 reported cases of self-administered MAID…This pattern is consistent with other international jurisdictions that permit both practitioner and self-administered MAID" (p. 19). Not, however, consistent with international jurisdictions that do not permit practitioner-administered assisted dying. All assisted dying in the jurisdictions within the United States permitting assisted dying fall into the self-administered category, and the state of California represents the second largest international jurisdiction to provide assisted dying, only behind Colombia's population of 50 million.

California's population alone, at approximately 39.5 million, is larger than Canada's population of approximately 37.5 million. Further, the *First Annual Report* (2020) indicates, "Some health institutions and regulatory bodies within jurisdictions have developed policies that discourage self-administration. Of note, Quebec's legislation on end-of-life care only permits provider-administered assisted dying" (p. 19). This contravening of Canada's MAiD law by Quebec and other sub-jurisdictions in Canada has gone under the radar during the five years following the royal assent of Bill C-14.

Four Positions on Assisted Dying

Positions on assisted dying fall broadly into four distinct categories, as noted by Fins (2006, pp. 39-41). Position one, referred to above as the *Never Compatible Group*, holds that physician-assisted dying and euthanasia are morally wrong and thus proscribed. This is the position currently taken by the vast majority of the nations and subnational jurisdictions around the world. Callahan (2014) articulated position one regarding a decision for assisted dying forcefully: "Those of us who are bystanders…to such deaths know that a fundamental kind of taboo of a rational kind has been broken, some deep commitment to life violated, and that no relief of pain and suffering can justify that" (p. 84). Position one emphasizes further, the decision to pursue assisted dying flows largely from the experience of losing control and not primarily from one's subjective experiencing of pain: "Much…seems to depend on individual differences in values, not in bodily responses to pain or impending death" (Callahan, 2014, p. 90). Additionally, those in position one fear the use of assisted dying as a means of cutting ballooning health care costs, particularly among the elderly. A cost analysis of MAiD found reductions in "annual health care spending across Canada by between $34.7 million and $138.8

million, exceeding the $1.5–$14.8 million in direct costs associated with its implementation" (Trachtenberg & Manns, 2017, p. 101).

Position two holds physician-assisted dying and euthanasia might be acceptable in rare or exceptional circumstances, yet they should still not be permitted due to the potential for unintended and potentially harmful consequences. The risk is too great. New York's Supreme Court upheld the State's ban on PAD in 2017, continuing to articulate the position two perspective. Judge Jenny Rivera wrote in the lead decision:

> Plaintiffs initially assert that we should interpret the assisted suicide statutes to exclude physicians who provide aid-in-dying. Such a reading would run counter to our fundamental tenets of statutory construction, and would require that we read into the statute words and meaning wholly absent from their text. (Cournoyer, 2017, September 8)

Position three holds that physician-assisted dying is permissible and should be legalized. Proponents of this position draw the line on euthanasia because they fear it cannot be properly regulated. This mixed position was the basis for legalized physician-assisted suicide in Oregon in 1997. Position three finds its voice most prominently through the Death with Dignity National Center in Portland, Oregon, which promotes laws in jurisdictions within the United States based largely on the Oregon *Death with Dignity Act* (1997, October 27).

In 2020, physician-assisted dying statutes stand in eight U.S. states and in D.C. The State of Montana permits physician-assisted dying as a result of a Montana Supreme Court ruling in 2009. Oregon passed the *Death with Dignity Act* in 1997. The State of Washington came next 11 years later, and over the course of the intervening nine years, the remaining seven states and D.C. began offering physician-assisted dying on an individual basis only. No state programs

exist to aid patients seeking a physician-assisted death. At the end of 2020, the remaining 41 states in the U.S. prohibit physician-assisted dying and 34 of those 41 states have laws on the books specifically prohibiting physician-assisted dying. Euthanasia remains prohibited in all 50 U.S. states and territories under general homicide laws (Britannica, 2019, July 25).

Position three rejects euthanasia as an acceptable form of assisted dying, and accepts only physician-assisted dying, which Canadian Bill C-14 allows for in s. 241.1(b) *the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death*. For position three, however, only the "prescribing" of the lethal dose in order for the patient to self-administer at the time of his or her choosing would qualify, and generally not the "providing" of physician-assisted dying by the medical practitioner assisting the patient to orally administer the medication, or with the medical practitioner present in the room. In some Canadian jurisdictions, the prescribing of medication in order for the patient to self-administer at the time of the patient's choosing is restricted, highlighting differing provincial applications of 242.1(b). Five years following the implementation of MAiD in Canada, no Canadian province or territory practices position three with anything close to an established regularity. The process of a patient self-administering a prescribed medication at home (or in another private setting), at the time of the patient's choosing, to end life, is essentially non-existent in Canada.

The *Oregon Death with Dignity Act* (1997) serves as the prototype for position three and articulates a necessary adherence to the imminence of death. In the case of *Oregon*, and all other U.S. jurisdictions permitting physician-assisted dying to date, the patient's death must be foreseeable within a six-month timeframe. Also, crucial to position three, the physician involvement must remain exclusively in assisting the patient by writing a prescription the patient

then has opportunity to fill, or not, on the patient's own schedule. In U.S. jurisdictions allowing for physician-assisted dying, the patient must be both mentally competent and "diagnosed with a terminal illness that will, within reasonable medical judgment, lead to death within six months. You must also be able to self-administer and ingest the prescribed medication" (Death, 2020a).

The fourth position on assisted dying holds that both physician-assisted dying and euthanasia are morally acceptable and should be legalized, because they offer benefit to individuals and society as a whole. Canada falls most securely into this fourth position, yet to date physician-assisted dying as understood from within position three, and somewhat surprisingly not euthanasia, remains unavailable or severely restricted. From within this fourth position, where both physician-assisted dying and euthanasia are permissible, though not necessarily available, several gradations in Canada have emerged, in large part revolving around Bill C-14's "reasonably foreseeable" clause and around the capacity of an individual to consent at the time of the MAiD procedure or the capacity of an individual to make an autonomous decision. An examination of the five Canadian levels, each from within this fourth position on assisted dying, follows.

The five levels under consideration flow from the fourth position on assisted dying in the Canadian context. The levels drop down out of the fourth position like drop down boxes where one goes further into the options available on a web page. Consideration of each of the levels within the Canadian context are run up against the specific wording found in the existing federal legislation, Bill C-14 (2016). One could envision other international jurisdictions coming under position four assisted dying, having their own specific drop-down levels. Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, has been the law in Canada since 2016. Accordingly, all existing and future

challenges revolving around medical assistance in dying in Canada will grapple with the legislation at hand. Language taken directly from the legislation serves to delineate the gradations of permissiveness regarding assisted dying in Canada. The goal is to provide a clear reference point to return to in understanding the history and evolving place of assisted dying in Canada.

The Preamble to Bill C-14 reads in part: "The Parliament of Canada recognizes the autonomy of persons who have a grievous and irremediable medical condition that causes them enduring and intolerable suffering and who wish to seek medical assistance in dying." Access to MAiD for:

1. Autonomous individual
2. Grievous medical condition
3. Irremediable medical condition
4. Enduring and intolerable suffering

The Preamble goes further in "permitting access to medical assistance in dying for competent adults whose deaths are reasonably foreseeable." Access to MAiD for:

5. Competent adult
6. Death reasonably foreseeable

Fourth Position – Level 1 Assisted Dying in Canada

Those in *Level 1 Assisted Dying* recognize and uphold all six conditions found in the Preamble of Bill C-14. *Level 1* opposes the 2019 Québec Superior Court decision in *Truchon and Gladu v. Canada (Attorney General) and Quebec (Attorney General)*, which struck down the requirement found in Bill C-14 that death be reasonably foreseeable before someone can qualify for MAiD (Lemmens, T., & Jacobs, L., 2019, October 24). *Level 1* interprets Justice

Christine Baudouin's ruling as having exceeded needed restrictions on the reasonably foreseeable criterion and they uphold Bill C-14's amendment to the Canadian *Criminal Code* (s. 241.2(2) d), which includes the following: *(d) their natural death has become reasonably foreseeable, 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* (Bill C-14, 2016). A *Level 1* acceptance of assisted dying may prefer the specific length of time be included (preferably the time remaining falling within six months), however, "reasonably foreseeable" serves as an acceptable check. For any patient qualifying for medical assistance in dying, death is coming soon; the suffering is enduring and has become intolerable.

- Level 1 – Conditions 1, 2, 3, 4, 5, and 6 met

Fourth Position – Level 2 Assisted Dying in Canada

Adherents to *Level 2 Assisted Dying* recognize the administration of MAiD as compassionate when an autonomous individual's condition is grievous and irremediable, enduring and intolerable, and whether or not death is reasonably foreseeable. In fact, death may remain months or years away. Presumably, this is where Kay Carter, the inspiration behind the constitutional challenge brought to its culmination in the 2015 SCC *Carter* decision, would have fallen (at least where her circumstances placed her, without attempting to divine her personal views on the permissiveness of what became known as MAiD, six years after her death in a Swiss Dignitas clinic). Carter might have gone on in her condition for months or years. She would have likely met criteria 1 through 5 and qualified for MAiD at *Level 2*.

- Level 2 – Conditions 1, 2, 3, 4, and 5 met

Fourth Position – Level 3 Assisted Dying in Canada

Level 3 permits MAiD without death necessarily being foreseeable and without competency necessarily having been established at the time of the administration of MAiD, after having been established when the process of MAiD was initiated by the patient. This issue emerged prominently when 57-year-old Nova Scotian Audrey Parker, in 2018, chose MAiD earlier than she wanted over her fear of losing competency at the time of the scheduled MAiD procedure. In Parker's case, qualifying for MAiD was not the issue, her death had been deemed reasonably foreseeable. The issue revolved around her desire to issue a directive in advance. Through an advance directive, the argument goes, Parker would have been relieved of the worry of maintaining competence on the day of the procedure, potentially restricting medication to manage pain in order to remain competent (Colabrese et al., 2018, November 1). *Level 3* represents a considerable leap in established medical ethics. For a patient to not have competency at the time of the procedure means consent cannot be established, which represents a violation of individual autonomy.

The Canadian *Tri-Council Policy Statement* (*TCPS2*) on the consent process makes clear, all consent in research involving humans is to be "free, informed and ongoing" (p. 35). "Ongoing" is of course impossible if the patient lies incapacitated, even if consent was given at a previous time. The *TCPS-2* guides research involving humans in Canada and regards free and informed autonomous choice to be central in research. If this is the case for research, should clinical practice hold different standards? Should ethical guidelines on medical procedures be less stringent? Within *Level 3*, consent to MAiD presents a considerable challenge; advance directives present additional complexity, as there must be a designated surrogate. Here, of course the surrogate is not dealing with minimally invasive procedures, which may present challenges of their own. The surrogate is tasked with considering life-changing (or life-ending)

procedures. Quite another layer of complexity is added. The Canadian Medical Protective Association makes clear in its *Handbook*:

> An Advance Directive may also be used to appoint or designate an individual who will be authorized to make substitute decisions about consent or refusal of treatment in the event that the patient becomes incapacitated…. Consent to medical assistance in dying cannot be given by way of Advance Directives. (Evans, 2016)

Toward the end of 2020, Canada's Parliament appears on its way toward acceptance of amendments to the existing legislation allowing for *Level 3* medically-assisted dying.[7] It does not appear there exists significantly strong influences to prevent the movement toward *Level 3*, despite a lack of clarity on the time frame for receiving a medically-assisted death without second consent. This may promote a division in *Level 3* between those physicians and nurse practitioners who would want a strict time frame around the length of time that can expire between first consent and the time of the administration of MAiD, and those who do not require adherence to an established timeframe. Other Canadian physicians and nurse practitioners may restrict their practice to *Level 1* or *Level 2* medical assistance in dying. The initial iteration of Bill C-7, *An Act to amend the Criminal Code (medical assistance in dying)*, is not clear on the issue of a time frame between the first consent and the carrying out of medical assistance in dying. Bill C-7 seeks to move Canada from *Level 1* to *Level 3*, by repealing "the provision that requires a person's natural death be reasonably foreseeable in order for them to be eligible for medical assistance in dying" (Bill C-7, p. 2), and:

[7] An extensive review of Bill C-7, *An Act to amend the Criminal Code (medical assistance in dying)*, assented to on March 17, 2021, lies beyond the scope of this research study.

> Permit medical assistance in dying to be provided to a person who has been found eligible to receive it, whose natural death is reasonably foreseeable and who has lost the capacity to consent before medical assistance in dying is provided, on the basis of a prior agreement they entered into with the medical practitioner or nurse practitioner. (Bill C-7, p. 2)

Bill C-7 presents a mixed bag: the bill says yes to *Level 2* (the elimination of "reasonably foreseeable"); next, seemingly positioned as a red herring, the bill says no to *Level 5* (when the "sole underlying medical condition is a mental illness"); and then yes to *Level 3* (when a person "has lost the capacity to consent before medical assistance in dying is provided") (Bill C-7, p. 2).

Consideration of *Level 4* (MAiD available to minors, or mature minors) does not show up in Bill C-7. Parliamentary deliberation over Bill C-7 was delayed due to the coronavirus shut down in spring 2020 and the prorogation of Parliament in summer 2020 and began again in October 2020.

- Level 3 – Conditions 1, 2, 3, and 4 met

Fourth Position – Level 4 Assisted Dying in Canada

At *Level 4*, minors suffering a grievous and irremediable medical condition, which promotes enduring and intolerable suffering, may qualify for MAiD. Depending on the age and cognitive development of the minor, competency may or may not be established, and not necessarily to the level of a competent adult. Additionally, establishing a minor as an autonomous individual requires the individual reach age 18 at the time of the MAiD request. At first reading, there is no reference to MAiD for minors in Bill C-7. This area remains highly contentious and unpalatable for many Canadians. Its inclusion in Bill C-7 would likely have opened the door to broader condemnation of the bill overall.

Bluebond-Langner (1978, as cited in Hauerwas, 1990) identified the intricate progression of "self-definition" a terminally ill child passes through (p. 136). First the child recognizes "I am seriously ill," and the gifts pour in (p. 136). The child is no longer expected to continue to go out to play or necessarily attend school. Next, following a remission and "a few rapid recoveries" the child holds, "I am seriously ill and will get better" (p. 136). The cognitive dissonance present in the next phase represents the crushing turning point in self-definition for the child: "I am always ill and will get better" (p. 136). Here pretense emerges powerfully to force a sinking hope back to the surface. According to Bluebond-Langner, "As long as they support the illusion that the children will get better, or at least can be made more comfortable, they can carry out the procedures and duties that in part define them as physicians" (p. 142). With disease increasingly intruding in the child's self-definition, with pain relentlessly present, with fewer people coming around, the child accommodates the pressing reality, "I am always ill and will never get better" (pp. 136-137). When a peer suddenly stops coming by and the messages cease, the child comes to understand the roller coaster "of relapses and remissions… [does]… not continue indefinitely" (p. 137). Finally, the child accommodates the starkest reality, "I am dying" (p. 136). Where in that intricate sequence, one might reasonably ask, might a conversation concerning medical assistance in dying arise? In a poll conducted at a session on MAiD at the Canadian Medical Association (CMA) General Council meeting, 69 percent of respondents reported support for MAiD for "mature minors," which included support for medically-assisted dying in cases where a parent requested MAiD for a terminally ill infant (Vogel, 2017, September 11).

- Level 4 – Conditions 2, 3, and 4 met

Fourth Position – Level 5 Assisted Dying in Canada

At *Level 5*, adult individuals suffering from a persistent mental health condition can pursue medically-assisted dying. Mental health conditions cannot qualify as both grievous and irremediable under the existing MAiD criteria. A psychiatrist cannot gain the kind of near apodictic certainty with mental health conditions other physicians gain with advanced disease "in irreversible decline" (Government of Canada, 2020, October 9). A requirement for an autonomous individual to receive a psychiatric diagnosis, like Major Depressive Disorder, or Bi-polar Disorder, or a personality disorder like Borderline Personality Disorder, could potentially establish enduring and intolerable suffering. That is, the "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" (Government of Canada, 2020, October 9). Competency cannot be clearly established when a severely mentally ill person seeks to end life, and death, when the mental health condition is the sole motivation for seeking MAiD, does not likely mean death is reasonably foreseeable. At *Level 5*, an autonomous individual seeks MAiD on the basis of enduring and intolerable suffering alone.

- Level 5 – Conditions 1 and 4 met

This research study provides the public an enhanced understanding of the unique Canadian implementation of medically-assisted dying, looking beyond the immediate concern of the patient accessing assisted dying to those surrounding the decedent – those planning for, grappling with, opposing, implementing, and in general responding to the new assisted dying regime. A resultant needs assessment can serve to identify areas within the entire structural matrix of medical assistance in dying in Canada which would benefit from increased attention. The research contributes an initial framework for understanding experiences and impacts of the implementation of medically-assisted dying in Canada on groupings of early witnesses. Entering

the experience of medical professionals, those who care for the bereaved, and various community actors, provided the building blocks for constructing the initial framework. The research is to provide the data for the development of a clinical module to assist practitioners in health, mental health, and spiritual care, based on a needs assessment derived from interviews of those surrounding medical assistance in dying in the Canadian context. The study aims to elicit the meanings each individual and/or group from within the three groupings attaches to their interfacing with medically-assisted dying, all in the Canadian context. The elicitation of the meanings attached produces several questions this research moves closer toward answering: What is their experience surrounding medically-assisted dying in Canada? How can that experience be better articulated? How have these various individuals and groups experienced the new Canadian medical regime? What are the axiological implications of the institution of medical assistance in dying within the Canadian context? What does their experience individually and collectively mean for the wider Canadian community?

Similarities and differences emerged from within a grouping and from one grouping to another. Though the experience of the individuals and groups within the three groupings remains crucial, particularly due to the fact that no existing study makes this the primary research aim, the rationale for the proposed study goes beyond entering the experience of those closest to assisted dying in Canada taken together. These experiences, though by no means perfectly representative, may prove a harbinger for the larger Canadian experience going forward, based on the course of the early and ongoing integration of MAiD. Jurisdictions beyond Canada have opportunity to consider the Canadian implementation as a further test case in the earliest international assisted dying regimes. MAiD in Canada furthers the ongoing medicalization of ethical decision making. In a broader global context, as an increasing number of jurisdictions

debate the efficacy of assisted dying within their purview, Canada will likely be looked to as an important benchmark for two reasons. First, Canada's implementation of medically-assisted dying was carried out in large part through the judiciary and therefore bypassed the haggling as a matter of course present within the parliamentary legislative process. Second, the implementation involved a thoroughgoing transformation of the Canadian constitution, and therefore sidestepped the difficulties inherent with subnational governments determining the limits of the scope of the implementation. An additional rationale for looking to Canada as a pilot for future implementation will flow from the experiencing of medically-assisted dying by those closest to it, those surrounding the dying.

In hospital, hospice palliative care, long-term care, and community settings, questions emerge over whether stigmatization is present among professionals or others regarding their decision to either support, on the one hand, or to express conscience rights and to refrain from participation on the other hand, in the practice of medically-assisted dying. How have witnesses to MAiD in Canada experienced this unfolding dynamic? This question has gained attention in Ontario, as several doctors have chosen, for various reasons, to remove their names from the Ministry of Health and Long-term Care list of registered physicians available to provide MAiD. The tabling of Bill C-7 created strain on an already strained system in Canada's largest province. The potential move from *Level 1* MAiD to *Level 2* or *Level 3* MAiD, should Bill C-7 amend the existing legislation, may produce unintended consequences, "diminishing the number of health care professionals who are willing to provide the service, thus worsening access overall. Removing the foreseeable natural death criterion [required at *Level 1*] would represent a radical change for MAID providers" (Frolic et al., 2020, February 23). This shows the differences in assisted dying positions, from one to four, can prove as contentious as movement within the

gradations of the levels within position four, one to five. To what degree do the witnesses here, the participants in this research study, present experiences not easily characterized as either/or positions, but rather fall somewhere within the various positions and level gradations?

Review of the Literature

The literature on the impact of medically-assisted dying in Canada increased as various concerns surrounding the implementation of MAiD invariably developed. Of the three groupings under consideration in this research study, medical professionals have articulated their varied experiences as much as any other group, as they are continually at the front lines in the new regime's implementation in Canada. This flows mainly from reactions to clinical experiences involving medically-assisted dying, often confronted for the first time, or from the consideration of policy and procedural application in the clinical setting.

Medical Professionals

Literature in the grouping of medical professionals surrounding medically-assisted dying in Canada increased considerably leading up to and following the four-year mark of the Canadian legalization of medical assistance in dying. A good deal of the literature to date revolves around guidelines for implementing assisted dying in various medical settings, or responses to the implementation, including surveys. There is additionally literature surrounding the potential expansion of the regime in Canada to include mature minors, those with an advance directive, or to those whose sole consideration in seeking medically-assisted dying is mental illness. Various responses emerged, as well, related to court cases since Bill C-14 received royal assent.

The Canadian Medical Association offered various submissions and policy statements regarding assisted dying in Canada, going back before the SCC decision in *Carter* to the

National Assembly of Quebec's passage of Bill 52, *An Act Respecting End-Of-Life Care*, on June 5, 2014. In a November 23, 2020 appearance before the Senate Legal and Constitutional Affairs Committee, regarding Bill C-7, *An Act to Amend the Criminal Code (medical assistance in dying)* past CMA president, Sandy Buchman spoke in favour of the broadening of assisted dying in Canada. Buchman introduced herself as a palliative care physician in Toronto and a MAiD Assessor and Provider. Though not addressing directly the elimination of the phrase "reasonably foreseeable" with Bill C-7, Buchman stated: "The CMA supports the government's prudent and measured approach to responding to the Truchon-Gladu decision." Regarding the addition of advance requests eliminating the requirement for a second and final consent before the administration of MAiD, Buchman stated: "Our members are in strong support of allowing advance requests by eligible patients who may lose capacity before MAiD can be provided." Buchman also reiterated what have become, since 2017, the CMA's guiding principles for Canadian physicians, surrounding MAiD:

> [1] We believe that the choice of those Canadians who are eligible should be respected. [2] We also believe that the rights of vulnerable Canadians must be protected. This demands strict attention to safeguards. [3] And we believe that an environment must exist that fosters the insistence that practitioners abide by their moral commitments. (Canadian Medical Association, 2020, November 23, pp. 2-3)

The Canadian Nurses Association published the *National Nursing Framework: On Medical Assistance in Dying in Canada* (2017), which presented the findings of a national taskforce focused on the role of nursing in the implementation of medical assistance in dying. This 50-page document signifies the significant impact medical assistance in dying is having on the nursing profession in Canada. With the vast majority of MAiD in Canada thus far taking

place in the hospital and in private homes, nurses are directly involved. The document stresses the potential for conscience conflicts for nurses surrounding the administration of medically-assisted dying, and appropriate responses. Additionally, the Canadian Nurses Association published their *Code of Ethics for Registered Nurses* (2017), an updated version of its code of ethics, to in part include consideration of medical assistance in dying. In the section on declaring conflicts with conscience, medical assistance in dying is listed as an addition to other types of care nurses may deem in conflict with conscience. New ethical responsibilities for Canadian nurses indicate, "Nothing in the *Criminal Code* compels an individual to provide or assist in providing medical assistance in dying. If nurses can anticipate a conflict with their conscience, they notify their employers…so alternative arrangements can be made" (p. 17). Research by Therrien and Pothier, both registered nurses, indicated even seasoned nurses in the field benefit from support and education when involved with medically-assisted dying. The feedback from participating nurses in the study as a whole indicated cases in homecare involving MAiD remain distinctive, requiring singular attention (Therrien & Pothier, 2019).

The Canadian Society of Palliative Care Physicians (2018, February) published results from a 2017 survey of members regarding MAiD. The survey data includes a section on the experiences of palliative care physicians and additionally includes data regarding opinions about expanding the eligibility requirements for assistance in dying to potentially include those who express a desire through an advance directive, or for mature minors, and when mental illness is the sole reason for the request.

Karsoho et al. (2016) focused broadly on aspects of medically-assisted dying, looking at palliative care, and specifically euthanasia in distinction from physician-assisted dying. Karsoho is an exception and has published broadly over the course of the early introduction of medical

assistance in dying to Canada. He has both independently, and with a research team provided help in understanding the Canadian phenomenon of medically-assisted dying. Karsoho (2015) is particularly concerned with dissecting the Supreme Court of Canada decision in *Carter v Canada*, along with dissecting the myriad documentation leading up to the decision. Flowing from this study, Karsoho et al. (2016) went on to conduct in-depth interviews with 42 key participants involved in *Carter* and collected over 4000 pages of legal documents generated by the case, from its inception in British Columbia through to the Supreme Court of Canada ruling. The analysis of the data shows the different ways proponents of medical assistance in dying construct relationships between suffering, mainstream curative medicine, palliative care, and assisted dying.

Karsoho et al. (2017) considered the social ramifications of the 2015 Supreme Court of Canada ruling in *Carter v. Canada*, along with the 2016 royal assent of Bill C-14, in the context of the 13 international jurisdictions that decriminalized or legalized medical assistance in dying. The 13 international jurisdictions all decriminalized or legalized medically-assisted dying since the Supreme Court of Canada first rejected the decriminalization of medically-assisted dying in the *Rodriquez* decision of 1993. As each jurisdiction has legalized assisted dying, new knowledge of the practice has allowed for an easier transition to its broader acceptance internationally, though the development remains relatively limited.

The publication of a position paper on medically-assisted dying by the Canadian Paediatric Society, entitled *Medical Assistance in Dying: A Paediatric Perspective* (2018, April 12), is revealing concerning the issue of minors potentially receiving both voluntary and involuntary euthanasia in Canada, and, more specifically, reveals attitudes regarding the administration of medically-assisted dying when mental illness is the sole consideration. The

Canadian Paediatric Society Attitudes survey received 574 responses out of a possible 1,979 (a 29 percent response rate), with 487 respondents completing all the questions. Almost one-half (46 percent) of respondents were in favour of extending the medically-assisted dying option to mature minors, experiencing progressive or terminal illness or intractable pain, though the CPS-Attitudes Survey reported 19 percent of responding clinicians would be willing to provide medically-assisted dying to minors added to the current regime. Fewer believed access should be extended to children or youth with an intolerable disability (29 percent) or with intolerable mental illness as the sole indication (8 percent). One third (33 percent) of respondents said medically-assisted dying should not be extended to the mature minor population under any circumstance. Regarding eligibility for medically-assisted dying, 55 percent of respondents held that an individual's capacity was most important, compared with 22 percent who favoured a minimum stated age (Davies, 2018).

A study looking at the early experience of individuals pursuing MAiD in the province of Ontario contradicts some of the early generalizations formed surrounding MAiD. Downar et al. (2020, February 24) found socially and economically vulnerable patients did not pursue MAiD disproportionately (p. 178). Further, the study found "physical" suffering on the part of patients pursuing MAiD emerged as prominently as did "psychologic" suffering as a motivation for going forward (p. 177). The findings in Downar et al. (2020, February 24) correspond with the findings in Wiebe et al. (2018, September) which indicated "illness-related suffering (pain, nausea, etc.)" emerged as the number one reason for requesting MAiD among participants in the B.C. study, ahead of both "loss of control and independence," and "loss of ability to do enjoyable and meaningful activities" (p. 677).

Bereaved and Those Who Care for the Bereaved

There is a general consensus from the limited literature on bereavement following medically-assisted dying that more data needs to be collected in order to distinguish this bereavement from other forms of bereavement. Accordingly, there is no specific study that draws from the experience of bereaved Canadians following the death of a family member from a medically-assisted death. There are, however, limited studies from various international jurisdictions referencing bereavement experiences following medically-assisted dying. The data seem, at this point, mixed on the question of whether or not medically-assisted dying creates a considerable distinction in bereavement experience.

Ganzini et al. (2009) pointed out, after more than ten years of physician-assisted dying in Oregon, that "little is known about the effects of this choice on family members' mental health" (p. 807). Fish (2017) pointed out there exists a much more significant amount of research regarding the effect of suicide on families than on those family members or close friends of those who choose to end their lives with an assisted death. Fish points out further, expectation of a poor grief outcome from an assisted death, as Beder (1998) suggested, is countered by Ganzini et al. (2009) who found there was no clear distinction in families bereaved by a family member choosing an assisted death compared to bereaved families responding to death due to an illness.

Gogolishvili and Globerman (2017) summarized two separate studies that indicate family and friends of patients who requested assisted dying "had less traumatic grief symptoms" when compared to the bereaved of a patient who died of natural causes (p. 1). Gamondi et al. (2015) recommend the management of requests for assisted dying need to include not only the patient but also the family members involved. Their findings indicate relatives of the decedent "reported fear of social stigma and did not openly disclose assisted suicide as the cause of death" with others (p. 146). One account of a relative's perception of the experience of secrecy refers to

"The impossibility to tell 'look, he has died of assisted suicide…' it was tremendous, it was sad" (p. 150). Trouton et al. (2020), explored the expectations placed on physicians of Vancouver Island who provide MAiD for additionally providing bereavement support to the families of those patients choosing medical assistance in dying. Though more than 70 percent of the physicians who participated in the research study acknowledged "the importance of bereavement support" for families, "the same number of respondents indicated they have neither the time nor the resources to provide family and friends with this kind of follow-up" (Trouton et al., 2020, p. 20). The study resulted in the creation of a resource guide for physicians to utilize in the support of bereaved family members surrounding MAiD (Trouton et al., 2020).

Community Actors

Community actors are relatively well represented in recent literature. Of note, the Government of Canada (2017(2), 2018, 2019, and 2020) has to date published four interim reports on the state of the implementation of medically-assisted dying across Canada, and published its first, more comprehensive, annual report in 2020. The *2nd Interim Report on Medical Assistance in Dying in Canada* (2017, October) noted the timeline for the ending of interim reporting in favour of the federal monitoring system. The federal monitoring system aims to "provide a more complete picture of who is requesting and receiving medical assistance in dying" (p. 10). The data collected under the federal monitoring system began formally by the end of 2018.

The six-month interim reports attempted to synthesize data from all Canadian provinces and territories, though Quebec maintains its own monitoring system and its findings are not included in all profiles. (Some data from Quebec is incorporated in the *3rd Interim Report*). In some cases, particularly in the territories, data was suppressed in order to protect the privacy and

confidentiality of patients in a particular data element where fewer than seven cases are reported (p. 13). The challenge of assimilating the findings from multiple Canadian jurisdictions, each with its internal mechanisms, is apparent in the reporting. Reporting includes fundamental data elements for further research and policy development. Some of the significant data include: total number of medically-assisted deaths; settings in which assistance in dying occurred; average age of persons receiving assisted death; the proportion of men and women receiving assisted dying; the proportion of individuals receiving assistance in urban centres versus smaller population centres; and the most common underlying medical circumstances of patients receiving medically-assisted dying. The data elements are provided both as combined national elements and as data from within most provinces and territories.

The Liberal government in Canada struck three committees in 2016 to look further at lingering questions regarding the expansion of medical assistance in dying to mature minors, advance requests, and requests for MAiD where a mental disorder is the sole underlying medical condition. A survey taken at the 2017 Canadian Medical Association annual meeting revealed a general acceptance of the notion of extending advance directives to the existing regime, limited support for the inclusion of minors, and even less support for the inclusion of mental health patients (Canadian Medical Association, 2017, September 5).

There are a limited number of comparative analyses of the implementation of assisted dying in various international jurisdictions. Patel (2004) compared the regimes in the Netherlands against the implementation in the state of Oregon, where the physician-assisted dying law is comparatively more restrictive (position 3, as noted above). Emanuel et al. (2016), in a more recent comparative study, looked closely at the attitudes and practices of euthanasia and physician-assisted dying in the United States, Canada, and Europe.

Roman Catholic Archbishop of the Archdiocese of Ottawa-Cornwall, Terrence Prendergast, became an outspoken, early opponent of the medically-assisted dying regime in Canada. Archbishop Prendergast gained international recognition in his opposition to the Canadian implementation. In a CBC Radio interview from Ottawa, Prendergast articulated a position very closely aligned to what Boston (2000) referred to as the Thomas Aquinas position on assisted dying. Prendergast said: "Life is sacred and it's received from God and it's given back to God at the time that God chooses, not our choosing" (Funerals, 2016). In the view of the Catholic Church, according to the Archbishop, the act of assisting in the death of another presents a "grave and moral evil" (Funerals, 2016). The Archbishop's answer to end-of-life suffering was greater engagement on the part of family members. Prendergast noted he often goes to nursing homes and discovers individuals whose families have all but abandoned them. For the Archbishop, medical assistance in dying short circuits the often challenging process of family reunification and reconciliation aging and illness invite. His emphasis remained on expanding palliative care and enhancing social connection to the end-of-life sufferer, all consistent with the teaching of the Catholic Church.

Archbishop Prendergast in his CBC Radio interview did not mention the planned 2016 expansion of palliative care facilities in Ontario. The Ontario Liberal Government's 2016 budget included a plan for opening an additional 20 hospices in Ontario. Some were to allow medically-assisted dying onsite and others would not, largely dependent on their private or public status and religious affiliation. Hospices are at the front lines of the medically-assisted dying debate surrounding implementation. Around the time of Archbishop Prendergast's CBC interview, Rick Firth, President of Hospice Palliative Care Ontario, reported 60 to 70 percent of Ontario's "forty-three hospices are adamant that assisted death will not happen on their premises"

(Laucius, 2016). The provincial government walks a fine line in Ontario, as in other Canadian jurisdictions. With approximately half of hospice funding coming from private donors, concern exists over alienating those donors. The Ontario government planned to invest an additional $75 million in community-based, residential hospice and palliative care, for a total of about $155 million. Specifically concerning hospices, the breakdown was roughly $55 million per year from 2018 to 2019 (Jobs, 2016). The final budget of the Ontario Liberal government (2018, March 28) reiterated its goal of improving and expanding hospice care in the province: "Ontario will invest an additional $15 million in 2018–19 to improve access to community-based palliative care…. by completing the government's goal of opening 20 new residential hospices across the province" (p. 13). The Ontario Progressive Conservative government's first budget (2019, April 11) highlighted expansion in hospice care (p. xxii). Not surprisingly, the Progressive Conservative's follow up budget (2020, November 5) focused on management of the crisis brought on by the novel coronavirus, particularly within long-term care. Increasingly, long-term care facilitates medically-assisted dying at the facility itself, relieving often frail patients from the burden of travelling offsite.

The increases for palliative and other end-of-life care, even before the impact of the coronavirus arose in spring 2020, prove out of step with the demographic shift taking place in the province of Ontario (and this is largely reflective of the rest of Canada as well). In 2006, the percentage of Ontario's population 75+ stood at 6.2 percent. In 2016 the demographic increased one full percentage point to 7.2 percent. Projecting ten years out, the percentage of Ontario's population 75+ jumps to 9.8 percent, nearly a three-percent increase in one decade, an astounding jump. The trend continues at a startling clip into 2036, when the 75+ demographic in the province of Ontario is to jump to 13.4 percent (Demographic, 2016, September 28).

Additionally, more individuals will not only reach the threshold of age 75 but will live longer than previously after age 75 as well. With a close to $50 billion annual health care budget in the province of Ontario alone, it was accurate to describe the health care situation in 2016, when medically-assisted dying was introduced in Canada, as an unmitigated crisis. With the 2020 coronavirus pandemic cataclysm within Canadian long-term care, new definitions of catastrophe are warranted.

Method

Participants

A purposive sample of five women, two men, and four participants remaining anonymous, all witness to medical assistance in dying in Canada from unique perspectives, participated in this phenomenological research study. All participants were significantly impacted by MAiD and thereby offer a vantage point instructive to the Canadian population at large. Inclusion criteria were (a) adult 18 years of age or older, (b) Canadian citizen living in Canada during the introduction of medically-assisted dying in Canada (2015-2016) and the three to four years following, (c) able to communicate in English, (d) identification with one of the three witness groupings: medical professionals; the bereaved and those who care for the bereaved; and community actors, (e) specifically for bereaved participants, a minimum of five months removed from the death of a family member through medically-assisted dying, and review of the *Mourner's Bill of Rights* with the lead researcher as a means of evaluating a potential bereaved participant's readiness to participate (Bentley & O'Connor, 2015) .[8] The study set out to capture the early experiencing of MAiD in Canada from three to five individuals

[8] Bereaved individuals in counselling settings are regularly referred to Alan D. Wolfelt's *Mourner's Bill of Rights* as a concrete resource for navigating the throes of the bereavement experience. Many bereavement groups utilize the resource, such as the Canadian Parents of Murdered Children and Survivors of Homicide Victims. http://canadianpomc.ca/resources/rebuilding-shattered-lives/guidelines-for-participants-mourners-bill-of-rights/

within each grouping. Five medical professionals participated, along with three participants who provide care for the bereaved, and three individuals participated who fall into the broader category of community actors.

The recruiting process and the semi-structured interviewing process did not address the concerns of bereaved individuals and families with the proper degree of sensitivity, and the potential need for follow up support in the form of bereavement counselling. This reality became apparent in the midst of recruiting and interviewing. The bereaved individuals' experiences were too distinct from other participants who maintain, however minimal, a degree of personal distance, protected as they are by vocational or missional involvement. Interviews with bereaved individuals and families may be better suited to a narrative methodological approach, where stories of individual bereavement experiences involving medically-assisted dying unfold. Following consultation with the researcher's supervisor and committee, the contribution of bereaved individuals was removed from the study. None of the remaining 11 study participants was considered foremost a bereaved individual with a family member having chosen to end life through medically-assisted dying. A separate study focused exclusively on the specific experience of bereaved individuals and families in Canada, following a death resulting from medical assistance in dying, is recommended. The loss of the immediacy of the MAiD bereavement experience, in close proximity to the introduction of MAiD in Canada, is noted and regrettable.

The researcher's decision to exclude potential bereaved participants from the study was informed by extensive experience providing counselling and mental health services to individuals, couples, families, and groups, in part seeking counselling support based on bereavement concerns in anticipation of a death (one's own or the impending death of another)

or following a recent death or a death that has occurred at any point in the course of a personal history. Often the impact of the death of someone important to another's personal history emerges in the context of a therapeutic experience. A client may begin to recognize important changes to an entire family system following the death of one or more of its members. Clients also regularly come to recognize the crucial importance of returning to the place of unresolved grief, and to allow for the integration of a death, and the impact of that death, into one's own ongoing story. The space between a death and that integration, or "acceptance" as Kübler-Ross (1969) identified it, is bridged with grieving, the grieving validating the importance of the loss. Medical assistance in dying presents an additional factor to consider in the overall grief experience, one not yet fully understood. Disenfranchised grief may for some come to describe the grief experience following a medically-assisted death, one for which "the grief experienced…cannot be, openly acknowledged, publicly mourned or socially supported" (Doka, 1999, p. 37). Though as Andriessen et al. (2019) noted, "In contrast to the large number of research studies on bereavement following deaths by suicide or other causes, little is known of the effects of euthanasia and PAS [Physician-Assisted Suicide] on those who are bereaved" (p. 2). The researcher's career in the mental health field was influenced early on by a practicum in a community hospice and the accompanying influence of observing a supervisor who displayed a unique presence while interfacing with bereaved individuals, families, and groups, a presence worthy of emulation.

Research Design

The overall design of the research study allows for consideration of the ethical implications of medical assistance in dying in Canada in light of the experience of witnesses to its integration. The underlying ethical assumptions of Canadians, collectively, and as expressed

in part by the Supreme Court of Canada, underwent a significant transformation during the 22 years between the two watershed assisted-dying decisions, *Rodriguez v. British Columbia (AG)* in 1993 and *Carter v. Canada (AG)* in 2015. A philosophical design, in this study grounded in axiology and the study of ethical decision making and ascribing value, is understood more as a broad approach to examining a research problem than a specific methodological design, like phenomenology. Understanding the values of an individual or group regarding medical assistance in dying forms the basis for ethical decision making. The philosophical analysis and argumentation challenges embedded assumptions underlying an area of study. This research study clarifies terminology and enhances the current understanding of the various gradations of assisted dying as they develop in the Canadian context. It would prove challenging to integrate an understanding of study participants' early experiences surrounding medically-assisted dying, the phenomenon at hand, without an axiological foundation (Creswell, 2018, pp. 17-21).

The research study then draws on the hermeneutic-phenomenological perspective, recognizing opportunities in interviews to be first attentive and descriptive to how things appear in participants' life worlds (the phenomenological component). Additionally, interviewing is interpretive, or hermeneutical, since most phenomena are interpretable when considered in context. The context is what is being experienced at the time of the interview, what is being experienced and how it is being experienced (Harrison & Sheehan, 2016).

Understanding more fully the experience of individuals representative of three vantage points on the Canadian implementation of medical assistance in dying opens a window on perspectives captured during the initial phase of the new assisted-dying regime's rollout, before the first five-year Canadian federal government review took place. No previous study encompasses the initial experience of MAiD's witnesses in Canada with the same breadth. The

hermeneutic-phenomenological methodology maintains as the stated goal *epoché*, and *epoché* as a means to achieving ataraxy, a state of serenity. Though, as Balaban (2002) made clear, there are various interpretations of *epoché* (often referred to simply as phenomenological reduction or "bracketing"), and numerous definitions of the Husserlian term have been offered over the past century, it remains an indispensable component of phenomenology and the research it inspires (p. 103). For the purpose of this research, Edmund Husserl's understanding, as articulated in *Ideas: General Introduction to Pure Phenomenology* (1931), served as the reference point for investigation:

> We put out of action the general thesis which belongs to the essence of the natural standpoint, we place in brackets whatever it includes respecting the nature of Being: this entire natural world therefore which is continually "there for us", "present to our hand", and will ever remain there, is a "fact-world" of which we continue to be conscious, even though it pleases us to put it in brackets. If I do this, as I am fully free to do, I do not then deny this "world", as though I were a sophist, I do not doubt that it is there as though I were a sceptic; but I use the "phenomenological" ἐποχή [epoché], which completely bars me from using any judgment that concerns spatio-temporal existence (*Dasein*). (Husserl, 1931, p.59)

This methodology is not without disadvantages. The subjectivity of the data leads to difficulties in establishing reliability and validity of approaches and information. Canada itself is so geographically and culturally diverse it may prove difficult to extrapolate in a meaningful way from one Canadian jurisdiction to another. Further, it is difficult to detect or to prevent researcher induced bias, and it can be difficult to ensuring pure bracketing, which leads to interference in the interpretation of the data. The presentation of results is necessarily highly

qualitative in nature, making the results difficult to present in a manner usable by practitioners. More to the point, phenomenology does not produce generalizable data, or the data is very limited in its generalizability. As is the case in this research study, the samples themselves are generally small, and so it cannot be said the experiences are typical. On a practical note, it is important to consider the possible difficulties of participants expressing themselves. Participants need to be relatively interested in the process and articulate themselves clearly. Problems may emerge with difficulties in expression, whether due to a foreign language barrier, an age or cultural barrier, brain injury, and emotional issues or embarrassment.

Procedure

With the approval of the Saint Paul University Research Ethics Board (see Appendix), persons who met the criteria for inclusion in the study were contacted either in person or through email and were sent a letter describing the study and were asked to consider participating. The lead researcher did not maintain a personal or professional relationship with any of the research participants prior to their involvement. Sixty to 90-minute interviews were conducted with each of the study participants. The individual interviews took place over the course of 15 months, either in-person or telephonically, with the spring 2020 novel coronavirus shutdown across most jurisdictions in Canada delaying some aspects of interviewing in the research study. Six of the interviews were conducted in-person and five telephonically. In-person interviews were conducted either at the participants' offices or at the office of the researcher in Ottawa, Ontario. After a purposive sample was chosen and various Canadian individuals were invited to participate and subsequently consented to participation, the qualitative interviews, best described as phenomenological in nature, took place. Those participants who at the time of their respective interview chose to have their identity revealed in the study were asked to sign a second consent

toward the end of the research study, to ensure the researcher's understanding matched that of the participant.

Interviews were conducted from within the three groupings: medical professionals; those who provide support for the bereaved; and community actors, each surrounding medically-assisted dying from their unique perspectives. The interviews focused exclusively on participants from within the scope of the Canadian experience of medically-assisted dying. No participants from jurisdictions outside Canada were invited to participate. Participants were asked open questions regarding their experience interfacing with assisted dying in Canada. Interviews were constructed in two parts. Part one followed a similar format for each participant regardless of the grouping. The second part of the interview related to the uniqueness of the specific grouping yet remained sufficiently open in nature to allow for expansive responses. In addition to the overarching questions for participants, preconceived probes flowing from the questions themselves helped orient the lead researcher to deeper meanings, or broader considerations inherent in the question, as emphasized in McNeil et al. (2012). The research intended to incorporate findings from at minimum three interviews from within each of the three groupings discussed. Data analyzed inductively allowed meanings to emerge from the interviews, without preconception. As founder of modern phenomenology Edmund Husserl put it, "To the things themselves." The participants were themselves the storehouses of the early experiences of medically-assisted dying in Canada (Harrison & Sheehan, 2016).

The initial questions asked of each of the participants followed a similar format. Participants were each asked to consider the initial experiencing of medical assistance in dying, when first discovering they would from their unique vantage point interface with the new regime in Canada. All participants were then asked to reflect on the evolving experience, on how their

personal experiencing of MAiD changed over the three to four years since the federal legislation received royal assent in June 2016. Finally, all participants were asked to consider in what way the introduction of medically-assisted dying in Canada impacted them at the level of belief, meaning, or spirituality.

Subsequent questions addressed the three groupings individually. Medical professionals considered what the experience of integrating the medically-assisted dying regime into the various medical policies and procedures they adhere to had been like, and additionally what represented the most significant challenge personally of integrating MAiD into their particular medical practice. Those who provide care for the bereaved considered how grief experiences observed had been impacted by a family member or friend's decision to pursue a medically-assisted death, and further to consider how the decision to pursue MAiD impacted families surrounding that death at an emotional level. Community actors considered how the integration of assisted dying into Canadian society impacted them personally, as contributors to Canadian public life, and further how that evolving integration impacted their personal interfacing with other community actors in their specific field and beyond. The lead researcher remained aware throughout the interviewing process of the potential for third parties to unwittingly be revealed by participants, those not consenting to participation in the study. The study seeks to protect the identities of all unwitting third parties.

An additional aspect of the phenomenological nature of the research study can be found in the sometimes-challenging process of recruiting participants. For every participant there were more potential participants that failed to reply to the initial inquiry by the lead researcher, or there were those that initially followed up and then decided not to go forward. There were those wanting to participate but reported an ethical or professional boundary stood in the way,

preventing them from participation. There were instances where the correspondence between and individual witness to MAiD in Canada and the lead researcher carried on for some time and remained robust throughout, only to result in a decision not to participate. The failure of a medical research ethics board to follow up after initial dialogue with the lead researcher suggested sensitivity surrounding the implementation of MAiD in Canada remains, particularly at the institutional level. In the mind of the lead researcher, however, the ethics boards of institutions receiving federal or provincial funding in order to provide medically-assisted dying remain obligated to at the very least provide a rationale for a decision not to participate in early research on the practice.

As purposive interviews, the goal revolved around identifying individuals who can represent the larger involvement of others from within the same grouping, while also providing opportunity for the uniqueness of the individual experience to emerge unabated. This strength of the qualitative process is enhanced in some cases by personally identifying the individual interviewed. By identifying participants, often more can be learned about individual background, experience, and world view. In some cases, however, it may prove important to conceal the participant's identity in order to allow for more complete transparency.

In the case of this research, bereaved family members' identities were to remain entirely anonymous had they been included, while the identities of all other participants could remain anonymous, or participants were free to allow their identities to be revealed. Though each participant remained free throughout the duration of the study to change from having one's identity revealed to having one's identity remain anonymous, it would have proved challenging to conceal the identities of the community actors by virtue of the significant contextualization of their experience. Whereas other participants' anonymous contribution potentially speaks to part

of the larger experience of others from within the grouping, the experience of community actors had a more singular focus. The Canadian *Tri-Council Policy Statement* (2018) chapter on qualitative research, under concerns for privacy and confidentiality, reads:

> In some research contexts, the researcher may plan to disclose the identity of participants. In such projects, researchers shall discuss with prospective participants or participants whether they wish to have their identity disclosed in publications or other means of dissemination. Where participants consent to have their identity disclosed, researchers shall record each participant's consent. (Canadian Institutes, p. 140)

The rationale for the inclusion of individuals whose identities are revealed in the research study flowed in part from reading Creswell's *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (2018). Creswell identifies Denzin and Lincoln's definition of qualitative research conveying the "ever-changing nature of qualitative inquiry." Making the world visible through representations, in this case largely interviews, involves an interpretative and naturalistic approach. Revealing identities of participants has the capacity to bring the research closer to the natural setting where the interpretation of phenomena takes place in terms of the meanings participants bring to them. If at its best qualitative research "represents a legitimate mode of social and human science exploration," distinguishing it most clearly from quantitative inquiry involves illuminating the way things appear. Identifying the individual participant has the capacity to enhance the phenomena as it appears (pp. 6-7).

Within the social constructivist interpretive framework, the goal is to "rely as much as possible on the participants' views of the situation," and to "inductively develop a theory or pattern of meaning" (Creswell, 2018, p. 24). In attempting to convey this understanding to potential participants in the research study, the introductory letter included the following

statement: “Due to the unique position of some of the participants in the research study, the revealing of the participant’s identity may go to establishing a participant’s place in the Canadian context for understanding of the implementation of medically-assisted dying.” The letter went on to highlight that remaining anonymous was entirely acceptable, and that no bereaved individuals would be revealed in the study. Without implying the contribution of a participant remaining anonymous proved less valuable, the researcher indicated providing more context around an individual participant may help the audience better understand the experience of those closest to the implementation of assisted dying, and frankly make it potentially more relatable and engaging. Elucidating that context of course involves an interpretive process. The study is therefore both phenomenological (oriented toward lived experience) and hermeneutical (interpreting the ‘texts’ of life) (Creswell, 2018, p. 77).

The hermeneutic-phenomenological methodology is utilized when wanting to describe an event, activity, or phenomena. The approach combines several methods: conducting interviews, reading documents, watching videos, and visiting places and events in order to understand the meaning participants place on whatever is being examined. Clearly, there existed a great deal of reliance on participants’ own perspectives to provide insight into their unique experience of medically-assisted dying. There was no well-formed hypothesis to begin. Themes, in the hermeneutic-phenomenological approach emerge from the interviews themselves (Van Manen, 2014). The study aimed to elicit, through interviews, the meanings each participant attached to interactions and the classifications they employed to make sense of their lives within this context. Data was analyzed inductively, focusing on allowing meanings to emerge from the interviews. Specifically, this process entailed examining statements from the interviews and

clustering them to form common themes linked to understanding the meanings individual participants attached to their interactions.

Data Analysis

The analysis of the 11 interview transcripts relied on Moustakas's (1994) phenomenological research methodology as the broad outline. The incorporation of the textual descriptions (what the participants in the study experienced with the phenomenon – what actually happened) led to a composite of those textural descriptions, and then structural descriptions (how those experiences happened, considering the setting and context in which the phenomenon was experienced) moved toward a composite of the structural descriptions. The researcher remained aware throughout the process of analyzing the data, interviews can wind down various avenues. Participants do not provide composites of equal parts textural and structural descriptions. The composites of the textural and structural descriptions were brought together into a textural-structural synthesis, or final composite. According to Moustakas, this ultimately provides "a synthesis of the meanings and essences of the experience" (p. 145). This textural and structural composite, or context, represents for Creswell "the essence of the experience," and "the culminating aspect of phenomenological study" (p. 201). This analytical process occurred for each individual falling within the three groupings, and in response to each question posed. There may have occurred an unwitting and infrequent example of a comparison from within one grouping or between groupings, but this was not intentional. The intention was for the composite experience of each participant to stand alone, to receive bracketed treatment. This approach allows for the reader to understand more fully the experience of the participant, within a particular area of consideration, without the initial interpretive interference of the researcher. Reaching a composite of each participant's experience, without preconceived

reference to hold up against that experience, represented the indispensable component of the research.

The textural and structural descriptions emerged within each of the three groupings and for each of the questions posed to participants within the interviews. Each theme was addressed by each participant within the groupings and followed a pattern of (1) revealing combined significant statements, (2) articulating textural-structural responses from each individual participant, and (3) ending with combined formulated meanings which emerged from within the particular theme. The approach combines both blended data for each theme and also allows for the individual experiences of identified participants (some anonymous and some revealed) to emerge within the various contexts.

Results

Taken from verbatim transcripts of 11 participants, significant statements emerged along with various formulated meanings. Tables 2 to 31 include significant statements and formulated meanings from each of the participants in the study. From the semi-structured interviews and from the significant statements and formulated meanings, three meaning units (themes) emerged for each of the 11 participants. Two of the three shared meaning units flow from the importance of time to the study, capturing initial and evolving experiencing of the phenomenon within Canada. From there, attempting to make sense of the experience is crucial, determining what it means and if subjective experiences transcend horizontal understanding for participants, entering the spiritual. Two additional meaning units emerged specific to each of the three groupings. Medical professionals considered how the introduction of medical assistance in dying impacted the policies and procedures they are subject to in medical practice. Additionally, they considered what has represented the most significant challenge in that process. For those that provide care

for bereaved individuals and families, consideration was given to how their own grief experiences, and the grief experiences they have witnessed, have been impacted by a family member's decision to pursue medical assistance in dying. More specifically, those that provide care for the bereaved were asked to give an interpretation of what they thought bereaved family members experience on an emotional level. The grouping of community actors considered how the integration of assisted dying into Canadian society impacted them personally, as contributors to Canadian public life. From there, community actors considered how the integration of assisted dying in Canada impacted personal interfacing with other community actors in their specific spheres of influence and beyond.

Interviews With Medical Professionals

Northern Physician (Family Physician)

The Northern Physician works with medical patients in remote locations, either in-person or through video link, across a massive section of the Canadian North, very often utilizing the services of a translator.[9]

Tina Cuerrier (Registered Nurse, Carefor Ottawa)

Cuerrier's nursing career began close to 50 years ago within the National Health Service (England). Early in her career, Cuerrier moved to Canada and continued nursing in Ontario. In this most recent chapter of her career in nursing, Cuerrier provides home care to palliative clients in the Ottawa region through Carefor, a provider of integrated home care and community supports.[10]

Gerald Ashe (Family Physician, Palliative & Geriatric Medicine)

[9] Here the Canadian North designation is based on the delineation made by Statistics Canada, between northern and southern Canada. See Statistics Canada (2019). *Map 1 – Delineating northern and southern Canada*. https://www150.statcan.gc.ca/n1/daily-quotidien/190704/mc-a001-eng.htm

[10] Carefor. (2020). https://carefor.ca/

Dr. Gerald Ashe, MD, CCFP (PC), FCFP, is a family doctor who has practised for 39 years, six of those in PEI and the last 33 in Brockville, Ontario. He has a special interest in palliative and geriatric medicine. Dr. Ashe has supported the right to die both by speaking up in his local community and by submitting letters, published in the *Globe and Mail*, in support of end-of-life choice.[11]

Nurse Practitioner (Palliative Care)

The Nurse Practitioner began serving patients as a palliative care specialist years before the 2016 introduction of medical assistance in dying in Canada. Since 2016, the Nurse Practitioner additionally serves as the MAiD coordinator for an established region within a provincial health system. The Nurse Practitioner meets palliative patients both in their homes and in the hospital setting. Living and working in rural and lower population settings creates unique rewards and challenges not faced by medical professionals working in Canada's high population centres.

Urban Physician (Palliative Care)

The Urban Physician exclusively serves patients who are deemed palliative, in one of Canada's large urban centres. The Urban Physician's career in medicine began years before the introduction of MAiD in Canada.

Theme 1: Initial Experiencing of MAiD

Experiences regarding the introduction of medically-assisted dying in Canada varied considerably within the medical professionals grouping and within the other two groupings to follow as well. For some, the experience was welcomed freely, with anticipation. For other participants, a degree of reservation pervaded their initial experience. All of the medical

[11] Retrieved from Dying with Dignity Canada. (2020). *Dr. Gerald Ashe*. https://www.dyingwithdignity.ca/dr_gerald_ashe

professionals, those who provide support to the bereaved, and the community actors indicated the introduction of the MAiD regime represented a shift within Canadian medical practice, bereavement care, or community interfacing.

Northern Physician.

The Northern Physician expressed initial concern over the introduction of medical assistance in dying within Canada, after having followed the entire process closely, "from advocates in the community thinking that it would be a good option, all the way to legalization, and then all the way to the practical application in my medical field." Concerns emerged over a potential compromise to personal ethical standards, and whether the implementation process would preserve those standards. For the Northern Physician, there emerged "lots of questions, definitely some underlying concerns, and lots of discussion, with both the medical people in my world and also the people in the rest of my social construct." The potential for compromises to personal ethical standards of practice (in large part over not knowing what the implementation of MAiD would require of physicians) were met with equal concern for marginalized populations, which the Northern Physician considered leading up to the legalization and implementation of MAiD in 2016.

Significant work with marginalized populations, over many years, left the Northern Physician concerned these various groups would be left out of the discussion surrounding medically-assisted dying, left without a "voice or the resources to access information, or make some of the decisions." The Northern Physician specifically referenced: disabled individuals; those suffering with severe mental health disorders; and various First Nations communities the client serves or has visited. "I was concerned specifically how it was going to look for those populations." Though acknowledging the appearance of built-in safeguards for medical

assistance in dying procedures, concern remained after observing the marginalization process first-hand in Canada, and in particular Canada's North, many times before.

The Northern Physician's response to the introduction of MAiD flowed from within the context of working exclusively with patients from Canada's North. The reality of the Northern Physician's white skin remained at the forefront. Ongoing concern existed surrounding the sensitivity necessary to provide medical care in various Northern communities. The approach is one of "humility," and of "love," of "gently ask[ing] the question, rather than [offering] definitive answers." Listening is vital. An historical awareness of myriad injustices informs the Northern Physician's approach. Considering all of this, MAiD in one sense seemed absurd. Trying to introduce medically-assisted dying into already challenging conversation, fraught with the potential for misunderstanding and misrepresentation, seemed daunting, if not impossible. The Northern Physician remained skeptical.

Tina Cuerrier.

Cuerrier's experience surrounding the introduction of MAiD in Canada was one of unequivocal approval and relief – "a big advocate." The focus of her initial approval rested on the nature of the patient experience surrounding the illnesses encountered at end of life, and the ability of clients (as they are often referred to in the home health care setting, rather than "patients") to gain a sense of control. "They don't have any control over their illnesses and the fact that they are going to die, but they can control *how* they are going to die, and *when* they are going to die." Working in home health care, Cuerrier observes in that intimate space profound physical suffering, and does so without the accoutrements nurses may rely on for periodic relief in the hospital setting. These, according to Cuerrier are "pretty awful illnesses…some pretty horrendous things that they are dying from." Over the course of a nursing career going on 50

years, one that began in England before transitioning to Canada, Cuerrier isolates the recent experience surrounding a client's decision to pursue medically-assisted dying. "I've seen a lot of stuff, and it's the only thing they have control over."

Though Cuerrier recognizes MAiD is not an avenue for all palliative clients to walk down, she observes clients who do come to that decision doing so unreservedly. "They are so ready and they're so much at peace about it," yet, "it's not something everybody can accept or be prepared to be involved in." Cuerrier stressed the personal nature of the decision for clients, distinct from family, and despite a families' proximity to the client. For clients, "it's a very personal thing, on a personal level." Cuerrier privately embraces the client's decision, however difficult personally, content in the client's experience of peace around the decision. "They're tired. They don't want to fight this any longer." It is not the clients Cuerrier struggles to observe, it is families of the client making the decision to pursue assisted dying. "Watching the families, that is very hard." It is hard because this is a different sort of death experience. "Watching somebody end their life that way is very surreal." In Cuerrier's experience, families remain supportive, and they remain in the room at the time of the procedure.

It's not only families who grieve over the death. Home health care professionals regularly work in a client's home for weeks, months, even a year or more. Grief is palpable for those professionals as well, though the anguish often goes unseen. "You do build up a rapport and you do grieve. I grieve as a professional when I lose any of my clients, whether it's through MAiD or otherwise, whether they die naturally or through palliative coma,[12] you grieve." Cuerrier's openness and connection to her emotional state, alongside her obvious humanity, have

[12] Palliative coma is now more regularly referred to as palliative sedation.

contributed mightily to her ability to work with vulnerable people and their families for nearly a half-century.

Cuerrier's description of an early experience involving medically-assisted dying speaks further about the intimacy of the home health care setting. Cuerrier worked with the early client to access MAiD over a long period of time, and the client confided in Cuerrier regarding the decision to pursue assisted dying within a larger conversation over looming death. Without prompting, and as an extension of their existent warm relationship, the client invited Cuerrier into those existential conversations. The client made a final comment to the family, indicating the client's peace with the decision. It was challenging for Cuerrier to watch the family, manage her own internal grieving, and carry out her professional responsibilities following the procedure. On that early occasion, Cuerrier remained with the family for about an hour before leaving the home one last time. It didn't take long after before she was on the phone with one of her supervisors at Carefor. "My company is very good at debriefing," she said. "I have really good rapport with my supervisors; they're great." After keeping it together for so long, being available for so long, allowing herself to enter into the experience of another's inestimable suffering month after month, she cried.

Cuerrier continues to find the moment of a medically-assisted death difficult to describe when reflecting back on the experience. "Surreal" seemed the best descriptor. "You know, one minute they are talking to you and then basically just go to sleep, and they pass." She continued, "It is hard to get your head around it, even though you can rationalize, you know, 'This is what the client wanted; they're tired of the pain and the suffering, and their struggle, everyday struggle.'" Leading up to and during the procedure, Cuerrier's focus remains on her professional responsibilities, monitoring and supporting the client's wellbeing. Almost immediately after the

client "passes," and the struggle has ended, her attention turns to those remaining in the room. Cuerrier understands the experience of families, many of whom provide countless hours – *days, weeks, months* – of often unrecognized caretaking: thankless, constricting, often disorienting. She had difficulty putting into words that transition from care for the client to a powerful awareness of family. For the client, "I'm happy," she said, "but anybody that's caring for someone that's end-of-life care…all that they have to do…it's watching the family that I find…I can support them…but I find it can be brutally hard…watching that process is difficult…it can be heart-wrenching." Cuerrier connects with the family following the death, offers condolences and hugs, and then pulls back, giving the family space to be with the deceased, however long they need.

The heart-wrenching nature of the care Cuerrier provides makes self-care vitally important. Cuerrier conceded without it she couldn't continue to fulfill her role for clients and families. Self-awareness serves as the umbrella, covering all aspects of her self-care experience. Self-awareness allows Cuerrier to recognize when it becomes necessary to step back from end-of-life palliative care and accept some clients in a place referred to as "stable palliative." These clients require, usually once or twice weekly, perhaps bi-monthly: a medication review; pain management; and potentially PICC care, but generally little else. When clients near end of life, at 20, 30, or 40 percent, responsibilities increase exponentially: preloads; multiple orders; pumps. Additionally, "you've got family; it can be very overwhelming, and it can be very draining, especially in the home setting because you don't want to make an error...you've got the families." Cuerrier walks her three dogs every day. She listens to music, reads, and allows herself to grieve the loss of clients.

Table 2

Selected Significant Statements From Medical Professionals

The thought of it was quite concerning for me, mostly for some ethical questions about it and how it was going to be implemented in a way that could preserve those ethics.

Any sort of interface with cross-cultural spaces, one has to be very aware of one's white skin and the burden that comes with that. I would say that across the board they are very warm, welcoming, quite relieved to see a doctor. In some of these Northern spaces that's a bit of an anomaly all its own.

I was actually very happy to hear it had become legalized. They don't have that fear of the pain, or 'When am I going to die?" What I find hard is the families, watching the families I find personally very hard. It's always a room full of love and peace.

It seems to fit for me because a lot of people…I'm already seeing these patients anyway and doing pain and symptom management, so it was an easy flow into, 'If we're doing all these palliative care things and you still aren't getting the symptom relief that you think is worthwhile to continue living,' it flows right into MAiD.

We live in a suffering averse culture. It's something that certainly raises concern for me and for our society. I see medical assistance in dying as providing people an opportunity to avoid that process.

Gerald Ashe.

For Ashe, the experience surrounding the introduction of medically-assisted dying to Canada has been highly transformative and utterly surprising. Ashe described his experience as "a life-changing thing," particularly coming as it has toward the end of his long career as a family physician. When Ashe attended medical school in the 1970s, he explained that not only

was voluntary euthanasia (as it was referred to then) not talked about, but "at that time [I] never did fathom that at some point we would be able to do this for people." Furthermore, Ashe explained, "I mean, I was brought up Roman Catholic…it was just…wouldn't have been on our family's agenda." Over the course of several years, doing a great deal of palliative care as part of his family medical practice, he gradually came to "realize that people, some people, have really difficult deaths…and suffering's difficult to control under some circumstances." Ashe lived with that understanding for many years: some deaths would remain very challenging for patients and for families; he would continue to manage a dying patient's distressing circumstances as best he could. This explains the "epiphany" Ashe has experienced since MAiD became available for patients, the realization has "been really, really wonderful for me in my career."

Coming to view medical assistance in dying favourably took time. Ashe recalled beginning to think about assisted dying in the late 1980s or into the 1990s, largely when Michiganian, Jack Kevorkian emerged as a strident proponent of euthanasia. The media labeled him, "Dr. Death" for his belligerence and his steady use of the "suicide machine," contained within the back of his 1968 Volkswagen van. Ashe recalled around that time euthanasia and its chief proponent seemed "sinister." After three years of increasing exposure to Kevorkian, Canadian Sue Rodriguez's story emerged. Rodriguez lived with amyotrophic lateral sclerosis, also called Lou Gehrig's disease, after the famous Yankee first baseman. Ashe recalled the tremendous shift in his perception on assisted dying. If Kevorkian presented as sinister and antagonistic, Rodriguez appeared sincere and motivated, worthy of consideration. Ashe thought, "Oh my God – this poor lady!" This early encounter with the case of Sue Rodriguez opened Ashe to a new set of questions regarding the end of life.

According to Ashe, his lengthy palliative care experience did not serve as some kind of prerequisite for the provision of medical assistance in dying to patients. The administration of MAiD in Canada does not require palliative care experience. Ashe recognizes, however, his palliative care background enhances his advocacy for MAiD in his community. His experience is very much linked to the "passion" which provided him the impetus to establish the provision of MAiD as an extension of the palliative care team on which he plays a part. Particularly younger physicians Ashe encounters may lack the same commitment to MAiD in part due to a lack of palliative experience. He noted: "I don't think it's absolutely necessary, but it certainly helps. I mean, it really helps to have been down that road with patients who've had difficult deaths." The "difficult deaths" have, more than any other feature of the palliative experience, motivated Ashe to promote MAiD as an end-of-life option. Ashe recalled patients throughout his career who committed suicide, violent deaths – shotguns, overdosing on pills. He contrasts these deaths of desperation, the patient alone, without family, to the medically-assisted dying procedure he performs for patients. Ashe has emerged as one of Canada's foremost advocates for assisted dying.

Nurse Practitioner.

Several years before 2016, and the introduction of medical assistance in dying in Canada, the Nurse Practitioner recalled hearing palliative patients and their families express frustration over perceived limitations in the management of physical and emotional distress. There was the frequently recited line, "'We treat our dogs better than this,'" and from a prolonged state of exasperation, some variation of, "'There has to be a more humane way!'" The Nurse Practitioner, a specialist in palliative care, empathized with these patients and their families, and provided symptom management whenever possible. When conversation about some eventual

form of assisted dying increased, particularly following the Supreme Court of Canada *Carter* decision in February 2015, the Nurse Practitioner felt "happy" for patients and experienced a sense of relief. Once MAiD was legalized, the Nurse Practitioner moved immediately to integrate the process into the Nurse Practitioner's existing practice.

The process of integrating MAiD into the existing provision of palliative care proved somewhat challenging initially. For more than a year the Nurse Practitioner worked on streamlining the new system within the Nurse Practitioner's region, attended conferences, and pored over any available literature. Despite initial challenges, and the anticipation leading up to the legalization of assisted dying in Canada, the rollout seemed anticlimactic. According to the Nurse Practitioner, "Personally, it hasn't been as big an issue as I thought it might have been." The beginning of the Nurse Practitioner's specialized career in palliative care, years before the introduction of MAiD, presented a greater hurdle. People in the communities where the Nurse Practitioner worked began to associate the Nurse Practitioner with palliative care and therefore death. Having already faced this initial hurdle within various communities, and after having established a reputation for a supportive approach to end-of-life patients and their families, the introduction of medically-assisted dying did not result in any discernable shock.

The Nurse Practitioner generally serves as the second assessor in the MAiD process, along with conducting the pre-counselling and the assessment process with a patient inquiring about MAiD. The Nurse Practitioner works in a jurisdiction yet to formally allow nurse practitioners to administer the lethal dose, though every other facet of the MAiD process falls within the nurse practitioner's regular scope of practice.[13] On the day of a MAiD procedure, the Nurse Practitioner prepares all of the medications utilized, and hands the various syringes to the

[13] Quebec is exceptional in this regard, requiring physicians to administer medical assistance in dying. There is currently not provision for the inclusion of nurse practitioners.

physician as the physician "pushes" the medications. Though no significant distinction exists between the current role of the Nurse Practitioner and the physician regarding MAiD, the Nurse Practitioner looks forward to a further streamlining of the process, when Canadian nurse practitioners are given the option of providing MAiD in their respective jurisdiction.

Urban Physician.

The Urban Physician approached the introduction of medically-assisted dying in Canada with "trepidation." The trepidation arose after recognizing the MAiD procedure would likely become increasingly common and that the new regime would likely impact the Urban Physician's palliative patients directly. Going back to the 2015 *Carter* decision, the Urban Physician became concerned about the role palliative care physicians would be asked to play. Two initial questions emerged: "Would [I] be asked to behave or act outside of my moral conscience"? and "Would [this] alter the kind of career that I have"? Furthermore, early consideration created a philosophical quandary for the Urban Physician: "As a palliative care doctor whose goal is to provide people with as natural a death as possible, and to support them in their dying process, it was concerning…Maybe this will be the path that everybody takes." This may be a bigger deal than even imagined.

Working as a palliative physician allows for the reality of death to emerge, uninhibited. For most, the truest reality of the human condition may only emerge in a significant way when death is looming. The Urban Physician recognized what former French President, François Mitterrand described as "the freedom of being true to [oneself]…when the body breaks down, at the edge of eternity" (Hennezel, 1997 p. ix). It's a window of opportunity many will otherwise miss altogether. In dying the Urban Physician recognizes "a redemptive process," an opportunity to forego the "layered-on ideas of my value coming from what I can do…or from

career, or my success, or my appearance." Herein lay the Urban Physician's initial fear regarding medical assistance in dying, "that people would miss out on this redemptive process in their li[ves]." Patients choosing to hasten death may miss the opportunity to again experience their true self, unencumbered, uninhibited.

The introduction of MAiD challenged the basic philosophical approach the Urban Physician has adopted in treating palliative patients. The Urban Physician referred to the transformation as "a big adjustment mentally." The fundamental role of the palliative physician is not, as many might assume, to prolong life per se, but "that peoples' lives are as high quality as they can be, and that they aren't being cut short unnecessarily." The Urban Physician felt the tension profoundly as medically-assisted dying was introduced: working diligently to prevent patients from losing time at the end of their lives, while considering the procedure designed to limit the preservation of that end-of-life time. For the Urban Physician, this time is of particular importance for many individuals. Granted, there are individuals, rare individuals, "who had the wherewithal to actually live into who they were, without needing to get to the end of their life to do it," but they are the exception. A good deal of life is spent anxiously running from the reality of death. Distractions mount and are indulged. Not having lived life as freely and authentically as envisioned may require the permanence of death looming to face oneself, finally.

Table 3

Theme Cluster With Formulated Meanings

Initial Experiencing of MAiD
Followed the process closely
Quite concerning
A space of underlying concerns

Felt like a big broad question

Happy it became legalized

Big advocate

They can die with peace

They basically go to sleep

Surreal

Their choice

They're at peace with it

Life-changing thing

Been an epiphany

Just really wonderful

Good thing for patients

On board right away

Started talking about it

Wasn't a bad thing anymore

No judgements

Uncertainty as to how significant

Some kind of discontent around it

Important piece missing

Theme 2: Ongoing Experiencing of MAiD

Dependent on when the participant interview with the lead researcher took place, sometime between spring 2019 to summer 2020 (a worldwide pandemic not withstanding), three

to four years passed since Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* received royal assent in Canada, enough time to have seemingly traversed the initial introductory phase of the MAiD implementation, and before the initial five-year review by the federal government.[14] During the intervening years, from 2016 to 2019 or 2020, participants' experience surrounding MAiD invariably changed, however broadly.

Northern Physician.

Throughout the passage of years, the Northern Physician continued to experience the internal questioning, even "angst," which began months before medical assistance in dying became legal in Canada. For the Northern Physician, "those initial questions…they still exist when I think about the ethics of how we continue to offer that service [MAiD], or have the resources to support what people who are at the end of life need." Though the questions remained and the concern over the inequitable distribution of resources for those nearing end of life remains a matter of unrelenting ethical principle, the Northern Physician in the intervening years since Bill C-14 experienced a degree of relief over observations of the tangible implementation of assisted dying. Recognizing the sample of those initiating medically-assisted dying in Canada's North remains relatively small, the Northern Physician witnessed "scenarios" that "went very well for the people involved, the family and the patient [presumably] were really content with how it happened." Having indirectly experienced the MAiD process within the Northern community hospital setting (not directly as the physician responsible for carrying out the voluntary euthanasia), the Northern Physician's perspective shifted.

[14] Quebec legalized the practice of what in Quebec is regularly referred to as "medical aid in dying" through the passage of Bill-52, *An Act Respecting End-of-life Care*, in 2013.

The Northern Physician can reasonably maintain a degree of ambivilance over involvement in the MAiD process, in large part due to the infrequency of requests from Northern patients, yet the Northern Physician recognized the same level of personal "hesitancy" and "resistance" had diminished. From a position of resistance, the Northern Physician moved toward a desire to be "involved in the process and the assessment and probably a referral on to someone else." The notion of being the physician to carry out MAiD remained outside of the Northern Physician's comfort zone as a practitioner, "but I would really want to facilitate the strength of that process and make sure that there's due diligence, and access to care was provided," the Northern Physician added. The step toward a greater degree of comfort standing as an assessor is made easier now that assisted dying is legal in Canada; it provides a parameter. The law allows the Northern Physician to gain a degree of distance from a personal hesitancy. Furthermore, the Northern Physician pointed out the standard practice of bringing an ethical concern forward for whatever reason, whether MAiD was involved or another circumstance or procedure, should there exist any concern in assessing a patient's needs, provides additional relief.

Tina Cuerrier.

Cuerrier maintains concern over the current restriction of assisted dying to those whose death is "foreseeable," as Bill C-14 stipulates. For Cuerrier, her ongoing experience as a nurse confirms her own desire to avoid being a "burden" to her family, being fed, and in an adult diaper. "I don't want to end up like that," she said. According to Cuerrier, this sentiment is shared by many of the nurses she has interacted with in her role. Alzheimer's disease represents the biggest concern. "I would like to be able to say that once I get to that point, even though I may not be able to say, 'Yes, I'm ready,' I would like for my life to end at that point." Cuerrier

feels burdened by questions from patients related to the ability to provide the second, and final, consent before the administration of MAiD. She relayed the concern she feels over the reluctance of a patient to access morphine over fear of a loss of awareness.[15]

Unprompted, Cuerrier's reflection on her evolving experience since the introduction of MAiD turned to mental health. She seemed to indicate an awareness of the three areas of consideration by the Expert Panel Working Group on medical assistance in dying, areas not covered in Bill C-14: medical assistance in dying for mature minors; advance requests for MAiD; and where mental illness is the sole underlying medical condition. According to Cuerrier, "we're going to see more and more issues with mental health." Though she stressed the necessity of holding out hope for individuals struggling with debilitating mental illness, the decision, she said, is ultimately their own. Cuerrier hesitated to draw a clear distinction between mental suffering and other suffering: "Whether it be for mental health or illness…sometimes life becomes too painful, too difficult, too much of a struggle." Provided stress is placed on improving current mental health standards, and provided healthcare professionals are protected, Cuerrier's experience moves her toward the provision of a contained alternative to suiciding, alone, in desperation.

Table 4

Selected Significant Statements From Medical Professionals

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[15] On the day of her interview for the research study, Tina Cuerrier was aware of the September 11, 2019 Quebec Superior Court decision in *Truchon and Gladu v. Canada (Attorney General) and Quebec (Attorney General)* and was in part linking her experience to the decision (though for Cuerrier the concern expressed revolved specifically around loss of capacity to perform the activities of daily living, regularly associated with Alzheimer's disease and related dementias, and not necessarily concern over the loss of autonomy as in the capacity to make decisions).

I think I'm less certain of my position. It felt as I talked to my colleagues and also with people in the environment that there was a great deal of peace and contentment about how it played out, and that there was thankfulness that the service was provided.

I don't know that they could go five years, but right now there's a time frame. People have to have all their mental capacities. That's the one thing I get asked, if people are on morphine, they are afraid to have it because when the time came, they want to be totally aware. I would like to be able to say that once I get to that point, even though I may not be able to say, 'Yes I'm ready,' I would like for my life to end at that point.

Any time you get more experience, and you feel more confident about your ability to not just assess patients for their eligibility, but also to provide the service…I'm much more confident now. It certainly has helped me in my own medical practice because it was always difficult when you had palliative patients who were really suffering, and you did your best, but you had nothing else to offer.

Some people say, 'Ah no, that's not for me,' but other patients, they're glad to be reminded of that, or some of them, believe it or not, don't know that it's available. There are still people that really don't understand that it is available.

Once they've signed, they almost always have MAiD, unless they deteriorate really quickly and end up having a natural death. One time in these whole few years, I had a scheduled date and the patient's [family] actually called me that morning and said, 'Don't come; we don't want to do it.'

I think it's more when the suffering is for loss of independence and things that are a bit more existential, and not a physical symptom, because I can treat pain; I can treat shortness of breath; I can fix those things, but the loss of independence, the gradual spending more

> time in bed and not being able to enjoy life, those things, where people have those symptoms they tend toward MAiD.
>
> It's very nuanced because palliative care is all about autonomy. In many ways we're asking clients very specifically how they want to see their death unfold. You always have clients who are saying, 'I want to be as alert as I possibly can, and when I'm no longer alert life isn't worth living for me.' Classically, at that point we would pursue a more sedating course. With MAiD the big focus is on autonomy, is on individual choices. It's hard for me to say I see it conflicting with palliative care. The piece I find difficult is the hastening of a person's death.

Gerald Ashe.

Ashe reflected on his first cases, nearly three years before. There wasn't much available at that time in terms of reference points. Quebec had been providing assisted dying beginning in December 2015 and thereby became the model for the new routine for the pioneering Ashe in Ontario. It was a considerable burden. Anxiety mounted. Ashe followed Highway 29 out of Brockville, Ontario turning it over in his mind. "If there is any procedure in medicine…it is a procedure that you want to go well, because you want the patient to be comfortable and you're also dealing with families, and you want it to go well for them." The questions coursed through his mind: *Is it going to be totally peaceful? Is there going to be any struggling? Is there going to be any kind of gasping, or whatever?* It did go well, a "beautiful experience." And that experience has changed. After more than 50 procedures Ashe's anxiety has entirely subsided, replaced with a perfect record of satisfaction with the patient experience and that of the family as well.

Nurse Practitioner.

Having a network of support represents the single most important change for the Nurse Practitioner. In the early years surrounding the introduction of MAiD, the Nurse Practitioner felt somewhat isolated, and this feeling was enhanced working in a smaller population centre. Over the course of more recent months, a network has emerged of medical professionals working in a similar role, specializing in palliative care, offering medical assistance in dying as an end-of-life option, and doing so from small population centres. The connection remains important to the Nurse Practitioner. "We're in daily contact with one another, trouble-shooting issues, helping each other out." The contact is predominantly virtual, though in-person consultation is at times possible as well.

Beyond the positive development of an expanded network of support, the changes experienced by the Nurse Practitioner surrounding MAiD remain minimal. The client continues to provide virtually the same palliative care assessment to a particular patient that was provided before the inclusion of MAiD. When the Nurse Practitioner receives a referral, the family is contacted and a meeting with the patient is established, generally in the patient's home. The Nurse Practitioner leads the patient through advance care planning and addresses end-of-life care, often with family members present. Nothing thus far has changed since the legalization of medical assistance in dying. Since then, the Nurse Practitioner makes an additional comment regarding the list of end-of-life options available, listing MAiD as an option, in keeping with the Nurse Practitioner's understanding of the appropriate application of informed consent for patients. The Nurse Practitioner finds many people remain unaware of the procedure, and the initial assessment provides an opportunity to describe the potential option.

The preferred end-of-life scenarios involving MAiD, for the Nurse Practitioner and reportedly for the families involved, are those scenarios allowing for deliberate consideration of options. The Nurse Practitioner remains available to patients and families as questions emerge: "We all have time, and everything is straightforward." Time is often in short supply, which presents a challenge for the Nurse Practitioner when the situation becomes urgent. "Those are harder emotionally…because you don't really have time to process it all." In some cases, the ten-day waiting period is waived due to the rapid decline in the client's condition.

Urban Physician.

The Urban Physician's experiencing of medical assistance in dying since its legalization in 2016 is mixed. "In some ways my fears have been comforted and some have been intensified." The Urban Physician has found the medical community in general steadfast in upholding individual physicians' freedom of conscience regarding a decision to participate or refrain from participating in a medically-assisted dying process. Mechanisms like centralized coordination of the dissemination of MAiD information has permitted a relatively comfortable coexistence among medical professionals. The Urban Physician did not anticipate this positive development.

The Urban Physician has been additionally encouraged and reassured by the ongoing decision of so many to go through with a natural death. Putting it succinctly, "It's not like every client of mine is pursuing medical assistance in dying," and most would qualify. Like the mid-60s storm around Dylan's decision to go electric: Significant, well yes, but it's not like everybody tossed their acoustics into the bonfire as a result. Recall Canadian Neil Young's powerful 1971 performance at Toronto's Massey Hall, an acoustic folk masterpiece. "The ambivalence around death is a powerful tool, in the sense that most people, even in their darkest

moments of wanting death…there's a piece of them that's fearful of it. They want to remain alive and continue on." Though the rate of assisted dying in Canada has gained significant momentum since 2016, the Urban Physician anticipated a more profound impact.

In some ways, though, the Urban Physician's fears have intensified. What the Urban Physician came to realize is the reality of MAiD has opened up a decision-making process for patients and families no one likely considered – it never before existed, except in a few jurisdictions around the world, and only within the last 25 years. The mere existence of the reality of MAiD creates a new anxiety, an extra layer of complexity. The option is present for both those who view MAiD favourably and those who view it less favourably, and both have a decision to make as a result. The process of dying, entering late-stage care, is inherently uncertain; remaining in a state of uncertainty requires Herculean fortitude; MAiD offers a certain alternative to uncertainty. Uncertainty breeds questioning in the minds of patients: "'Will this alleviate stress and strain on my family?'" For the Urban Physician the impact of MAiD since 2016 extends far beyond the room of the dying individual and those gathering around that bed. Every thoughtful Canadian, whatever the individual predilection, decides.

MAiD impacts the Urban Physician's clinical approach. "Nuanced complications" have arisen for a palliative specialist, not necessarily for patients certain of a desire to pursue MAiD, or for those utterly opposed, but for those "who previously would have never voiced a desire to end their life, we're having conversations about it because MAiD exists." The Urban Physician does see examples of patients foregoing treatments, previously designed to provide comfort in the pre-active stage of dying, in order to maintain their capacity to give final consent, just before the procedure is carried out. The Urban Physician encounters patients who have come to a decision to pursue MAiD and anticipate it will happen soon after, as when a patient makes one of

a variety of other requests. The ten-day window, which regularly turns into two weeks, produces additional anxiety not previously requiring attention.[16]

Table 5

Theme Cluster With Formulated Meanings

Ongoing Experiencing of MAiD
Relieved and happy
Not entirely sure
Healthcare professionals have to be protected
Well established system
They've all gone well
Not one case of angst or suffering in a patient
Delirium is the biggest cause of palliative sedation
Most palliative care teams do not allow MAiD
Not a lot of people were aware of it
They are pretty straight forward
Worry about advance requests in dementia patients
An extra layer of complexity
A new realm of activity

Theme 3: Impact of MAiD on Belief, Meaning, Spirituality

Northern Physician.

[16] This reality is the impetus for amending the existing legislation, Bill C-14, to forego the final consent when the patient has lost capacity. The proposed legislation, Bill C-7, encountered delay as a result of COVID-19 restrictions on the regular functioning of Canadian Parliament.

The Northern Physician revealed an upbringing in a Christian faith tradition, though connection to faith and Christianity is "less structured" than has previously been the case. Despite a less structured linkage to the faith that informs belief, the Northern Physician recognized "discussion about [MAiD] brush[ed] pretty close with some…deeper sensibilities about life, and the sanctity of life, or where life comes from, where it's going to, what involvement humans have in when it starts and when it stops." The initial discomfort the Northern Physician experienced with the introduction of MAiD was certainly woven into an existent set of established beliefs, along with the aforementioned understood principled role as a medical practitioner, and the rooted ethic (of particular concern to the Northern Physician) of providing "equal care across the board." The complex construal remains in process. Personal misgivings about the offering of assisted dying (stemming from a commitment to a foundation of nonmaleficence) are softened by an embedded commitment to place personal perspectives aside in upholding established law, and medically-assisted dying being the law in Canada, seeking equal application of those services to marginalized populations.

The equal application of medical care in Canada is at the level of deep-seated meaning for the Northern Physician. It's a focal point, the object of the Northern Physician's cathexis, and thereby inherently spiritual in nature, transcending self. The Northern Physician presents as caring, thoughtful, and steadfast. If elevated emotions arise it likely has to do with the issue of inequality in access to healthcare services. Consideration of the integration of MAiD in Northern communities has become an additional example of that inequality. The Northern Physician pointed out, "Simply good quality of care when you're sick is actually really challenging to access…. we've said as Canadians we should have access to [MAiD], but the honest truth…my populations aren't even accessing ICU care immediately when they need it."

The same is true for access to clot busters after a heart attack, or access to a termination of pregnancy requiring travel, logistics, money. "MAiD is another one of those I want them to have access to…but on the scale of ethic about things that get me fired up in my belly about inequalities, right now, it isn't MAiD." This seems understandable when it is "need versus provision capacity, all the time." The concern infuses the Northern Physician's beliefs and convictions surrounding the provision of palliative care as well.

Having worked in Canada's North for a substantial period of time and having previously worked in various marginalized spaces in large population centres, like with homeless populations in Canada, the Northern Physician has lived with the vast disparities. The conversation around MAiD remains misplaced when marginalized populations cannot reasonably rely on "the simple things" in the process of dying. The simple things: a nurse that can come in to regularly deliver pain medication; provision for dying at home – "Every elder of any First Nations or Inuit community I've ever looked after wants to go home to die." The provision of healthcare intersects with the beliefs, meaning-making capacity, and spirituality of patients, and particularly in delivering end-of-life care. "If," the Northern Physician pondered, "we could have the resources and the capacity to provide high-quality palliative care, as it is certainly delivered in some corners of Canada, that gives this alternative to the MAiD discussion that opens up the possibilities further." The Northern Physician recognizes no simple solutions exist in considering the limitations in remote communities of the North. If the goal is an equitable, compassionate delivery of healthcare in Canada, that which touches individuals and communities at the deepest levels of human experience, those spaces deserve more than an afterthought.

Tina Cuerrier.

For Cuerrier, belief in a higher power does not preclude her appreciating the individual decision to end life when a client is living with serious illness, and neither does her spirituality. Some people appeal to their religious beliefs in opposition to medical assistance in dying. Cuerrier remains comfortable with that perspective, yet for her the opportunity to access MAiD represents a hopeful path forward when hope has run out for many who are seriously ill, "and they know they are going to die." For Cuerrier, choice is paramount. "I believe people should have that choice, especially when they're so seriously ill." This is one clear way of helping people who are living in irreversible decline. Respecting a client's thoughtful wishes to end life, when serious illness has taken over, is a compassionate response to those clients. Individual choice and respect for a client's wishes remain central to Cuerrier's belief system.

Cuerrier felt it important to note she did not arrive at this perspective flippantly. "I didn't come to this lightly," she said. In a sign of respect for the position of her nursing colleagues, she recognizes this is not something every nurse is equipped to participate in. Further, Cuerrier knows other medical professionals who are "*totally* against it. Totally." This is a seasoned perspective, having experienced a great deal of patient suffering over a long career, and the family remains a central part of the understanding. Cuerrier contrasted a "room full of love and peace," which she has experienced with families observing MAiD deaths, to "watching somebody struggle to die." Either death can be very difficult for families. Cuerrier respects the choice of those making a decision for MAiD, a decision to die gracefully, preserving dignity, and preventing the family from undue hardship.

Table 6

Selected Significant Statements From Medical Professionals

The process of accessing care to die in the place and in the way you want to die is a real challenge.

Some will say it goes against their religious beliefs, and that's fine. Obviously, it doesn't go against mine, because I believe we were given this, we were given this option to be able to help people. And that's the bottom line, is to help people.

I've seen so many people with just awful diseases that it makes it like, 'Come on. I'm not going to worry about anything.' You know, nothing's important [relative to this]. I don't find I worry that much anymore.

I do journal about all my [experiences] …because they all taught me something. I can see someday looking back and reading that over, so I don't lose the value of that. There's just the feeling of satisfaction that those people aren't suffering anymore.

From a meaning perspective, I feel like every time a patient asks me for medical assistance in dying, and maybe this applies to anybody, it doesn't necessarily matter where I stand. A person is in front of me asking to die; they feel their life is no longer worth living.

Gerald Ashe.

Ashe finds great meaning and purpose in serving people through the delivery of medical assistance in dying. For him, the experience has broadened his appreciation of human suffering, human frailty; "it really has impacted me in terms of what's really important in life." Since offering MAiD, Ashe is referred patients from a much wider group than he otherwise would have encountered. Ashe is clear he's no longer Roman Catholic, in fact he reported, "I'm probably…I'm probably an atheist." What is important to Ashe is connecting with that "poor soul" dealing with debilitating disease or illness. Pulmonary fibrosis and ALS were offered as

examples. "It's reinforcing for me the beauty of love, of family, partners." Ashe noted he has had the privilege of providing MAiD to individuals within same-sex couples – it is "beautiful to see the love that [is] …there, and then to appreciate the fact that they're willing to sacrifice all that because their partner is suffering." They don't want to lose their partner, but they're willing to let go. Together they decide, "let's go for it."

For Ashe the moments leading up to and following the death of a patient, family in the room, are deeply meaningful. Dozens of times he's been in what he described as a privileged position. Visibly impacted, emotion welled up as he considered these moments: "To see the support, it's really, really beautiful. So that makes me feel like (chuckling) maybe there is a God." It became apparent what Ashe had in mind when he described his involvement in providing MAiD serving to transform his medical practice; it's personally transformative as well. In those intimate spaces human interaction becomes elevated. Ashe described a burst of goodness in its purest form. Rhetorically he asked: "But I guess we don't understand why people are good to each other, do we?" The sense of the goodness present in those rooms and additionally the satisfaction, for Ashe, of helping to relieve tremendous suffering, keep him motivated to continue this work, this mission.

The alleviation of suffering for Ashe is linked almost exclusively to painful and debilitating disease. Though respectful of palliative care, and recognizing the value of such care for many, Ashe acknowledged, "there's no magic in palliative care" when it comes to serious conditions, like ALS or Parkinson's disease or severe neurological conditions, in particular. Ashe expressed his relief over the apparent trajectory and momentum in place for challenging the "reasonably foreseeable" eligibility criteria within Bill C-14. He referenced Ontario Superior Court Justice, Paul Perell's 2017 ruling which permitted an anonymous 77-year-old Ontario

woman, suffering for decades with osteoarthritis, to secure a medically-assisted death after several failed attempts at securing the support of two physicians (Hasham, 2017, June 19). Slightly exasperated, Ashe recounted too the experience of Kay Carter. "Carter, she could have lived another five years, right. That was what the *Carter* case was all about, that she should have had the right." The core experience of MAiD for Ashe is the relief of suffering. That meaningful experience should not be confined to only those whose death becomes imminent.

Nurse Practitioner.

The Nurse Practitioner has experienced what are described as spiritual moments surrounding the delivery of MAiD, though not entirely certain how to frame the experiences – "not particularly religious; I guess I'm a little spiritual, kind of agnostic." One experience stands out:

> I want to tell you…I had the nicest MAiD experience about [some time] ago. An older [person], cancer, was definitely progressing toward end of life, maybe had a couple of weeks left to live, but…wanted to go ahead with MAiD. [The patient] had…the whole family present. They did last rites; and [the] pastor was there; they stayed during the procedure; they did more prayers once I and the doctor arrived. It was really beautiful…spiritual experience. It just went so perfectly.

The Nurse Practitioner lets patients know during consultations there is no real limit to how many people can be present, even if the family has to squeeze into the room. The patient's wishes are what is most important. Though larger groups of support are not uncommon, a much more subdued setting is what the Nurse Practitioner has generally experienced: "Usually, I would say there's two or three people there, a small group."

The support of family is present with most of the numerous MAiD experiences the Nurse Practitioner has encountered. For the Nurse Practitioner, the place of family in the entire palliative process is pivotal, from the initial assessment (not the assessment at the time a decision to pursue MAiD is considered) through to either natural death or the decision to pursue medical assistance in dying. Understanding the patient in the context of family is vital to providing appropriate patient care, recognizing identification with family generally runs even deeper as the reality of death can no longer be avoided. More practically, the Nurse Practitioner seeks to understand the role family plays in the life of the patient in order to ascertain any "outside pressure." If a palliative patient decides to initiate the MAiD process, the Nurse Practitioner benefits from already understanding the patient in the familial context, accordingly, enhancing the quality of the assessment.

Urban Physician.

The Urban Physician recognized a clear connection between the pursuit of purpose, meaning, and value in life and the spiritual. It may be the two are nearly synonymous. And "Religion might be part of it, but it doesn't capture the full totality of spirituality." As spiritual beings the journey begins with promise. According to the Urban Physician, "We are born the way we are intended to be, receptive, in the moment, loving, kind, accepting of what we are and who we are…almost immediately we start being fed mistruths." The hastening of death through MAiD, for the Urban Physician, may represent the final mistruth:

> I think the process of medical assistance in dying, this idea that at some point there's a determination at which our life no longer has value, and that we should end our lives based on a set of generally external factors – 'I can't walk anymore; I can't talk anymore; I have pain; I'm no longer able to contribute' – those I see as somewhat dangerous, in the

sense that those are all tied to some of those things that we're taught from the time we're babies…. Maybe our value is more inherent than that.

The Urban Physician values the relationships formed with palliative patients. Though they are sometimes brief, they are often infused with deep meaning. Relationships, those relationships that allow for it, are perhaps the greatest means of stripping away the external. "My reason for doing palliative care was to help people on this journey, to understand themselves better as they go through the process of death." Entering into the valuing of the other allows the Urban Physician to better understand a patient's determination to pursue a medically-assisted death. The Urban physician reported, "I find sometimes when you sit with people and you understand their situation you get a sense…you can have compassion for their decision and understanding why they want that." In this sense, the Urban Physician reported placing value in the process itself, in relating to others, and not solely in an understanding of one's perception of a desirable or undesirable outcome.

Table 7

Theme Cluster With Formulated Meanings

Impact of MAiD on Belief, Meaning, Spirituality
Looking at the face of dying
Going home to die
A personal thing
Difficult thing to define
They don't want to lose them
Resurrected my interest
Varies patient to patient

Meaning in relationships that evoke changes

Affirmed values and beliefs

Stripped of the external source of value and meaning

Goal of understanding

Theme 4 – Integrating MAiD Into Medical Policies and Procedures

Northern Physician.

Developing a system to allow for the integration of assisted dying in small communities and in the small hospital setting presents significant challenges. It remains challenging enough to protect patient medical records related to minor, non-invasive procedures. With medically-assisted dying the challenge is exponentially greater. The Northern Physician reported that for colleagues in various parts of rural, not necessarily Northern, Canada it has become necessary to send a patient and the family to another location to have MAiD administered, all due to concerns over maintaining patient confidentiality. In the hospital settings where the Northern Physician works, "we try to keep things confidential, but everyone knows who is in hospital and why they are there…it is a very small town, a small community." Finding space and privacy for an initial MAiD assessment, for people to have the ability to discuss their needs, proves challenging as well, requiring a great deal of diligence.

Translators are "absolutely imperative" in the Northern Physician's medical practice. Days go by where almost every patient interaction happens with a translator present in the room. This creates significant practical and ethical challenges. The Northern Physician recognizes "it's not the same as sitting across from someone [with whom] you share their cultural tradition and speak the same language." Often what are generally perceived as routine questions of patients

who enter the hospital through the emergency department become family-wide consultations. It is not uncommon for up to 30 people gather to consult over a patient's medical decision making. With such care taken over what has come to be perceived as relatively routine decision making, it makes more serious concerns difficult to address. For the Northern Physician, "when it comes to discussions about end-of-life care needs or the MAiD discussion, I think that also causes me some great hesitancy in the full comprehension of what a person needs." The "collective voice that is their First Nations way of making decisions is a challenge," requiring great sensitivity.

The Government of Canada's *Fourth Interim Report on Medical Assistance in Dying in Canada* notes:

> As was the case for previous reports, provincial and territorial governments were asked to provide Health Canada with information on MAID that was available for their jurisdiction. The territories (Yukon, Northwest Territories and Nunavut) could not share any data for this reporting period due to small numbers and associated concerns for the privacy of the patients and the providers involved (p. 3).

The Northern Physician works to better understand the First Nations cultural dynamics in order to enhance the patient, family, and community experience. Part of the richness of the cross-cultural relationship, "one of the beauties," is an awareness of the value of "time and community and space, spent together." Autonomy of the individual patient, which largely drives healthcare today (medical assistance in dying being no exception), ranks low within First Nations and Inuit communities. Despite the challenges inherent in navigating various cultural considerations, this represents "their version of what dignified care looks like." A concerted effort is made to make the appropriate accommodations. While the Northern Physician recognizes attempts often fall short, the genuineness of the intention remains.

Tina Cuerrier.

For Cuerrier, the procedure itself demands attention. MAiD stands alone, distinct from other surgeries or procedures. "Somebody's ending their life! Whatever the reason, they are ending their life. It's huge." And it has an impact. Cuerrier reported knowing several nurses who do not feel emotionally able to participate in the MAiD procedure. Cuerrier understands; everyone arrives from a unique vantage point. Cuerrier's total immersion in the reality of what is going on is at the heart of her integrative experience. Some "disconnect" in order to deal with what they have to do. This is not an option for Cuerrier in her involvement in MAiD. In recognition of the seriousness of the procedure, of its full impact, Cuerrier remains very much present with the client and with the surrounding family.

Table 8

Selected Significant Statements From Medical Professionals

Each new introduction of a concept like that, across language barriers, even across medical literacy, trying to help people understand even what is happening with their body in a simplified way, and then also combining that with the ethic of the collective, the whole, it's a challenge – definitely.

It's been somewhat affirming to see the ways that people in leadership have tried to implement things in a thoughtful way. It's also something that's imperfect in that what is communicated on a political level or at news conferences are a reflection of what's going to happen but may not be exactly what is going to happen. While on the news a person may say this is something we're implementing across Canada, the way that plays out can vary dramatically, even a few hours outside of [large urban centres].

It's not as though somethings happened, and it's done. It's a thing that's developing and so the impacts of it, it's hard to know what they will be at this point.

I know not a lot of nurses can do this.

Gerald Ashe.

Ashe pointed out his community took a proactive stance toward the integration of medical assistance in dying. Well before the legislation achieved royal assent, a committee was struck, and community stakeholders developed MAiD policy. Hospital boards were additionally activated early, as a lead-up to the new law. Ashe practices in a designated health region known as the South East Local Health Integration Network, a region of Ontario which includes his city of Brockville, and the cities of Belleville, and Kingston, and surrounding areas.[17] Ashe's more current concern has less to do with his region and more over other health regions within Ontario, as well as more remote locations around Canada. Ashe reported he receives regular calls for his services outside of his health region. He looks forward to a more efficient referral system.

Beyond the Ontario MAiD referral system, which Ashe believes can improve, he is concerned over the ongoing work. "I'm looking forward to the day when there are more providers around, and I won't be…have as much work to do in that respect." And the number of providers is not Ashe's only concern: "Some of the younger physicians now that are coming up, I don't think they feel the passion that I felt to make this happen." Ashe expressed hope that this could change. He joked that someday he may need medical assistance in dying himself and wants to know competent providers are out there. The forms present a significant hurdle for

[17] In 2019, Ontario Deputy Premier and Health Minister, Cristine Elliott initiated the plan to bring all 14 Ontario Local Health Integration Networks under a centralized agency known as Ontario Health (Ontario, 2019, November 13).

physicians – "that is what's going to discourage doctors." Physicians providing MAiD went early on from having no official forms to a system requiring a burdensome and exacting paper trail.

Nurse Practitioner.

The overarching concern for the Nurse Practitioner comes from the organizational level. Months have carried into years and nurse practitioners remain unable to directly perform medical assistance in dying through the Nurse Practitioner's organizational health unit. "It's frustrating; it's been so low [a priority]." Everything else remains in place: standardized documentation forms, brought into the process soon after MAiD became legal; and a streamlined process of filling prescriptions with the local pharmacy. The Nurse Practitioner designed the form used for the initial assessment of palliative patients, which incorporates a section on medical assistance in dying.

The assessment is meant to address individual patient needs. No significant opportunity has emerged to evaluate the assessment from within non-dominant culture groups. There are some younger patients (which the Nurse Practitioner dreads), predominantly older patients, and a relatively equal distribution of men and women, but "it's generally middle-class white people." The Nurse Practitioner thought aloud, "When I mention it…I actually don't know that I've had any Indigenous patients do MAiD." A patient at the high end of the age spectrum assessed individual needs in a clearly defined way. Though the patient remained alert and aware, and there existed no obvious cognitive decline, the patient did not choose to transition into a state of more direct dependency on the support of others. When bedbound and unable to toilet independently, the patient decided to end life through MAiD.

Urban Physician.

The integration of MAiD into the Urban Physician's practice, into the policies and procedures present, has opened up several questions (some of which the Urban Physician anticipates being answered when the procedure is reviewed at five years and beyond). One significant question has arisen surrounding the way assisted dying gets introduced in the first place. If the legislation suggests it remains incumbent on patients to bring up the topic, that it remains an entirely voluntary conversation free of any potential for coercion by a medical professional, does it then violate the ethics surrounding informed consent? Should the full panoply of options be put on the table, or does that expose the most vulnerable in society to the possibility for heinousness?

The time frame around a request for medical assistance in dying presents more questions. "The minimum time is ten days, what's the maximum time?" the Urban Physician wonders. "How long can that request remain," before a patient would require reevaluation? This issue becomes increasingly concerning as Canada considers a move toward the elimination of the final consent requirement, permitting MAiD to be carried out if the patient lost capacity, say due to dementia. Additional questions have emerged for the Urban Physician which impact policy statements and the procedures that convey those statements: "Do patients who want medical assistance in dying always get a palliative consult, and always get a psychiatric consult? Are those part of the assessment?" The Urban Physician highlighted these areas to emphasize the fluid nature of the policy and procedural implementation to date. This in part stems from the nature of introducing a monumental change to established health systems across the nation. The process is also the result of the disparity between the SCC decision in *Carter* and the actual implementation in law and accordingly in policy. "What the Supreme Court passed was essentially, 'If the person doesn't feel their life is worth living, this is something that's available

to them.' That's a lot broader than what actually happened." The Urban Physician wonders aloud about the societal impact as well: How will assisted dying impact the "social conscience." Perhaps due to the newness of the availability of assisted dying in Canada, there may be "increased uptake" for a few years. What about longer term? Will negative experiences turn people away from pursuing assisted dying? Or will a multitude of positive stories increase the likelihood of MAiD's normalization and increased utilization? The "whole thing…it's unfolding," according to the Urban Physician.

In Canada, where predominantly euthanasia is administered over against physician-assisted dying, the Urban Physician expressed concern over the role the ambivalence of the patient can play in one but not the other. The rates of completed deaths go down considerably in jurisdictions where physician-assisted death is utilized over euthanasia. People can change their minds, remain ambivalent more easily if they have the medication in their home and are able to determine whether or not to utilize it. Once euthanasia is established a date follows, expectations are raised, an entire process is activated. "It takes the role of ambivalence out of the equation." Backing out of euthanasia means letting people down.

For many within the palliative care community there is no integration of medically-assisted dying with policies and procedures. Palliative care stands opposed to the hastening of death, yet the Urban Physician noted considerable exceptions exist. While "palliative care in large has been…opposed to medical assistance in dying, as a larger body…individually, within it, there's the full range on the spectrum." The Urban Physician noted the challenge in sustaining the resistance to accepting MAiD from within palliative care. While continuing to emphasize "the dignity of life, and the sanctity of life…not hastening or prolonging life," the reality remains: "These procedures are being done." Early on in policy discussions concerning the

introduction of MAiD there existed hope that a palliative care physician would meet with a patient considering the procedure: for symptom management; avoiding suffering; and presenting a plan for dissuading the patient of wanting to go forward with an assisted death. Despite the final eligibility requirement including the person giving "informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care," (Bill C-14, Sec. 241.2 (1), (e), p. 6) the Urban Physician remains skeptical the palliative care option is consistently and thoughtfully articulated to patients.

> I suspect that palliative physicians are just as much part of our society and are nurtured by the society we live in just as much as anybody else. I think a lot of these things which feel like big issues today will very quickly meld into, or blend into the collective consciousness, and people may not give much thought to it. I'm not trying to say that means they are any more valid; it's just human nature.

For now, the division between the palliative care community and those promoting medical assistance in dying remains.

Table 9

Theme Cluster With Formulated Meanings

Integrating MAiD Into Medical Policies and Procedures
It's not one person making a decision for themselves
Autonomy is not really a piece; it's the collective, the whole
Committee going before the law came out
Good participation from all of the stakeholders
More work that has to be done

Forms are burdensome at times

Still don't have organizational policies to allow nurse practitioners to administer MAiD

Interesting to watch this process unfold

Some physicians are actually saying to them, 'You know, one of your options is medical assistance in dying'

Every year, as time marches on, things become more normalized

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Theme 5 – Personal Challenges Integrating MAiD Into Medical Practice

Northern Physician.

Thinking in terms of integrating MAiD fully into the palliative care philosophy and its delivery presents a challenge. The Northern Physician conceives of palliative care and medically-assisted dying as distinct: "When I think about the practice of palliative care and the discussions around it, it does feel in the transition from palliative goals to the MAiD discussion that it's almost like choosing a different intervention." The Northern Physician alluded to cancer care for a comparison, where a patient may choose between the option of chemotherapy or radiation and surgery – "you choose one or you choose the other, but they feel like they're separate trains of medical care." The Northern Physician finds the "offering and capacity" a significant concern. Palliative care "should be very much present at baseline," and distinctly, resources need to be made available if the choice is to pursue MAiD, "but I feel it's hard to put them together as the same kind of treatment line." Patients experiencing significant suffering regularly discuss the ending of their life, regularly express a desire to die. Meeting despairing patients is a recognized feature of the palliative approach which predates any conception of legalized medically-assisted dying. However, if the conversation surrounding a desire to die

persists and medical assistance in dying is the patient's established choice, the Northern Physician sees a definitive pivot in the course of treatment, one requiring a new intervention altogether.

Tina Cuerrier.

For the Cuerrier the integration of MAiD in her medical practice has not been personally challenging. The incorporation of MAiD meant an extension of her existing philosophy of choice in medical care. Cuerrier framed it this way: "I'm not happy that somebody has to end their life, obviously, but I'm happy that people have that choice…it's about choice." Cuerrier sees the challenge in others' experience, including some of her colleagues. Though for Cuerrier the transition to MAiD remains a benefit to patients, she recognizes others remain unable to integrate assisted dying and medical care. Despite the differences, Cuerrier has found she does not feel judged by those in her profession who have competing views. Similarly, Cuerrier respects others views if they choose not to participate. Some ask, "'How can you do that?'" Cuerrier rests comfortably in the knowledge that "that person has made that decision for them, for themselves."

Table 10

Selected Significant Statements From Medical Professionals

It's probably going to take a generation of doctors. Some of the new graduates are going to really be supporting medical aid in dying. I think we are talking probably ten years of still some resistance from some doctors who feel it is against their ethics and moral background.

I don't think it's for everybody. A natural death can be just as peaceful, and just as beautiful as MAiD. I guess it depends on the individual and the symptoms they have, and their whole life experience.

I think the most challenging thing is that, like most issues, it's not as black and white as people want it to be.

Gerald Ashe.

For Ashe, the integration of MAiD into his medical practice has presented challenges to his already demanding schedule. The development required a reorganizing of his routine and the need to bring in additional staff. Paperwork has represented the biggest challenge for Ashe, yet he recognizes the necessity of thorough documentation. "The Canadian public has to know that this is being done for the right reasons. I don't see any other way than providing lots of documentation to the chief coroner's office." Ashe explained it can prove challenging to keep track of patients in the progression of their illness as well. Disease is not static. Two groups tend to emerge. One group expresses interest in MAiD. "They even make an official request, signed request, witnessed etcetera, and they go through having the two opinions and they…so they get permission for MAiD, but you get the feeling they may never want it." According to Ashe this provides a sense of security for some patients: "They feel they've got it if they need it." The other group is challenging to keep up with due to rapid decline and the potential for associated loss of competence, especially if the ten-day waiting period is not completed. Though getting permission from the other physician to proceed within the 10-day window is a possibility if loss of competence becomes a legitimate concern, it does present a logistical burden. Additionally, Ashe regularly travels to patients in far flung locations. It is not always entirely predictable to know what he will face when he arrives.

The potential for future inclusion of medical assistance in dying in advance directives presents challenges for Ashe as well. For Ashe, in order for medically-assisted dying to be

considered ethical, it must include two features. The MAiD procedure must include informed consent, and an appraisal of the level of suffering (whether the suffering is unnecessary). Ashe hesitates to consider the inclusion of an advance directive if the patient at one time provided an autonomous indication of a desire to die, but presently does not appear to be suffering. Ashe went so far as to say, "I just can't see that happening…if you link it to suffering when that person gets to the point that he can't recognize his family." He went further: "I would not feel comfortable being a provider, going into nursing homes, starting IVs on people and giving them a lethal injection because they don't recognize their family anymore." Ashe would support it as part of the law if there was a shorter, set duration built in. The potential inclusion of open-ended advance directives presents not only an ethical challenge for Ashe – both the autonomy and unnecessary suffering criteria need to be met – but it presents a personal challenge as well. For Ashe, "one of the things that makes it truly amazing is that connection with the patient just before they pass. It's really, really an amazing gift, if you will, to have that kind of connection with a fellow human being." That personal and seemingly spiritual criteria would be challenging to omit as well should a patient receive MAiD long after losing competence, and thereby autonomous decision making.

Nurse Practitioner.

Integrating MAiD into the Nurse Practitioner's own practice flowed smoothly from the beginning. When coordinated services necessarily extend beyond the Nurse Practitioner to include registered nurses and procuring proper medications, challenges arise. The Nurse Practitioner respects medical professionals' right to conscientious objection to MAiD. Accordingly, the Nurse Practitioner is at times tasked with responsibilities that in any other area are shared, or the Nurse Practitioner is able to assign to others with the goal of maximal

efficiency and reduced stress within the circle of care. Living in a small population centre means "medications can be an issue because they're never in stock in these communities, and you don't know when you are going to need them." With heightened expectation and anticipation from patients and families leading up to a scheduled death event, changes surrounding the availability of medications produce significant additional stress.

When the medications arrive on time, and the Nurse Practitioner effectively manages staff shortages due to conscientious objection, the MAiD procedures generally go smoothly. The Nurse Practitioner knows the procedure well, beginning with the benzodiazepine, Midazolam. "Once the first one goes in the patients are sedated and they don't know all the subsequent ones…it's a lot of drugs." The medication protocol has become largely standard across Canada, in keeping with the recommendations of the Canadian Association of MAiD Assessors and Providers, though a degree of variation exists (Miller et al., 2020). The Nurse Practitioner explains the procedure to patients and families as part of the preparation for the day MAiD is administered. "When we walk into the room, we probably have 12 syringes full of medication. Some of them are just flushes in between meds, but it's a lot." During the initial sedation phase, the Nurse practitioner explained that some talking continues within the room, "but after that it's very quiet." The reality of the death takes hold. "There's not really any sound except us dealing with syringes." The whole process takes about 10 to 15 minutes, depending on how quickly the medications are pushed. In the Nurse Practitioner's experience "It's always: Midazolam, [followed by] Propofol, and [finally] Rocuronium." The Nurse Practitioner noted Bupivacaine is sometimes used next or "sometimes people actually use Potassium Chloride fourth, or nothing at all, just be done with the three."

Urban Physician.

For the Urban Physician the greatest challenge is "knowing where you stand." This has become increasingly challenging as the years pass since MAiD's introduction in Canada. Early on it was easier to take a concrete position on medical assistance in dying. Initially, the Urban Physician said to himself: "'I'm not going to be involved in MAiD; I'm not interested in assessing clients; I don't want to provide the procedure, nor do I have to.'" Upon reflection the Urban Physician recognized practicing in a large population centre has likely made it easier to take a firmer stance on the MAiD question. There are others available to provide those services; in a smaller population centre that may not be the case. Easier doesn't mean easy.

Palliative care physicians, perhaps as much as in any other medical specialization, form relationships with patients and often family members surrounding the patient. The Urban Physician put it succinctly, "I'm the primary provider for that client and that client trusts me." Patients wanting to talk about their condition and their death regularly bring up medical assistance in dying. In fact, they are instructed to speak with their primary provider about MAiD by anyone within their circle of care. Whether a palliative physician takes a firm stance on MAiD or not, whether the physician is in favour of its implementation, remains ambivalent, or stands opposed, any given patient may want to discuss it and therefore the physician is drawn into the conversation, is a part of the decision-making process. The Urban Physician has wrestled with the level of involvement in the process: "You're in there and you're speaking with this person about the process of MAiD, and then they are asking you about the forms they need to fill out. And you have this question, 'Should I give them the forms?'" The Urban Physician has resigned to showing the patient the forms, reviewing how they are filled out, and faxing them in to facilitate the referral, "which they are going to undergo anyways," presumably. At that point, the Urban Physician would prefer to wash hands of further involvement, but faxes

sometimes fail to go through, responses aren't always forthcoming, and the involvement can run deeper than anticipated.

Table 11

Theme Cluster With Formulated Meanings

Personal Challenges Integrating MAiD Into Medical Practice
Some East Asian and Southeast Asian communities are very similar, where it's the collective
Hesitancies related to marginalized populations
Worry people are going to lose competence or get sicker
Burnout comes and goes; it depends on how cases have been
How grey it is
Having to be responsible for something you shouldn't have to be responsible for

Interviews With Those Who Care for the Bereaved

Personal Support Worker (Carefor Ottawa)

The Personal Support Worker has a great deal of experience as a personal support worker (PSW) in the palliative care homecare setting, having served in various settings including most recently at Carefor Ottawa.

Laurie Rail (Bereavement Specialist)

As a certified grief educator and support facilitator, Laurie Rail has extensive experience helping to navigate bereaved individuals and families through the means of peer support and education. Following the introduction of medical assistance in dying in Canada, Laurie began facilitating the first exclusive MAiD support group in Ottawa. Since completing further

certification in crises and trauma, becoming a death doula, and presently working on completing a thanatology degree, Laurie recently co-founded Ottawa Grief Care+, an organization which provides grief and bereavement education to individuals, community, and workplaces.

Jennifer Mallmes (End-of-Life Doula)

Jennifer Mallmes serves as co-director of the End of Life Doula Association of Canada. She has worked as a doula for the last five years and prior to that she worked as a palliative care worker. Jennifer's passion is that all persons will have access to and be knowledgeable of the resources available to them, while advocating for better end of life care.[18]

Theme 1: Initial Experiencing of MAiD

Personal Support Worker.

Coronavirus disease 2019, declared a pandemic by the World Health Organization on March 11, 2020, brought unprecedented attention to personal support workers and the place they occupy in Canadian society. Before the pandemic began, PSWs remained largely in the shadows, relegated to an inferior status as their compensation reinforced – expendable. With long-term care facilities the veritable epicenter of the coronavirus, PSWs have been brought under the full scrutiny of the spotlight. Added to their inferior status, PSWs are often now maligned, scapegoated for a societal disregard for the elderly. Though their status remains uncertain, PSWs are not likely to return to the shadows.

In the Carefor Personal Support Worker's pre-COVID-19 interview, the work was described as personal support: giving a bath, ("sometimes we give a full bath in a bathtub and

[18] Retrieved from End of life doula association of Canada. (2020). *Our Story*. https://endoflifedoulaassociation.org/about/

sometimes we stand by so if the person needs us we're there"; sometimes we "just wash a back and feet"; and "sometimes as a person's health deteriorates, we give a sponge bath, either in the bathroom or in the bed, and sometimes they're not moving out of bed and everything is in the bed"); there is help with dressing and undressing; making a bed; tidying a room, including the bathroom; preparing light meals; and providing the activities of daily living. Beyond these indispensable responsibilities, the Carefor PSW pointed out perhaps the most crucial features of the role: (a) "We typically see the…clients more than any of the other professionals, because we are in there the most," and (b) "We are generally speaking the only one that sees the client's entire body, and [thereby] notices physical changes with our own eyes." Simply put, the Carefor PSW serves as "the mouth of the body." The PSW relates observations to a nurse for assessment: "Mrs. Jones has a bruise on her left knee the size of a quarter." Accordingly, there exists great potential for embeddedness within clients' milieu, particularly in the community setting where Carefor employees provide support, and the PSW occupies a unique position between the client and encircling medical care professionals. A PSW working in the palliative community care setting becomes immersed in the unfolding bereavement.

The Carefor PSW described the relationship to families. "I've seen both, where it works well and where it doesn't." In another room, a family member often asks about the client's medical condition. The Carefor PSW remains clear about maintaining the boundary between the daily personal care of the client and medical inquiry. If the latter, the information is communicated by the PSW to the nurse through the binder, or the chart in the home. "I don't overstep that barrier; I'm very clear about that, even if I've seen it 3,000 times. It's not mine to answer." Family members deal with impending death differently. Some bring various levels of denial or hostility into the home. The Carefor PSW views the priority squarely, in providing care

to the client. If a family member pulls the Carefor PSW aside to correct the record, make sure another version of the story is communicated, the Carefor PSW respectfully reiterates the priority to serve the client's needs and honours the client's telling of their own story. Whereas many elderly clients maintain the notion of "present[ing] for the medical people," with a PSW an authenticity steeped in familiarity regularly breaks through.

The Carefor PSW welcomed the introduction of MAiD in Canada. "I was fine personally when the law came out…I listened to everybody's opinion, but my opinion is back to opinion one: This isn't me." The Carefor PSW went further, "Pro-choice: it's not my body…not mine. I shouldn't have an opinion about this, and I've maintained that." In an early interaction, when the Carefor PSW encountered a client inquiring about MAiD, there was little hesitation in responding, as with all medical concerns. In this case, "The first thing you have to do is talk to your doctor." The client reported that conversation had already happened, and now the client was asking the Carefor PSW "to stand by [the client]." The answer was "yes," and then the full reality hit home: "Oh my god, this is real." The anticipation was palpable. "In a way it was exciting because I was happy for [the client] …and I was going to see it up close, and this is new and different." The Carefor PSW remained aware the client could change [his or her] mind and recognized the gravity of the private decision, and the honour it was to be a part of the client's earliest consideration surrounding MAiD.

Laurie Rail.

Rail anticipated the introduction of medical assistance in dying in Canada well before it came about. The legalization of MAiD prompted Rail to become involved in the movement to support individuals and families considering assisted dying, and the bereavement experience associated with it. "It is something that I strongly believe in. It was something that I wanted to

be involved in right away." Rail began supporting existing bereavement groups, groups specifically designed for various bereavement: a loss by suicide, the loss of a spouse, or the loss of a child, among others. She recognized a notable gap in support for people who had experienced a family member or friend deciding to access the medical assistance in dying process and responded by launching a group for bereaved individuals surrounding MAiD.

Rail found the process of forming the unique MAiD support group exhilarating. According to Rail, "I was very excited about it, because I knew that there was a large need for this." After attending educational seminars on bereavement support, Rail spoke with an increasing number of individuals wanting to access support specifically addressing MAiD, particularly in the initial months following the legalization of MAiD in Canada. Rail early on recognized the uniqueness of the bereavement experience surrounding assisted dying. "It was so heartwarming to know that I was part of…providing people this type of support that is found nowhere else in Ottawa." Rail recognizes in the hospital setting (if MAiD takes place there) the families receive some support through the process of MAiD and from a clinical perspective. Though this alone can assist families in their grief journey, it is best seen for many as the beginning of needed support. Rail began providing a continuation of support for people following their interfacing with this new procedure, this new way to die.

Table 12

Selected Significant Statements From Those Caring for the Bereaved

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The rest of that week was about cleaning out the apartment, getting rid of stuff, sending stuff off, making arrangements for equipment to be picked up, and then the last day a good friend was there with us for a good portion of the day. Right to the end he was cracking jokes. We went through the emotions very much together.

I was very excited about it because I knew there was a large need for this.

Now there's this new decision that they can make, and for sure I must be involved in that. I have to be so careful in how I'm sharing information.

Jennifer Mallmes.

For Mallmes, the introduction of MAiD in Canada remains "a date that stays in my head." The royal assent of Bill C-14, in June 2016, coincided for Mallmes with both the writing of end-of-life curriculum and determining how MAiD would impact her role as an end-of-life doula. Her title itself led to some confusion: "The biggest thing…for me was that with my role and my title, my job title, people thought that was what I did. People thought that I was an initiator, I was involved somehow with medically-assisted dying." The most striking example of the misunderstanding came when Mallmes received a call from an international jurisdiction asking if she would travel to the location to provide training in MAiD. After more than 20-years assisting patients and families with palliative and end-of-life decisions, the introduction of MAiD necessitated a renewed effort to carefully articulate the scope of practice. "I never had to do that before. Now, I'm having to tell people when they call: 'Oh, you do that [administer MAiD]?' 'No, that's between you and your doctor…That's not my role.'" Clear communication became increasingly important.

The advent of medically-assisted dying meant a complete other avenue patients could explore. Mallmes considered the delivery of information, and the ethical issues at stake. What if the family is not on board with the patient's decision making, one way or the other? What if Mallmes is viewed as having applied outside pressure on a vulnerable patient? When MAiD enters the conversation, Mallmes finds herself putting on a different cap, sensitive to the various

ethical considerations at play. The above alluded to confusion was exacerbated by the fact the role of the end-of-life doula was gaining more exposure around the time medically-assisted dying was emerging in Canada. In Mallmes's understanding, MAiD has served to "increase the conversation." Since June 2016, "the death-positive movement definitely has changed. People are willing and open to talk about it."

Table 13

Theme Cluster With Formulated Meanings

Initial Experiencing of MAiD
Some families can make it difficult
Willing to stand by him
Like sitting on a big secret
Even more careful
Surprised actually

Theme 2: Ongoing Experiencing of MAiD

Personal Support Worker.

Over the years since the introduction of MAiD in Canada, the Personal Support Worker has grown increasingly comfortable with the procedure, resulting in large part from the actual death itself: "The death is *so* peaceful." The Personal Support Worker with years of experience has seen the opposite as well. According to the Personal Support Worker, "The body is a chemical composition and stored experiences, and it doesn't always play nice at the end. There are things that can happen that are really gruesome, really ugly…unappealing, and this (MAiD) is not." In each of the Personal Support Workers MAiD experiences "the person was sound

asleep, so relaxed…a good sleep and then gone, seconds in between." Then, cementing the distinction, "If every death could have that peacefulness, palliative care would be really easy." Not surprisingly, the Personal Support Worker reported, "I think I'm even more pro than I was." Where the Personal Support Worker found a level of congruence between an assisted death and palliative care dying was in what followed. Despite a scheduled medically-assisted death, it was the "same surprise, shock – Oh my god; it actually happened" that comes an hour or two following any death event. Grieving followed.

With both palliative care dying and with assisted dying some degree of preparation for the death generally takes place. Sometimes with a palliative care death a PSW will be taken out of the home and a nurse put in place, should the care become increasingly complex. This can present a challenge for PSWs and the families of patients. It's not uncommon, as the Personal Support Worker explained, for families to grow accustomed to the presence of a PSW in the home, someone one step removed from the medical professionals, someone relatable. PSWs can provide a buffer for the family in the midst of imminent reality of a death in the room. Gifted PSWs can cultivate or enhance an atmosphere which invites reminiscing in the presence of mom or dad or whomever it may be.

Laurie Rail.

The early experience surrounding MAiD for Rail, versus two years since its inception are "vastly different" for those whose family member received assisted dying. In Rail's experience, "the beginning was quite disjointed; families received a lot of push and pull." The early experience of family members created a great deal of "stress." For some, according to Rail, the experiences went beyond stressful and can accurately be described as "somewhat traumatizing." Individuals seeking a medically-assisted death were also early on confronted with "a number of

iterations of the process that [were] quite discouraging," causing "a great deal of stress." In some instances, potential recipients of MAiD remained unsure of their status right up to the tentatively scheduled procedure. It was a new procedure, unprecedented in Canada and most of the world. Liability remained a concern for those involved and the delivery systems required the specific overlay of provincial or territorial administration.

Three years since the introduction of MAiD in Canada, Rail drew a sharp distinction from those early days:

> When you talk to people who are going through the same MAiD process now [2019], it is a softer process. It flows a lot easier….They understand the mistakes that were made at the beginning, things that needed to be improved in the process, things that need[ed] to be added to the process to make it not as jarring for the recipient and for the families.

Rail understands the impact of this evolution in the delivery of medically-assisted dying by having listened to participants in bereavement groups. Early bereavement experiences compared to bereavement experiences more than a year or two following MAiD's introduction "are very different stories." The differences in the bereavement experiences over the course of three years has surprised Rail. In bereavement groups a commonality tends to emerge. In a suicide loss group (one such bereavement group), Rail noted "everyone has had a loved one that took their life. That's the commonality." Suicide loss groups avoid focusing on the myriad factors involved in, leading up to, each suicide. The group gravitates to a centre point of shared experience: the inexplicable loss, the empty space, comes to overshadow all else. The commonality with bereavement following MAiD is the intense focus on the process itself. Not the similarities noted, as one might expect of what is designed to be a uniform process, but rather the minute differences experienced.

The seeming fixation on the particulars of the MAiD experience for those bereaved individuals emanates from "what is going on around them, through the MAiD process, on an emotional level." Rail noted, some of these bereaved individuals agree with their loved one's decision to pursue an assisted death and some stand opposed. Some support or supported their loved one's decision outwardly, while harbouring an internal conflict about the decision. An acquiescence to the decision revolves around an awareness of family members' influence over how an individual proceeds through the MAiD process. The pain over a silent disapproval of the MAiD decision can be enhanced by the decedents direction to family members to maintain absolute silence around the decision for a medically-assisted death. They arrive in "group and they have *so much* bottled up that they need to share…and they need to work through, but they can't do it outside the confines of this support group because they've been sworn to secrecy." Every participant's experience revolves around the medically-assisted death within the family, though external factors significantly impact the processing of that grief.[19]

Table 14

Selected Significant Statements From Those Caring for the Bereaved

Even though in all cases it's expected, the immediate reaction and the grief that followed were the same.
They kept tweaking the process and adding more and more gating checkpoints.
My first experience was quite soon after MAiD was made legal in Canada. A family member reached out to me who could never believe that their brother would ever choose this.

[19] Unique to a MAiD bereavement group, family members anticipating the scheduled death of a family member through medically-assisted dying may attend the group as well. Rail felt it "very important to permit those people in the group." The information delivered clinically by doctors or nurses about the pending process could not compare to embeddedness in a group of those who have been in that place and have navigated through.

I was shocked at how quickly it happened, and then how quickly the doctor was in and out.

Jennifer Mallmes.

Mallmes explained her role as an end-of-life doula succinctly: "Our whole goal is to protect the memory of the family and the dignity of the client." That role can look different depending on a family's wishes. Often Mallmes completes legacy work with families, and helps patients communicate wishes for after death, all with a focus on encouraging families to pick up the conversation themselves, making her place redundant – "I get the family to the point where they don't need me." Mallmes described this process as "the ripple effect." Family members integrate the experience through open communication surrounding the dying in their midst. Ideally, they carry this with them. Some dying clients ask Mallmes if she will be there to hold their hand at the end. Perhaps surprisingly, Mallmes declines these requests. This represents an important boundary she sets for herself and an acknowledgment of the family role.

Often Mallmes finds communication lacking within families experiencing the death of a family member. "People have a lot of fears around talking about death. They're afraid to take away the hope from the person; they're afraid to have a negative conversation." In society, "It's not socially acceptable to talk about death." With limited conversation taking place, Mallmes finds when she arrives at the home the dying person is very ready to talk about the experience. Even among couples that have been together for decades, and despite each one knowing death is imminent, there remains a reluctance. "Neither one of them wants to let the other one know that they know." The lack of communication generally cloaks an overall lack of planning for death. Beyond advance care planning, people often have yet to discuss funeral options when an end-of-life doula enters the family circle. If there is planning, Mallmes reported, a will is likely referred

to, yet often concerns remain. Mallmes has come to expect one near constant: fear. "Fear is huge – lack of conversation, lack of communication, and fear." The fear generally relates to the dying process, or leaving loved ones behind, or finds its roots in regret over not having done enough in life, or fear related to what comes next. *Is there something more?* Mallmes emphasizes grieving while the family member is dying, not bottling up the experience of grief until after the person has died. The two go together. Opening up communication to express authentic sentiment – *I'll miss you after you die; I don't want you to leave; Remember that time* – itself expresses grief and begins that journey. Concern for the dying person's comfort is unfounded. They are generally quite aware they are dying and welcome opportunity for integration as the end looms.

Table 15

Theme Cluster With Formulated Meanings

Ongoing Experiencing of MAiD
Very controlled
Prepared for it
Processing it very differently
A lot of work to do
Don't talk about those things

Theme 3: Impact of MAiD on Belief, Meaning, Spirituality

Personal Support Worker.

The Personal Support Worker credited the introduction of medical assistance in dying with conjuring self-reflection. "It forced me to look at my own place in life." The Personal Support Worker's spirituality revolves around "someone I will call a god and will change that

title to meet someone else's clarification." This accommodationist spirituality translates into a sensitivity to all client perspectives. PSWs at Carefor are not permitted to initiate religious or spiritual conversation, though listening respectfully while patients and families articulate their perspectives opens the conversation, which is encouraged. The Personal Support Worker feels free to ask questions when clients initiate a spiritual conversation, but that's as far as it goes. The community setting creates challenges, though the Personal Support Worker attempts to connect the client with spiritual resources.

Going further, the Personal Support Worker reported a belief in "something further than this, that we have many returns." Through long reflection and intrapersonal healing, the Personal Support Worker establishes meaning through the gift of extending compassion to the dying – "My purpose on earth." Incorporating MAiD means extending compassion to the person, and "whether you end it sooner or later isn't any opinion to me," the Personal Support Worker explained. In the midst of these decisions "God stands by us." The Personal Support Worker avoids the word "allow," bristling at the notion of God capriciously "allowing" indiscriminate suffering. "Why did God let me get this sick? I must hear that a million times," the Personal Support Worker relayed in frustration. If God isn't "allowing, or condemning, or punishing," it follows that MAiD provides a "kinder way to let you move on." For the Personal Support Worker, MAiD in no way contradicts, and may well enhance, service grounded in compassion for the dying.

Laurie Rail.

For Rail the impact at the level of personal belief is negligible, having strongly desired the implementation of medically-assisted dying well before the legislation came to pass in Canada. "I…held these beliefs prior to the legislation and I still hold true to those beliefs," self-

evidently for Rail. In a MAiD bereavement group setting, Rail observes individuals sharing the grief of several family systems, all invisibly bearing weight on the group dynamic. Religious convictions in opposition to a family member's MAiD decision show up as the most prominent reason for conflict and even ostracism within families. The MAiD group provides opportunity for those experiencing the intensity of a family death, channeled through religious conviction, to find mutuality in grief.

Table 16

Selected Significant Statements From Those Caring for the Bereaved

I actually believe that we are here on earth for a purpose and a reason, and we have to figure that out as we go along.
We talk about boundaries. For me, my beliefs have definitely been tested here, definitely. I've really had to do some self-work to make sure that I'm not going against my own beliefs.

Jennifer Mallmes.

For Mallmes, a belief grounded in the central importance of personal choice supersedes personal convictions and beliefs that may run counter. Mallmes respects a client's convictions (at least the right to hold them) including a decision to pursue a medically-assisted death, while accordingly respecting her own convictions, including the decision to remove herself from a setting where the decision to pursue MAiD takes place. The question for Mallmes became when to do so. The question remains unanswered:

> I was just leaving the house of a client who has chosen medical assistance in dying, and I really had to think about what…put some boundaries around what I'm able to hold space for…what I'm able to – for my own protection, for my own health, and for my own

beliefs (so I'm not infringing on my own beliefs) how far am I willing to go and what does that look like. I had a lot of things to think about.

Mallmes recognizes "faking it" fails to honour herself and diminishes the service to the client. For Mallmes attunement with clients, achieving a level of "felt awareness," describes her practice in a nutshell. "I'm not going to be able to support them well if it's against my beliefs." Inauthenticity with clients contradicts a central tenet of the work.

Table 17

Theme Cluster With Formulated Meanings

Impact of MAiD on Belief, Meaning, Spirituality
Something bigger
If there is nothing, there is nothing
Orchestrate the time of death

Theme 4: Impact of Decision to Pursue MAiD on Grief Experiences

Personal Support Worker.

In the training the Personal Support Worker has received, the procedure for approaching MAiD as a PSW misses the human experience and the potential for a disruption to the care a client is receiving at end of life. Policies serve a distinct purpose, and the Personal Support Worker reported an understanding of the need for clarity, yet "as a PSW, we've been with the client for a long time." If a determination by the client to pursue MAiD takes place, the PSW is informed of the decision in order to have the freedom to exercise conscience rights. "The problem is, if you've been with someone for a while and they choose MAiD, you can't upset their care. So, it's kind of an awkward position." If a PSW said, "'No, I'm not having any part

of that; that's against my religion; I have the right to opt out,'" the Personal Support Worker asked, "What does that do to you, the client?" The smooth continuation of care for clients and their families remains a high priority. Abrupt changes in care are avoided at all costs. If they must take place, it helps to communicate as openly as possible about the necessity of the change. When it comes to MAiD, the only existing option is to go silent about the change, or when necessary to lie.

As a PSW who is identified at Carefor as willing to serve clients planning on medically-assisted dying, as is the case with the Personal Support Worker, transitions can be abrupt as well. When a PSW is removed from a home due to a decision not to participate, PSWs like the Personal Support Worker are asked to step in, though as the Personal Support Worker explained that remains an assumption. The PSW never knows the reason. The Personal Support Worker finds these transitions an ongoing frustration. "If I'm suddenly your new PSW, I'll probably say [to the client and family], 'I don't have a clue; maybe [the other PSW's] in a different district, or maybe [the other PSW's] gone on holidays.' Because we're not allowed to ever know that."

At the Personal Support Worker's organization, Carefor, confidentiality surrounding MAiD remains highest priority. It took time for the Personal Support Worker, largely through a process of elimination (who showed up in MAiD settings, who didn't) or constrained conversations with friends, to determine who among colleagues remained willing to work with clients pursuing medically-assisted dying. The Personal Support Worker became convinced of being identified as a PSW favourable to MAiD. With inevitable administrative changes at Carefor, over the course of the intervening years since MAiD's introduction, it remains largely a mystery to the Personal Support Worker how this gets communicated. The Personal Support Worker remembered attending a training and asking someone in the field, "Have you had that

opportunity? And they said, 'Yes; have you?' And I said, 'Yes,' and that's as much as we discuss[ed]." The Personal Support Worker understands the policy: "I get the importance…it's frustrating as hell to work with though, because no one can say anything about anything!" The palliative book, which remains in the client's home, allowing various individuals in the client's circle of care to note changes, remains the Personal Support Worker's one means of communication and assurance.

Indiscriminate changes impact palliative clients who benefit from consistency in relationship to those around them. Grieving regularly begins during a palliative client's decline. The Personal Support Worker noted some clients make a decision to pursue MAiD relatively early on, before entirely bedbound. Changes in the circle of care at an earlier phase may produce less dramatic interruption to the homecare milieu, and to the client's grief process. Disruptions in care coming as a client's condition declines become more difficult to manage. The family and the client in the midst of their grief are subjected to a potentially distressing change. A PSW establishes a relationship with clients, often over the course of several weeks or months. Personal routines like bathing (in or out of bed) and toileting take time to establish, trust takes time to establish. The family is impacted and so is the PSW inserted into the home where the conscience objector is removed. The Personal Support Worker described the uncomfortable experience:

"Who are you?"

"I'm (insert name)."

"What are you doing here?"

A greater degree of clarity and communication between all parties involved may, according to the Personal Support Worker, minimize the challenges families experience, grieving in the homecare setting.

Laurie Rail.

Two prevailing factors impacted the grief experiences Rail observed over the course of the early introduction of MAiD. First, Rail noted the progression of the grief she observed, and became a part of as a facilitator for families and groups, hinged decidedly on whether the bereaved family members received instruction to keep the decision to pursue MAiD a secret or not (either from the patient or from a family member). The second factor impacting the grieving observed by Rail, and often intermingled with the first, depended on "whether or not their other family members were in accord with the person applying for MAiD." Some bereaved individuals held their grief experience to themselves until feeling comfortable enough to discuss the experience surrounding medically-assisted dying within a confidential MAiD group setting, thus creating an additional complexity to the grieving process. Others felt the sting of ostracism from family after having supported the decision to end life through MAiD. Some ostracized individuals stood before family accused of not merely supporting the decision to pursue medically-assisted dying, but further to have encouraged the decedent to pursue a medically-assisted death. These individuals in the MAiD group setting experienced isolation beyond the isolating experience inherent in other grieving. Starkly, Rail noted, "It's impossible to begin addressing your own grief when you're dealing with all of those outside factors as well."

Table 18

Selected Significant Statements From Those Caring for the Bereaved

In the beginning everybody talked MAiD to him, to the point where he threw up his hands and said, "Not one more person say, 'If I want to die I can.'"

I wish there was a way to be confidential and still more open with each other. I find they send us out to see clients and don't tell us anything until we've accepted the client. And once you've got it you have to keep it for two weeks before you're allowed to give it back.

If I've got three actively dying or end of life – so that's 30 and under. Say I've got three of them on the go…those three people are in the morning, and I don't have anything in the afternoon. 'Sure, I'll pick somebody up; it's only for two hours; sure, I can do that.' I may not be able to handle that much from an ALS person with three people who are already dying.

Their grief experience is impacted by whether or not they have been directed not to speak about this.

If they were the only one in the family that respected the decision and supported the person through the entire process and was there at the end and nobody else was, they're now often ostracized from the family.

I do have people sitting in groups whose family members have not spoken to them because they were supportive, and they feel not only that they were supportive but that they're accused of encouraging this with the person who went through MAiD. It's impossible to begin addressing your own grief when you're dealing with all of those outside factors as well.

It depends on how much they've had prior, and how good their communication was, and how involved they were in the process, or their planning.

There are definitely some strains in families. I do see situations where, 'Oh, he's not coming because he doesn't agree with this.' And that person is left out there by themselves to grieve alone. And they're usually not seeking support, and they're angry and frustrated.

It's a lack of control over the situation.

If somebody's dying, on their deathbed, going to die, you can't do anything to stop it, but if somebody's choosing MAiD, you could enter the room and try to change their mind. I've found there's always somebody who doesn't agree.

Jennifer Mallmes.

The insight Mallmes received about the family bereavement process surrounding MAiD has to do with the day medically-assisted dying takes place. "Usually, the family that doesn't support don't show up," and Mallmes has taken note. "So, I wouldn't see that experience…they usually go and do their grieving somewhere else." This avoidance may add complexity to the bereavement: "Those who don't show up, from my…from the people that I've supported, their grief is so much more challenging. There is a lot of anger; there [are] a lot of unresolved issues…if they're not on the same page." The angry, grieving individual contemplates the uniqueness of the unfolding MAiD sequence. "Normally, when someone is dying, you can't stop it from happening…it feels even more out of control…it's that they could, *could* do something to stop it." Mallmes painted the picture of someone on their deathbed. Normally entering that room there is nothing that can be done to intercede in the inevitable decline toward death. Entering a room where the choice is medical assistance in dying leaves open the question, and for some the seeming obligation, to convince the individual to stop.

Mallmes's experience suggests there is generally a family member, or members, that remains on the outside, not agreeing with the MAiD decision. In this person's mind, lingering after the death, remains the thought: "Did I do enough to try to change that person's mind?" In some cases, the client may not appear the most committed to the MAiD decision. It may be some other family member advocating vociferously for a medically-assisted death. (Though

Mallmes was quick to point out – "for the record," – she has not observed a coercive situation where a client was prevented from making a free choice).

Table 19

Theme Cluster With Formulated Meanings

Impact of Decision to Pursue MAiD on Grief Experiences
Can't talk about it
Feel isolated; feel alone
He just wants to know he has the support

Theme 5: Emotional Experience of a Family Member's Decision to Pursue MAiD

Personal Support Worker.

The Personal Support Worker referenced a phrase often referred to in palliative care circles, "We are a death-denying, death-defying society." Though supportive of a client's choice to pursue medical assistance in dying, the Personal Support Worker bemoans the impact of pushing the acknowledgment of death further to the periphery. From an emotional standpoint, "the biggest challenge I think is just the secrecy of it." A PSW potentially spends weeks, even months working with clients who are contemplating or have chosen MAiD. Imagine going home to one's spouse during that period, sitting down to dinner, and never having opportunity to talk about that day-to-day experience. The Personal Support Worker asked rhetorically, "How could I be that…involved mentally or emotionally and sit here and act like nothing is going on?" That remains the expectation, though Carefor provides outside, confidential counselling support for its staff. Even for a PSW with experience, "You think you're prepared going in," and as those involved in the procedure begin to arrive the tension mounts. "Until…the door opens, I don't

know who else I'm sharing this big secret with." The Personal Support Worker went further, "You're asking someone to witness or bear witness, or support – care, love, whatever that word is – another human being who's quite okay with losing their life, but we carry that and can't even talk to them…can't debrief." This uncomfortable reality epitomizes for the Personal Support Worker the lack of community in our society, which becomes glaringly apparent within the parameters of a procedural MAiD experience.

Laurie Rail.

Rail identified that in nearly every situation she encountered, the individuals were "in accord and respectful of their loved one's decision to go through with MAiD." Even with the exceptions, the individual generally remains by the side of the loved one and remains in the room while the MAiD procedure takes place. For each individual, regardless of support for the decision, the MAiD experience presents complexities on an emotional level. Rail put it this way:

> Even if your loved one is suffering and dying with cancer, you don't wish that for them, but as long as they are in that facility you can go and sit with them and hold their hand, talk to them and read to them – they're there for you…You're able to address your own emotional needs with that person being there. When you're going through and supporting a person who has requested MAiD, and you know there's a date on the calendar, and you wake up every single day and you cross off that date, and you know that you're one day closer to the day that they are going to die without fail, it's a very, very difficult thing for them to deal with on an emotional level. It's…more complex than that person who is dying of cancer in the hospital and the date could be next week it could be next month. So, your brain plays some tricks on you and gives you a little bit of a level of comfort knowing that your person is going to be there again tomorrow. When

you wake up *today* and you know *today* is the day, they're getting MAiD, you know there is no tomorrow.

When someone is terminally ill and a loved one knows death is coming, they are still able to escape that reality at times, or they are able to not experience the imminent difficulty to the same degree. When there is a date on the calendar it doesn't let up. Rail explained, "The finite versus the ambiguous date is difficult." Not only wanting their loved one around, but also avoiding the ominous date on the calendar. In some cases, the date on the calendar is a couple of weeks away, even a month or more away. When patients apply and the date falls within a few days (in some cases less than the mandated 10-day waiting period) the loved ones are left with "no time to process anything…like a deer in the headlights."

Table 20

Selected Significant Statements From Those Caring for the Bereaved

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Luckily for all the ones I've come out of…I've come out as equally balanced as when I went in, and I was able to use my own resources to process. But just the humanity, how can you expect someone to go through that alone?

We put someone in the hospital who's dying, and they'll get the first few visits and then they are alone. We see that time and time again. Even in the home, people don't know what to say. Of course, they don't – we [as a society] never talk about it!

I think if you go [to the] North they probably have a better palliative system, because they are all integrated. They have community. We no longer have community.

Many times, someone who has taken their life, it ends up in the media. The dynamics that come from that…the police involvement in a suicide versus someone whose parent has died of a heart attack is very different. That impacts how that person grieves, how that person

processes that death and how their grieving process is able to begin or not able to begin. The same with MAiD. We're looking at the components of someone who is grieving a MAiD loss and we are building that into the outline of a closed group.

If you can picture, when you have somebody whose spouse was dying of cancer and was going through every treatment possible to live and to not die, and then you have somebody sitting across the group whose spouse had the same cancer and decided to use MAiD, there's a lot of animosity from the spouse sitting on the other side of the table.

Jennifer Mallmes.

When asked about her experience with palliative sedation, Mallmes, reflecting on her long experience, identified some of the concerns she harbours around medical assistance in dying long applied to her observations surrounding palliative sedation as well. She referenced the "deepest, most intimate conversations when people are near the end of life or going through some suffering." The effort to preserve life in its final stages continues to stand forth as the highest priority in practice for Mallmes, yet not without great care in managing the various forms of suffering patients endure. In some cases, family members hoping to contribute to the alleviation of suffering for a family member fail to recognize the beginning of the process of palliative sedation often does not result in a return to coherency on the part of the patient. The final conversation, final reflection may have already happened. As with other matters regarding death and dying, medical professionals do not always make communication surrounding the significance of palliative sedation a priority. Families can languish awaiting the imminent death of the patient, for hours or often days. Mallmes expressed concern over consent as well. She wonders about the patient consenting a second time, at the time of the actual MAiD procedure,

following the designated waiting period. Hydromorphone is regularly given to someone no longer communicating, according to Mallmes, and that was happening well before the SCC *Carter* decision altered the Canadian trajectory toward revising the *Criminal Code*. Whether through palliative sedation or through MAiD, Mallmes voiced concern over complicating the grief process for families.

Table 21

Theme Cluster With Formulated Meanings

Emotional Experience of a Family Member's Decision to Pursue MAiD
We're more superficial
One day closer to that date
Not just because they want to die, it's because they want a choice at the time

Interviews With Community Actors

Sr Nuala Kenny (Professor Emeritus)

Sr Nuala Patricia Kenny, MD, FRCP (C) was born in New York and entered the Sisters of Charity of Halifax in 1962. She joined the Department of Pediatrics at Dalhousie in 1975 as the Coordinator of Regional Pediatric Services. In 1982, she became Director of Medical Education at the Hospital for Sick Children and the University of Toronto. In 1985 she was appointed Professor and Chairperson of the Department of Pediatrics at Queen's University in Kingston, Ontario. Dr. Kenny returned to Dalhousie as Professor and Head of the Department of Pediatrics and Chief of Pediatrics at the Izaak Walton Killam Hospital in 1988. In 1995, she became the founding Chair of the Department of Bioethics in Dalhousie's Faculty of Medicine. From February to November 1999, Dr. Kenny was seconded as Deputy Minister of Health for

the Province of Nova Scotia. Dr. Kenny was Chair of the Values Committee of the Prime Minister's 1997 National Forum on Health and is Past-President of both the Canadian Pediatric Society and the Canadian Bioethics Society.[20]

Konia Trouton (Family Physician)

Dr. Konia Trouton is a family physician on Vancouver Island. She has been involved in social justice aspects of health care since medical school in the 1980s, and she welcomes the legislation from Canada on physician-assisted death. Dr. Trouton is a founder and member of West Coast Assisted Dying, a healthcare team that is committed to offering accurate information and consultation when medical assistance in dying (MAID) is requested.[21]

André Schutten (Lawyer)

André Schutten is Director of Law and Policy and General Legal Counsel for ARPA Canada. Based in ARPA Canada's Ottawa office, he has the mandate of equipping the Reformed community for political action on a broad range of issues. He researches and writes on public policy, conducts regular analysis on the impact of different government bills and court judgments and also acts as ARPA's chief Parliamentary lobbyist. He also represents ARPA in various court interventions, having made arguments before the Supreme Court of Canada three times and three provincial courts of appeal.[22]

Theme 1: Initial Experiencing of MAiD

Sr Nuala Kenny.

[20] Retrieved from Health innovation forum. (2020). *Nuala Kenny*. https://www.healthinnovationforum.org/contributor/nuala-kenny/#:~:text=Nuala%20Patricia%20Kenny%2C%20MD%2C%20FRCP,Coordinator%20of%20Regional%20Pediatric%20Services.
[21] Retrieved from West Coast Assisted Dying. (2016). *Konia J. Trouton*. http://westcoastad.ca/
[22] Retrieved from ARPA Canada. (2020). *ARPA staff: Director of law and policy, André Schutten*. https://arpacanada.ca/about-arpa/arpa-staff/

Sr Kenny's concern over the implementation of medically-assisted dying in Canada emerges in the introduction of her *Rediscovering the Art of Dying* (2017). No longer functioning in a clinical or consultative capacity, Sr Kenny channeled her angst over the implementation of MAiD into the writing of the book and subsequent lecturing. Reflecting back on 2015 and 2016, Sr Kenny described her experience plainly, "It's hard to find an adjective to describe how horrific the experience has been for me." Two profound influences on Sr Kenny bring her to this unwavering conclusion: a grounding in moral and ethical issues through the lens of a career as professor and chief of pediatrics and devotion to the religious life with the Roman Catholic Sisters of Charity. With the focus on the child and a family surrounding the child, pediatrics "roots you in notions…different from the standard rhetoric of autonomous choice and autonomous individuals that seems to be replete in Western cultures these days." Working in pediatrics Sr Kenny became aware "the best interest of the child always will be served if their family is also being served." This became most apparent surrounding end of life. Before pediatric palliative care became a specialty, Sr Kenny stood with families in crushing hours of unspeakable realization and loss, at the Hospital for Sick Children in Toronto, at Queen's University in Kingston, and at Dalhousie University in Halifax. "The issue for me has always been the bigger issues of meaning in our decision making, protection of the vulnerable," Sr Kenny said. If ethical medicine meant consideration of the most vulnerable first, and ethical decision making naturally involved the family of the child or adolescent, medical assistance in dying contradicted that presumptive moral foundation.

Vast experience teaching medical professionals facing ethical decision-making surrounding death served as a regular confirmation of what Sr Kenny intuited long before, "that ethical decision making in complex disease and in dying is a profound, profound space for

questions of moral and ethical meaning." With her numerous medical students over the years, Sr Kenny upheld the central maxim: "Medicine is essentially a moral endeavour, not a market endeavour." Accordingly, reflecting back on the Supreme Court of Canada's 2015 decision in *Carter*, Sr Kenny as a doctor reported feeling "heart sick and devastated." The Hippocratic tradition was turned on its head – *I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect*.[23] Sr Kenny distinguished medically-assisted dying from current ethical quandaries, like cloning (something almost unimaginable until recent decades). A doctor's capacity to end the life of a patient is nothing new: "Docs have always had…hemlock around or arsenic or whatever else you want to find." Sr Kenny found the "breadth" of the *Carter* decision most shocking, and what was left out:

> The Supreme Court said nothing about dying, they said nothing about a terminal illness, nothing about a terminal diagnosis. It's a grievous illness, disease, or disability where the person in fact doesn't like the consequences of treatment, even if there's one available, and that causes suffering. It's about suffering. They did say that rightly, but it's the medicalization of suffering.

The *Carter* decision and subsequent regulation through Bill C-14 Sr Kenny found less disjointed than many have expressed. That is to say, Sr Kenny failed to recognize a glaring disparity between the language of the *Carter* decision and Bill C-14, many posited since the introduction of MAiD in Canada. Sr Kenny recognized Bill C-14 capturing the essence of the Supreme Court's decision in *Carter*. Even more disappointing for her was the general Canadian

[23] Hippocratic Oath - Classical Version. Translation from Greek by Ludwig Edelstein. From *The Hippocratic Oath: Text, Translation, and Interpretation*, by Ludwig Edelstein. Baltimore: Johns Hopkins Press, 1943. https://hslmcmaster.libguides.com/c.php?g=306726&p=2044095

response to the implementation of MAiD. After an uncharacteristic pause: "I think I was horrified that too few people were horrified."

For Sr Kenny MAiD is situated at the end of a long road toward total medicalization of Canadian society, the newly dug foundation for bioethical decision making. Even since the beginning of Sr Kenny's medical school days in the late 1960s, medicine has experienced an unprecedented transformation. Medical advancements have instilled in us an insatiable expectation for cure, continuation. Translating into theological language, and emphasizing she meant no disrespect or diminishment, Sr Kenny summarized the expectation: "Resurrection now is expected." Serving children and their families at the IWK Health Centre in Halifax, Sr Kenny was struck by the desperation of parents in the face of a child's terminality. She explained, "If we say, 'We've done all we can towards cure; we really now want to talk to you about comfort care, and the goals of palliative care, and assisting you – make it an eight-year-old boy – your little boy's dying,'" the near immediate response is something like, "Oh God, this is only Halifax; let's go to Toronto!" Sr Kenny went on to explain the same dynamic, the expectation of resurrection, emerged when she served as head of medical education at SickKids in Toronto: "When it happened in Toronto, which is our biggest pediatric, most highly specialized technology hospital…if it happened there, they'd say, 'This is only…Toronto. Let's go to Philadelphia Children's; let's go to the pediatric cardiac unit at Baylor.'" For Sr Kenny, MAiD serves as the final expression of a society fixed on medicalization as the answer. When medicine no longer provides answers, a medically-assisted death serves as a sequential response. We were only living to survive.

Konia Trouton.

For Trouton, making the decision to offer medically-assisted dying to individuals on British Columbia's Vancouver Island proved regenerative – "like going back to the beginning of discovering what I wanted to focus my work and my life about." The realization came gradually, emanating from a curiosity that led to reading, Sandra Martin's *A Good Death: Making the Most of Our Final Choices* (2016), and Atul Gawande's *Being Mortal: Illness, Medicine and What Matters in the End* (2014). Those influences and others affirmed for Trouton the uniqueness of medical assistance in dying in all of healthcare. "I approached it…because it integrated an ability to look at mortality, an ability to consider spirituality, and to talk to people…when they're at an interface between this life and whatever is next," Trouton explained. An informative early influence on Trouton came one month before the legalization of MAiD in Canada. In May 2016, Trouton attended the International Euthanasia Conference in Amsterdam. While there, she viewed a recording of an assisted-death procedure from Switzerland. It was at that moment Trouton asked herself squarely, "'I wonder if I can see myself in any of those roles?'" It felt beyond Trouton's comfort level in some respects, yet within her familiar wheelhouse of pursuing "justice and equity and dignity," in this case, "all within one fantastic envelope."

Trouton from the periphery tracked the debate surrounding assisted dying in Canada, going back to the end of her medical residency in the early 1990s. The Sue Rodriguez debate emerged as Trouton pursued a master's degree in public health in the United States. Watching the Canadian drama emerge from across the southern border she wondered, "'Is [this] ever going to come through?' And then it didn't." And the debate surrounding physician-assisted suicide (as it was routinely referred to in Canada in the 1990s and beyond) slid into the background following the 1993 Supreme Court of Canada decision in *Rodriguez*.[24] Accordingly, the 2015

[24] The term "physician-assisted suicide" occurs 10 times in *Rodriguez v. British Columbia (Attorney General)*. The shortened "assisted suicide" occurs 82 times in the 1993 Supreme Court of Canada decision.

Carter decision took many by surprise. For Trouton it was reminiscent of the Supreme Court of Canada 2004 ruling surrounding gay marriage, which she didn't see coming. "Almost like those Christmas cactus…(laughing); you lock it away for a while and you never know if it's actually going to put a bloom out, and then it does and you go, 'What! What!'"

Table 22

Selected Significant Statements From Community Actors

Death is not a treatment, but it has become so. It's the total abrogation of medicine, of its commitment to heal. It's not just if we can find no technology then let's end it. It's if you can find no technology, and if you have no way of giving meaning, then the only option is to use death as a treatment.

I don't have any drug or device or surgical procedure or cardiac defibrillator for heart ache.

Living with a disability that would have killed you before, or a disease, creates a different kind of environment – especially when you have no background for human suffering.

When it came, it was a really nice surprise.

I would say that I kind of saw it coming, and so in that sense I was already mentally prepared.

What's the message? What's the implicit message in that kind of a change in law?

André Schutten.

Despite involvement in the Supreme Court of Canada as an intervener in the *Carter* case, despite previously tracking the case as it followed its path from the Supreme Court of British Columbia to the B.C. Court of Appeal, despite anecdotal observations which suggested a societal shift in Canada toward greater acceptance of "medically-assisted dying" (for Schutten a euphemistic term which blurs an ethical line between euthanasia and palliative care), despite his

presence in the courtroom when the Supreme Court decision came out, and despite recognizing the likelihood of a decision affirming Kay Carter's initial quest, "it was still a shock," to Schutten, "because it was such a fundamental change." Schutten found the whole process, after gaining intervener status during the summer of 2014 leading up to the hearing before the SCC in October of that year, and his subsequent containment strategy regarding the likely legislation to follow the *Carter* decision in February 2015, "emotionally exhausting."

Following the Canadian federal election in October 2015 and the Liberal government's tabling of Bill C-14 in April 2016, Schutten, along with a friend and a family member (both diagnosed with Spinal Muscular Atrophy), testified before the Standing Committee on Justice and Human Rights, in Ottawa. Schutten, as part of the trio of witnesses before the Justice Committee, sought to "get the Members of Parliament [those sitting in the committee room] to listen to their voices, to understand where they were at." Schutten reckoned an articulate, legal-sounding statement from him, an able-bodied man in seemingly excellent health, missed an opportunity to enter the concern shouldered by many Canadians with visible disabilities. In describing this day and the preparation that went into that brief window of opportunity to draw in the members of the Justice Committee, Schutten in large part revealed his personal motivation for months of dogged commitment surrounding the introduction of medically-assisted dying in Canada.

Schutten argues unabashedly his religious convictions inform his approach to issues involving the rights of Canadians with disabilities. Consistent with the language of the majority opinion in *Rodriguez* (1993), Schutten promotes the ideal of the sacredness of human life in all its stages and going further holds all humanity reflects God's image:

> The appellant's claim under s. 7 of the Charter is based on an alleged violation of her liberty and security of the person interests. These interests cannot be divorced from the sanctity of life, which is the third value protected by s. 7. Even when death appears imminent, seeking to control the manner and timing of one's death constitutes a conscious choice of death over life (Rodriguez v. B.C. (A.G.), 1993 S.C.R. p. 520).

Schutten recognizes the centrality of this conviction no longer anchors the Canadian consciousness, as it had reflexively for many decades. He knows he communicates regularly with an audience that removes any religious or faith conviction from support for Canadians with disabilities yet holds hands with advocates for those with disabilities from whatever position they emanate. The shared concern as he sees it comes down to a discriminatory message sent to disabled Canadians: "The [Canadian] *Criminal Code* says it's illegal to assist somebody in their own death, in their own suicide, *but* if you're (here Schutten filled in the blank with any identifiable group) …then you're allowed to have assistance in your own suicide." If you are disabled, the implicit message states, "'then it's completely understandable that you would want to take your own life, and therefore we're going to allow you to do that and even have help in doing that.' That's what we're doing with people with…disabilities." Following the Justice Committee hearing in May 2016, Schutten and his two friends and their families gathered to process the experience. Schutten's early experiencing of MAiD came through palpably in reflecting back on that day, describing the disappointment expressed by his friends.

Table 23

Theme Cluster With Formulated Meanings

Initial Experiencing of MAiD
Particular concern

Some technology not life saving

Wasn't sure it was ever going to happen

Frustrating process

Who's it going to impact

Theme 2: Ongoing Experiencing of MAiD

Sr Nuala Kenny.

Sr Kenny paused in considering her ongoing experiencing of medical assisted dying in Canada. "Well," she said, "because my initial response was, 'This is horrific,'" and "'How come everyone else doesn't see it as horrific?'…and with most medical groups it was, 'Ho hum, let's keep moving on'…because I was horrified at all of that, as this thing has unravelled, it's exactly what I was worried about." The bleak portrait continued: "I have no surprises in where we are now. The rapidity of its normalization…both within medicine and healthcare and in society, that maybe has stunned me a bit." Two betrayals since the initiation of MAiD in Canada filled Sr Kenny with added horror. Flowing from both the SCC *Carter* decision (2015) and the subsequent federal legislation, Bill C-14 (2016), "we were promised…there would be protection of conscience, conscientious objection, and that there would be protection of the vulnerable.…It seems neither of these promises has been kept." According to Sr Kenny, conscience has been largely removed from consideration for medical practitioners, and the "wide parameters" of the legislation make protecting the vulnerable increasingly challenging. Sr Kenny's buoyant voice dropped off seemingly with the weight of her reflection. "Three years into this," she whispered, "if I had any hope that there was a way to respond as an ethical, moral physician, there would be

a way to respond as the Catholic Christian community…that has become quite discouraging and disappointing for me."

Konia Trouton.

For Trouton, her ongoing experiencing of MAiD has "changed quite a bit." Initially, Trouton approached medically-assisted dying cautiously, "At the beginning…there were so few of us doing it and wanting to do it…I was not sure the family physicians would always be supportive of a person's wish to request medical assistance in dying." Early on, Trouton made the public and physicians across Vancouver Island aware she was able to perform the MAiD procedure. She additionally made clear patients could self-refer, which generally meant patients had brought it up with a family doctor and did not receive a favourable response or the patients might have chosen not to inform a family physician of the decision. Trouton described this early experience as "operating more in a vacuum." She took care of the entire process herself: contacting a second physician to provide the second assessment; starting all IVs herself; making initial contact with a funeral home. "I thought I had to understand what happened to bodies after they die; I thought I had to provide spiritual care, bereavement care (chuckling)…it wasn't until…three *years* later that I realized the health authority was doing things in parallel." An office coordinating the logistics surrounding the MAiD procedure was opened on Vancouver Island. This discovery provided relief for Trouton, to discover there were others "who believe as I do." On reflection, Trouton couldn't say clearly why she believed she needed to tackle everything herself. The whole process is utterly transformed today: "Compared to four years ago, it's so much more a collaborative process, and there are people across the country working at different levels to make this happen." The ongoing challenge for Trouton and the rest of the network is to make sure the dialogue continues. Whereas initially Trouton recalled her mentality

of "head down," pushing forward to "make it work." Years later more time has emerged to allow for consultation with colleagues. Trouton's experience highlights the broader experience of the earliest practitioners of medical assistance in dying in Canada. No one knew how it was going to turn out.

Trouton's methodical early approach may have additionally developed from a concern over the resistance she might face. It never really came. "I expected much more resistance and there really has not been any. I had been prepared and ready for some sort of backlash, some sort of negative reprisal, as there had been for abortion care." By comparison with abortion, Trouton has found "widespread community acceptance…much greater tolerance, and not just tolerance, willing[ness] to engage and talk about it and say, 'Isn't this great.'" MAiD is a topic of discussion across various circles. Conversely, Trouton has found over the years very little willingness to discuss issues surrounding abortion with "non-abortion people."

Trouton acknowledged the uniqueness of the implementation of medical assistance in dying on Vancouver Island, and the comparison was made with the province of Alberta's early introduction of MAiD. From the beginning, Trouton felt free to offer self-referrals to patients on Vancouver Island, her name and the names of other physicians like her were broadcast without reservation. "There was never any cloak of silence at all, on the Island. We were all willing to do it, before we had a fee code…on top of our regular work commitment, knowing that we may not get paid for it." The public support remained intact from the beginning. The public on Vancouver Island seemed eager to engage the evolving conversation surrounding MAiD. In Alberta, where Trouton also holds a medical license, the process required streaming through a coordinated care system. The notion of self-referral proved too uncomfortable, and concern mounted over safety. Additionally, there was concern over backlash in Alberta Trouton did not

experience on Vancouver Island. Doctors providing MAiD in Alberta were intentionally kept from knowing who was providing assisted dying, over concern a backlash would ensue. Alberta, as in other Canadian jurisdictions, worked from the only model Canadian society could reference regarding recent and substantial social change, channeled through the provision of healthcare services.

With more time having emerged with the further integration of MAiD, Trouton considered potential amendments to the current MAiD legislation. The issue of expanding access to mature minors does not present an immediate concern. Despite completing a substantial number of MAiD procedures, the youngest person Trouton has encountered requesting MAiD was 40-years old. Furthermore, conversation with colleagues from Belgium and the Netherlands revealed there remain very few requests from the mature minor category. It's unique among other considerations for expanding MAiD in that parents are very much tied to the decision making. "There is too much potential for their future," making the decision for mature minors extremely rare. If it would come to that point, Trouton reasoned, the motivation for seeking an assisted death would likely emerge as abundantly clear, yet "it's kind of moot in some ways." Whether or not added to the existing legislation, it would very rarely happen.

Trouton has found issues surrounding mental health and MAiD particularly challenging. It's not that Trouton has failed in an initial assessment to identify a patient has "a grievous illness or an advanced state of decline, but the minute that they have been identified as having schizophrenia or major depressive disorder or substance use…or a personality disorder…they've got a psychiatrist involved with their care." This generally means a request for MAiD requires "a psychiatric assessment, or a geriatric psychiatric assessment…to attest to competence. That has proven very, very difficult for us." This additional psychiatric assessment, beyond the two

already instituted, creates a situation where "you may not have the clinicians willing and able to do that," which Trouton held the College of Physicians and Surgeons of British Columbia would require. Both with mature minors and with medical assistance in dying where a mental disorder is the sole underlying medical condition, Trouton foresees considerable barriers to their integration into the existing Canadian regime. Not so with advance directives.

Trouton divides advance directives, one of the three areas of consideration for the expansion of the current Canadian MAiD regime, into two parts. The division is based on Trouton's personal comfort level with the administration of the procedure: "I have to feel okay with it. When I'm providing someone their death, I want to feel like it's the right thing, that I've actually prevented suffering." Part A within the arena of advance directives for MAiD, Trouton can get behind. In Part A, the patient has gone through the process of establishing assisted dying and is awaiting the day of the administration of the procedure. During that interval of days or perhaps up to one or two weeks, the patient has lost capacity due to their medication or due to the disease itself and has become unable to offer consent to going forward at the time of the procedure. For Trouton this scenario falls within "proximity." Hypothetically she offered, "I get to their place and they've lost capacity on Friday, but we had a discussion about it on Monday – I have no issue with going ahead, not at all." Proximity. Part B proves less palatable to Trouton and is an area she would likely avoid. "I might choose to exempt myself from that aspect." In Part B of the offering of MAiD when a patient's advance directive is in place, a substantial amount of time has passed from the initial MAiD approval and the carrying out of the procedure. If a family were to call Trouton and ask for assistance two years away from the initial approval, and when Trouton arrives the patient is unable to speak, that scenario she would find "problematic." In order to better manage a situation that could potentially slip into Part B

territory, Trouton would implement a "staggered, careful approach." Trouton has already provided MAiD to patients long after she completed the initial assessment, the longest being 18 months, but in all of those cases a re-assessment took place. Trouton recognizes, "people do change their minds," and therefore, "always talk[s] with them in between just to make sure they still want it." Trouton identified dementia as the medical condition likely to spark the most controversy under a potential Part B offering of MAiD.

Table 24

Selected Significant Statements From Community Actors

They've rejected the notion of conscience as having a role in your professional responsibilities.

Now that it's all integrated, I see that we can all work collaboratively.

I'll rock the boat a little bit, but I'm not going to overturn the boat.

Mental health to me is very challenging…it's very complicated.

If they are withholding drugs and continue to suffer while waiting for MAiD, that's crazy, and it has happened a couple of times. I would like to be able to go ahead in that situation.

There are ethical codes among journalists that you never report favourably on a suicide, but it seems to be that's not the case with assisted suicide. If it's assisted by a doctor then it's reported favourably, dramatically, romantically it seems.

When the coroner records the death, it does not say, 'Death by…MAiD', since that's the term the law uses. It records the death being, the cause of death being, the disease that led to the request for MAiD. So, we're skewing truth; we're skewing the facts; we're skewing statistics.

Just because we've made it legally permissible doesn't mean we should be promoting it or selling it.

André Schutten.

Schutten finds the ongoing experiencing of MAiD in Canada disturbing, both in terms of its "expansion and its toleration…in society." His frustration is palpable and intellectualized. He cited several examples of the escalation of MAiD that from his standpoint clearly depart and are "hugely beyond what the Supreme Court said when they struck down the prohibition [on assisting in a suicide, under specific criteria]." Concerning the Council of Canadian Academies' 2018 report, *Medical Assistance in Dying*, Schutten expressed concern over the underlying message sent. The concern is not with the Council of Canadian Academies per se, in its attempt to provide thoughtful, critical analysis of various issues within Canadian society, including medical assistance in dying, but rather with the Canadian federal government's request of further exploration in the three additional areas of consideration for MAiD: requests by mature minors, advance requests, and requests where a mental disorder is the sole underlying medical condition. "In discussing the issue, we're normalizing," according to Schutten, subjects that "ten years ago…would [have been] questionable for anyone to try to mainstream a conversation about." This for Schutten "causes…great concern."

More specifically Schutten focused on the area of advance requests as an example of concerning compromises. If health law and criminal law have been conflated with Bill C-14, pushing further, in permitting the elimination of consent given in the moment, takes MAiD further from sound legal moorings. According to Schutten, "The legalization of assisted suicide in this country was made through an amendment to the *Criminal Code* – we're talking about criminal law." Accordingly, Schutten asks, what is the role of doctors in making these decisions.

> Doctors make assessments about competency all the time, they make assessments about consent all the time, but that's in making decisions about your healthcare. We're talking about here when we evaluate whether or not consent is properly given, or whether or not somebody's competent to give consent; we're talking about whether or not they qualify for this criminal law exception. That's something altogether different; that's something that a lawyer or a judge should be assessing, not a doctor.

When doctors consider this is a healthcare issue and not a legal issue, there exists concern (Schutten reported a specific example) of doctors violating section 241(a) of the *Criminal Code*, which maintains the criminality of counselling someone to commit suicide. If a doctor introduces medical assistance in dying to a patient as an end-of-life option, it places the option in the mind of often frail individuals, thus highlighting a significant power imbalance. If a doctor reports this is an option, patients will believe it is important to consider because a doctor is proposing the option. If, said Schutten, a doctor explained to a cancer patient either a radiation or chemotherapy course of treatment is on the table, the patient is burdened with a grave decision. "That's a burden we should not be putting on patients, but again that's doctors thinking this is a healthcare issue when in actual fact this is a legal, criminal law issue." Schutten was unambiguous: "I think that's a big problem."

Table 25

Theme Cluster With Formulated Meanings

Ongoing Experiencing of MAiD
Conscience and the vulnerable at incredible risk
Worried about a backlash

Could self-refer

Violate conscience

Rushing headlong into something

Theme 3: Impact of MAiD on Belief, Meaning, Spirituality

Sr Nuala Kenny.

The writing of her 2017 *Rediscovering the Art of Dying* served for Sr Kenny as "the most intense spiritual experience of my life." The research and writing of this book – a "new vision of compassionate care" – encouraged Sr Kenny in her faith. Despite her years as a practicing Roman Catholic religious woman, nothing before had the transformative spiritual impact of this work. It was in her anguish, in the face of the new reality of MAiD in Canada, of transformation within Canadian medicine and society, that Sr Kenny clung to inspiration from a familiar passage in Hebrews, to the high priest able to sympathize with our weaknesses (Hebrews 4:15a *NRSV*), and to the agony of the Christ in the garden of Gethsemane. Looking to Gethsemane, Sr Kenny recognized a familiar experience. When the Christ there pleaded, "'I don't want to do this; I don't want to do this,' that expresses the natural human desire to deny and avoid suffering." Gethsemane allowed her to identify with the source of her faith in the midst of suffering. "When the doc first gives a bad diagnosis, denial kind of kicks in to help; it's a psychological defence mechanism at that first level. It helps you buffer and gives you time to *whoa, whoa, whoa*." Sr Kenny often saw that "denial persist[ing] in the face of real threat to life or health." Connecting the faces of denial from human interaction over a long medical career with the source of her faith in the garden, provided solace and reinvigorated belief, inspired meaning, and ultimately hope.

Sr Kenny observed, either suffering "intensifies your faith, or it exacerbates that fact that you have no faith." Work with parents made this most obvious. "In talking to all these parents, whose little ones were dying…I can tell you that in all of the families…I would have talked to, the ones that had no faith of any kind would just crush my heart." There Sr Kenny encountered "no source of greater meaning or belief, that once their little one had died, they were not…going into the void," and no sense "that love endured." For Sr Kenny, the encounters with families "that had any semblance of faith, who could have some larger context for meaning, and particularly all of those faiths that would allow the understanding that love endures, it doesn't die, life has not ended," those families persevered. The lack of faith and meaning displayed in many parents confronting the loss of a child, plays out less starkly yet persistently within society in a lost "sense of the transcendent." Sr Kenny's homiletic response crescendoed in linking the observance of increased faithlessness in Canadian society and the appeal of hastening death through MAiD. "There are more and more people who when they come to these issues: serious illness, suffering, no meaning in suffering…are vulnerable because the society…does not support them in finding…ultimate meaning in what's happening to them."

Konia Trouton.

During her university days, Trouton spent a good deal of time with Christian groups. Before that, while in college, Trouton spent time with Muslim friends and their Imam. She recalled inquiry about prayer, time, and the afterlife. Those conversations and reflections were pushed to the sidelines as Trouton's life evolved and she poured energy into developing her medical practice over several years. Circuitously, Trouton's involvement in medical assistance in dying reinvigorated "that whole aspect of my life." She reported, "I actually think I have a stronger feeling about…an afterlife. I have a stronger feeling that the body, mind, spirit interface

is much stronger than I thought it was." The renewed spiritual emphasis translated into changes in patient interactions. Trouton listens more, "at a different level," than had previously been the case in patient interactions, and in interfacing with families. A broadened spiritual lens led Trouton to spiritual conversations with patients – "I always bring it up." Trouton recognizes there is no requirement in Canada surrounding spiritual care in the delivery of MAiD, yet she "always [says]: 'This is the end of your life and it is a physical closure of your life, but it's also a spiritual closure and an emotional closure.'" Trouton goes on, asking: "What do we need to attend to in those aspects of your life?" Trouton has found patients value this brief encounter at life's end. Even those patients who are not interested in any spiritual exploration appear to value the "opportunity [and] and that space to talk about it." The experience has been unique to Trouton's MAiD practice. She noted, "It's interesting because with my other patients…in reproductive healthcare…I never ask those questions."

Asked about unexpected realities in delivering MAiD to patients, Trouton's response came unhesitatingly. Unexpected for Trouton "is the serenity that people have before death." Trouton noted people regularly reflect on the serenity that comes over a body after a person has died; a calmness ensues and wrinkles fade. Fascinating for Trouton has been "the leadership that patients that are dying show the rest of their gathered family…the calmness that they have walking into that, and the confidence that they have walking into that, I think has taken…still takes me by surprise." Under the banner of the unexpected during the course of the MAiD experience, Trouton mused over a recent conversation. Trouton was asked, "Do people cry when they die?" She replied, "No." Reflecting further Trouton relayed, "they might shed a tear at their leaving their family or that their family is going to be sad…but they are so sure of their decision…that they just calmly offer me their arm to thread the IV." Sometimes, Trouton

suggested, a patient will say, "'I'm glad you're finally here; I'm so ready for this.' The calmness and confidence and serenity; it's just…don't look back; it's amazing."

The calm and serenity seen in patients before the administration of MAiD has been a universal experience for Trouton – to a person – and this after having provided medically-assisted dying to hundreds of patients. With patients, "there is no question; it's the right thing to do.…. And the family is so much calmer when they see that their loved one, that is about to die, is so confident about it that it gives them peace." The demeanour of patients allows Trouton to step back into a role of facilitating. It's the patient "giving me the right; they're leading this." Trouton facilitates in "creating a space," and "inviting people to be in a circle," however, it's patients' "guiding this ceremony."

Table 26

Selected Significant Statements From Community Actors

It didn't propel a loss of faith; it did the exact opposite.
Kids don't predecease their parents. There's something unnatural about it.
Yah, they look you right in the eye, and they go, 'This is the right thing to do.'
I'm not leading this; they're leading it.
With MAiD I am listening more.
It's made me appreciate more certain doctrines of my faith, the positive that it brings; not just to me personally, but as a whole worldview.
It's hard to see that if I treat them as the other.

André Schutten.

For Schutten, human value is derived from the inherent meaning of each individual life as a bearer of God's image – the *Imago Dei*. This clearly informs Schutten's understanding of the place of medical assistance in dying in society and his view that the acceptance of MAiD in Canada signals a continuing spiritual "devolution" and despairing. This for Schutten remained challenging. He is regularly challenged to place the value of those who stand in opposition to his positions ahead of the differences that emerge. These individuals too are bearers of God's image and deserving of respect. Schutten has been regularly challenged to keep the horse before the cart in not allowing his passionate appeal for the disabled and a seeming blindness "to the threat and the risk" the population faces, from recognizing his ideological opponents too "hav[e] dignity and [remain] worthy of respect." Step back, ask what makes this issue so crucially important to ideological opponents; what informs alternative worldviews, and crucially determine where common ground can emerge. It appeared to Schutten common ground exists in a shared desire for confronting suffering, an act of compassion, even if the stated means of pursuing it differ significantly. Schutten asked, "Where can we at least agree and maybe work on something together." The belief in the inherent value of all people creates opportunity for deep spiritual reflection, leading to acceptance, when others stand opposed to cherished points of view.

Table 27

Theme Cluster With Formulated Meanings

Impact of MAiD on Belief, Meaning, Spirituality
Spirituality became more rooted
In deep
Chosen the right time

Serenity before death

Look for the common element

Tension really comes down to questions of worldview

Theme 4: Personal Impact of MAiD as Contributor to Canadian Public Life

Sr Nuala Kenny.

Sr Kenny noted her lecture schedule had picked up exponentially of late, responding to both the introduction of medically-assisted dying in Canada, and the crisis emanating from the scourge of sexual abuse carried out at the hands of Catholic priests over decades. The 74-year-old quipped, "my lecture schedule would kill most 40-year-olds." The talks that Sr Kenny has given of late are largely to a Christian audience, either within the Roman Catholic tradition or interdenominationally. Regarding MAiD, Sr Kenny said, "I no longer will discuss this in public, secular arenas, because it's a given. Opposing this, there's no…traction. I mean people aren't inviting. People believe this is perfectly okay and it's happened…let's just make access improved, improved, improved." This reality of general acceptance within Canadian society leaves a vacuum of meaning. Sr Kenny observed, "So many people are grappling with this and the meaning for themselves and their families…. What if a family member wants to do this and you believe it's morally wrong? All of those issues are huge." Sr Kenny does not carry out her public speaking engagements for pleasure. She holds, "I do this public speaking because so few people can or are doing it, and I believe it's essential." Largely removed from the public square, Sr Kenny maintains purpose in reaching a limited, yet needy segment of Canadian society.

Asked when the transition took place from her vantage point, when the debate ended, the conversation turned, Sr Kenny responded emphatically, "It explicitly happened with the Supreme

Court decision. Overnight there was no reason to debate it anymore." It was particularly distressing to witness the Canadian Medical Association, which Sr Kenny was a part of for many years, and the regulatory provincial bodies roll over. According to Sr Kenny, "The medical profession in this country did not have to accept responsibility to do this, but they capitulated immediately." And so, "they don't have a conversation anymore." This for Sr Kenny reinforces the adage, "You can legislate morality." "Legal means moral for most…. It's done."

The only argument Sr Kenny can on occasion raise in a broader audience springs from the consequentialist argument. If the consequences of the various actions involved in MAiD do not produce a desirable outcome, they are by definition wrong. Looking at the number of vulnerable people in society may give pause, however briefly. Sr Kenny looked to several factors contributing to a heightened awareness: articles written about the economic benefit flowing from the instituting of MAiD; the ongoing mental health crisis in Canada; a dramatic increase in life expectancy over the course of the last 75-years; and an "enormous problem with residential long-term care facilities for the dependent elderly." Looking at these together, Sr Kenny concluded the "vulnerability issue is huge." Though Sr Kenny maintained "many, many who are not themselves advocates as such for medically-assisted death do understand this vulnerability argument," however, "in general, it's a done deed…the only issue is eligibility and accessibility."

Looking at the trajectory of the rollout of MAiD in Canada, Sr Kenny remained pessimistic. Looking back to 2015, she hammered the majority Conservative government for not taking action. "The Supreme Court decriminalized, but because it went the Supreme Court route it had to be regulated." The Conservative government "could have done a bunch of things to modify it…at least limit it to the issue of terminal situation or dying, rather than the huge

expanse; they did none of that." Next, "when the Liberal [majority] government came in, they did try to do foreseeable natural death, and immediately that gets contested."[25] Regarding the three additional areas under consideration: requests by mature minors; advance requests; and requests where a mental disorder is the sole underlying medical condition, Sr Kenny held "all three of these areas will be ultimately decided in the most liberal way possible. That's one. Two, within three years, four years, you won't have to have a medical diagnosis at *all*." The critique continued, "The clinical diagnosis is just this little…thing that they threw in to make you feel like this is about physical pain and physical symptoms, which of course it is not." According to Sr Kenny, "The main reasons people request medically-assisted death have very little to do with pain, especially when they get adequate hospice and palliative care."

Konia Trouton.

Trouton's medical career and her work as an activist have been linked throughout. Trouton didn't arrive in medical school with a lifelong passion for medicine. In fact, her focus was on humanitarian activities first. During university and medical school Trouton received the Terry Fox Humanitarian Award. In applying she articulated her motivation for humanitarianism. For Trouton the process of maintaining the award served as an important marker, "a sincere effort." During her third year of medical school, when the 1988 *Morgentaler* abortion decision came down from the SCC, Trouton was considering walking away, disillusioned as she had become watching "the way the gay population was being treated in the hospitals." She clarified, "HIV had just come out and we were treating a lot of people in Kingston [Ontario]." It was at that time, when Trouton heard Henry Morgentaler's speech describing the positive impact the decision would have, that something clicked: "I thought, 'Oh my god, you can be an activist; you

[25] Here Sr Nuala Kenny referred to the 2017 Ontario Superior Court *AB* decision.

can change things; you can impact people's lives and be a doctor.'" And the two came together, medicine and activism. Trouton recalled, "I don't know why I never put those things together." People already assume the draw to medicine emanates from a desire to help people. For Trouton, it was "significant that you were doing things that other people perhaps didn't want to touch, like abortion care. It's always been incredibly important to me that I work in…marginalized areas. Always."

Though Trouton served various marginalized populations throughout her career: in the Morgentaler clinic in Calgary, alongside work in the community health centre in the downtown east side; and in establishing the new public health system in Nunavut, all of which were rewarding, nothing prepared her for the renewed interest in medicine and activism MAiD produced in her. She said, "I didn't think I would be so riveted to work within an area after abortion care, but when MAiD came along I was so taken by it, by the combination of medicine and ethics and opportunity for change, and activism." As a Canadian community actor, Trouton's career in medicine has been truly unique, intimately involved as she has been in the two most consequential social, bioethical issues Canada confronted in the last half-century.

Table 28

Selected Significant Statements From Community Actors

The question is moot. This is now simply a personal idiosyncratic belief.

The whole thing in the procedure is where just before I inject you, I have to say, 'I'm double checking…. You said you want this; we've had a ten-day waiting period. Are you sure you want it?' would be bypassed.

In general, it's been really easy to talk about it, but I often couch it in that frame…well, in the same frame as I've been talking already: It's a kindness; it's an ending of suffering; and

it's an opportunity. People really resonate with that, and they understand that, and they want that. (Chuckling) They want to move to Canada.

Just like everyone has a right to healthcare, we're going to make sure that includes palliative medicine.

It's not a choice of one or the other; there are other options.

Even our own doctors don't know how to have conversations about palliative care, or they themselves have misunderstandings about what is involved. I don't think they all need to become experts in it. Surely, they could receive more education in it.

André Schutten.

Considering how medical assistance in dying has impacted Schutten as a contributor to Canadian public life gets to the heart of his work, which often centres around motivating a regularly apathetic public to consider a different perspective, consider a course of action and to act. He confronts regularly the all too human response: "'Well, it doesn't affect me directly.'" In reference to MAiD, Schutten again highlighted those Canadians with a visible disability. If a Canadian with a disability "is afraid to go to the hospital anymore unless he has his mom and or his dad with him, at all times…otherwise he doesn't want to go to the hospital, 'Well, that kind of sucks for [him], but it doesn't affect me, so *whatcha gonna do*.'" That is the point. Schutten emphasized he is many ways like a large percentage of Canadian adults: "I'm employed with a decent salary, I've got a massive social/safety network – my immediate family, my extended family, my church family." Schutten went on: "I'm happy, healthy, and I don't have any sort of disability. I'm still young and have a bright mind." Accordingly, for Schutten, "I can't say [MAiD] has impacted me personally, or at least not directly, and that's kind of the point I

suppose." Those that it largely impacts are those in need of increased awareness, lest their concerns slip into a widening sea of complacency.[26]

In addition to raising awareness around disabilities, Schutten expressed concern over the additional hurdle MAiD creates for the proper integration of palliative care in Canadian healthcare. Schutten has grown increasingly pessimistic on the issue: "There's no longer an incentive for it." The offering of a medically-assisted death can arise without an "obligation on the patient to even try palliative care before accepting or deciding to go with [MAiD]." This ends up furthering the "tonnes" of misinformation surrounding palliative care. Schutten cited the opening of the *Carter* decision as particularly unhelpful. "It's emotionally laden, and it puts up a false dichotomy." When suffering intolerably, one can "die this long painful, miserable death, or…you can take your own life, sometimes by violent means." According to Schutten, "No…we've got at least a third choice; we actually have palliative medicine, and it's doing remarkably well." If, Schutten emphasized, it was given a proper chance.

Table 29

Theme Cluster With Formulated Meanings

Personal Impact of MAiD as a Contributor to Canadian Public Life
No longer criminal in this country
People who aren't connected going to take the brunt of this
Frustration with apathy

Theme 5: Personal Impact of MAiD on Interfacing With Other Canadian Public Figures

[26] Schutten recognizes the issue of MAiD and persons with disabilities in Canada remains complex. Some want access to MAiD while others are wary of the new law.

Sr Nuala Kenny.

Sr Kenny was clear about her understanding of what her opposition to MAiD in Canada has wrought: "Because of my vocal criticism of the [Canadian] medical profession for failing to uphold its moral obligation…not a Christian obligation…a longstanding Hippocratic tradition, there are probably medical groups that would not invite me, that would have invited me before." Sr Kenny (chuckling) followed up, saying, "That's okay; I'm used to it." Upholding the moral obligation in the current Canadian scenario means protection of conscience rights, and this breaks out at two levels. At the micro-level individual physicians and nurses work in settings where MAiD can be requested. According to Sr Kenny, "right across the country, the provincial bodies have been weak, weak, weak on protection of conscience" for individuals.

On a macro-level, Sr Kenny reported concern for Catholic health facilities in Canada. The creeping concern has to do with public funding. Catholic health institutions go up against the belief, "If you're receiving public funding, you've got to do whatever the public funders expect." Provinces like Ontario, where there are many Catholic beds, experienced a reprieve from the consideration for the offering of MAiD, but Sr Kenny knows "guaranteed, it's not going to last." She referred to some of the most prominent institutions in Canadian Catholic healthcare: Saint Paul's Hospital in Vancouver; Saint Boniface Hospital in Winnipeg; and Saint Michael's Hospital in Toronto. "They've got an interesting challenge on their hands, because if they refuse to participate in any way…they're going to be challenged in terms of public funding." In considering Catholic health institutions refusing to participate, Sr Kenny referenced the interpretation on medically-assisted dying from the Catholic Bishops of Alberta and the Northwest Territories, issued in a statement in September of 2016, three months after the legalization of MAiD in Canada. The introduction to the statement begins thus:

> Death by assisted suicide and euthanasia has been made legal in Canada. These grievous affronts to the dignity of human life from beginning to natural end are never morally justified. The legal permission now granted to these practices does not change the moral law. (Smith et al., 2016, September 14)

Sr Kenny referred to the 2016 statement by the six Catholic Bishops as "the strictest interpretation of medically-assisted death," in Canada. The failing translation of this and other bioethical considerations into Canadian Catholic healthcare delivery remains a pressing concern for Sr Kenny, as does the diminishing capacity for that translative process. The concern centres around "the formation of people in Catholic healthcare ethics." Many practicing ethics in Catholic healthcare settings know contemporary ethics, according to Sr Kenny. That is, "they know Beauchamp and Childress and *Principlism*, but the spiritual and longstanding moral tradition of the Church, they're not that good on" (Beauchamp, 2015).

Konia Trouton.

As medical assistance in dying has "normalized" in Canada, Trouton has found herself interacting with a wide array of people, interacting about the new regime. Trouton has additionally experienced various people reaching out to her to discuss MAiD, people she didn't previously know. Perhaps most predominantly, Trouton has experienced a great deal of interaction with the funeral care group and the cemeteries and the people who do cremations. "Those people talk about [death] all the time; I never did [previous to involvement in MAiD]." Additionally, involvement in medically-assisted dying has opened up ongoing dialogue with the palliative care community. Trouton recounted, "I had no reason to contact or be in touch with any palliative care physicians before. My practice is women's health. My practice is abortion care and miscarriages." The interaction proved invigorating: "The interface with all the

palliative care team and understanding the multidisciplinary teams that impact all parts of healthcare, I've found quite interesting." Trouton's experience with the palliative care team boils down to "look[ing] after the people together. The palliative care folks will be in there. They'll say, 'Konia can you help out,' and if I can't help out, they will help out." She went on, "We look after each other, and we make sure we're looking after the patient who wants help, who is suffering." Trouton appreciates the model on Vancouver Island in action, a model she has been involved in creating.

An adjacent jurisdiction, not Alberta but the State of Washington, promotes a model that has left Trouton with concerns. In offering concern, Trouton acknowledged she had not yet attended a conference in the U.S. focused on physician-assisted death (the only model available in ten U.S. jurisdictions that offer it, while euthanasia remains prohibited throughout the U.S.). The relative lack of direct physician oversight in the U.S. physician-assisted death process highlights the most significant distinction between the two models and presented the greatest barrier for Trouton. She said, "The clinician writes the prescription that the patient then fills…and the clinician may or may not be involved in the timing of when they do it, and not be involved in the place they go ahead and do this [in]." Trouton expressed additional concern, the U.S. physician "cannot be sure that this medication works and has no backup." In British Columbia this approach to physician-assisted death violates the instituted guidelines of the Canadian Association of MAiD Assessors and Providers (guidelines Trouton helped create), which stipulate the practitioner must be present, even if the patient administers the medication themselves (Harty et al. 2018). This is a far cry from the standard physician-assisted death model in the U.S. which emphasizes:

> You can take (self-administer and ingest) the medications at a place of your choosing. Most people (92 percent in Oregon) choose to take the medications at home; those who reside in assisted-living or nursing home facilities tend to take them there (Death with Dignity, Frequently asked questions. p. 3).

In the hundreds of MAiD procedures Trouton carried out over the first four years of MAiD in Canada, she only participated in 12 "of the oral deaths." During each of the dozen procedures, Trouton was in the room, present with the patient when they took the medication orally. Incidentally, Trouton was herself involved in establishing the "best medication for the oral protocol" (Harty et al. 2018). In half of those scenarios, six of the 12, Trouton "had to intervene with an intravenous after an hour, hour and a half, because it hadn't worked." In those cases when a patient requests the oral medication option, Trouton brings the medication to the patient, and they have a conversation: "'Okay, at what point do you want me to intervene…. Is it an hour, an hour and a half?'" Referring to the six cases where death had not occurred after the allotted time, with the family aware of the agreement, "if they are in a coma, but they haven't died, I will help them with the final completion of their life." One might assume Trouton opposes the oral option in her practice, but this is short-sighted. Whether the patient elects the oral medication route, which to date few Canadian MAiD patients have opted for (or throughout most of Canada, had opportunity to opt for), or the standardized intravenous route, Trouton is clear: "I think the model we have in Canada is really good. It means that the healthcare system, and I am a part of that, will offer someone an option…and will make sure that the option works." As a physician, and a community actor, someone who represents Canadians beyond her immediate medical practice, the clear emphasis is on clarity and the proficiency of the procedure. Trouton said, "I think that's been so important, that we'll support someone all the way."

On a practical level, Trouton reported concern over the actual delivery of the oral medication route, particularly the capacity of many patients to successfully carry out the procedure when the day comes for their scheduled medically-assisted death. Trouton indicated it is not infrequent for a patient to express interest in the oral route, "and then when it gets closer to the day they want to have it, they are so weak, and so frail, and so close to death, they do not have the strength to drink it and hold it down." Trouton explained, many patients: "haven't eaten for four days…they are so ravaged by their disease." As an example, "Someone with lung cancer gasping for each breath, the last thing that they are able to do is drink down 150 mils of something bitter in four minutes. I mean, that's a struggle; it's a struggle for them to take a breath." Regarding cancer patients Trouton explained, "Sometimes [they are] so nauseated they can't eat without vomiting. So, to take an oral medication and think, 'Oh, I've got to be well enough to mix the medication, and drink it, and not vomit, and hope that works." Practically speaking, in Trouton's experience, the oral route remains feasible for a select segment of those pursuing MAiD, and a considerable challenge for many.

Table 30

Selected Significant Statements From Community Actors

I had been extensively involved in all kinds of medical groups.

Catholic health facilities have been wrangling with the question of the obligation that they have when a request is made in their facility.

Some of them have outright, in their requirement for what they call an effective referral, have by any interpretation of the principal of moral cooperation, compromised many of my colleagues.

The other part is the legislative group. At the federal level I have talked quite a bit with the people who have developed our reporting strategy, and also [at] the provincial level developing our MAiD curriculum…to safeguard and ensure that people are well trained before they go forward. There's never an ethical hiccup getting involved with that.

The intravenous we essentially borrowed from the Dutch. I spent quite a bit of time with the Dutch Medical Association who work very closely with the Dutch Pharmacy Association. But yes, I have worked at trying to establish that guideline for Canada.

I really value my palliative care colleagues over the last four years. They've been incredible. I really think that we've forged such a great partnership in me knowing more about their world and how they can help people, and being able to say to people who are asking for assisted dying, 'Look, you don't have to do this. You are going to have a journey with palliative care for a while, and that might be the only journey that you need.' I'm there at the end of the road, after that has been exhausted. I really like working with them in that way.

I'd like to see our model of care move across Canada, where people feel that when the palliative folks have done all they could and despite that or in addition to that people want some assistance in the end, so they can name the day and time and place. It provides people the greatest dignity and reduced suffering and opportunity to both experience the great benefits of palliative care, but also to still maintain that autonomy of time, place, and who.

It's certainly brought me closer together with particularly other advocates within the disability rights community.

My impression, and it's only that, it was a missed opportunity…that it was pushed after the [federal] election [of October 2015]. The recommendations from the expert panel…maybe I'm being a bit too cynical, but this is a great way to deflect responsibility away from those who are ultimately responsible. By creating an expert panel, it's an easy talking point. It's like, 'Oh well, the expert panel (Harvey Chochinov an expert in palliative medicine…a disability rights advocate and human rights lawyer from Ryerson, [Catherine Frazee], and…a constitutional expert from Quebec, [Benoit Pelletier]) they're dealing with it; we're going to wait for their recommendations and their report.' It was deflection, deflection. In fact, their report was pretty good, all things considered…. We were thankful for that.

We're talking about a minor, in the sense that it's not a complicated amendment to the *Criminal Code*. Major in the sense of its social implications, but minor as far as the actual text of the *Code* being changed. A minor adjustment like that probably could have been done relatively quickly.

André Schutten.

Schutten noted his advocacy for the disabled in Canada, in light of the MAiD decision, brought him closer to the disability rights community. He said, "It's forged new friendships because we have common cause; we're fighting for something good together." In the political arena, where Schutten reported doing regular advocacy work, he found though regularly falling on the right side of the political spectrum, "we can actually cross party lines quite a bit." He noted, "There are a lot of people on the left side of the [political] spectrum that are fierce advocates of disability rights. I've gotten to know them, and appreciate them, and learn from

them." An important early example of this cooperation came during "the lead up to *Carter*. We were able to endorse a [palliative care] motion by Charlie Angus, NDP [New Democratic Party] Member of Parliament." The motion passed in the House of Commons and Schutten ended up at a reception that evening. Many of the faces were unfamiliar and he assumed he was among people ideologically opposed on many fronts, "but on this one; we were united on this one." MAiD in Canada unwittingly "built bridges, particularly around palliative care, and around the language of disability rights." Thinking about the way forward, to the 2021 five-year legislative review of MAiD and beyond, Schutten expressed a desire to see this coalition remain intact, to avoid the political splintering that can occur over the passage of time. He remained cautiously optimistic that an opportunity may emerge for the strengthening of safeguards around MAiD for the disabled in Canada, as well as improved awareness surrounding and access to palliative care in Canadian healthcare.

According to Schutten, the legal rise of autonomy as the supreme reality in Canadian social policy, provides the backdrop for medical assistance in dying and other significant social change. Particularly in the legal realm, where most weighty social policy is determined, Schutten recognizes an ongoing drift toward individualism and autonomy and personal choice. Though Schutten recognizes the vital need for personal choice and responsibility, it has become "the driving…the number one consideration; the driving force behind our social policy." Not claiming to know what the end result will look like, he worried it is not sustainable for the singular focus to rest with the individual and the unbridled supremacy of autonomous choice, over the individual in the context of family, community, and society.

Table 31

Theme Cluster With Formulated Meanings

Personal Impact of MAiD on Interfacing With Other Canadian Public Figures

Two kinds of conscience protection issues

Huge challenge

Such a fantastic experience

Discuss it with more people

Autonomy is something to be weighed

Tough moral, ethical questions

Discussion

In this research study, Canadian participants from one of three groupings described lived experiences of the implementation of medically-assisted dying in Canada. Each of the participants' reflections on their experiences came from involvement throughout the pre-implementation period, particularly beginning with the February 2015 Supreme Court of Canada decision in *Carter v. Canada (AG)*, through to the three to four years from the 2016 legalization of medical assistance in dying in Canada.

Medical Professionals – MAiD and Palliative Care

The medical professionals grouping provided valuable experiential insight about the direct offering of medically-assisted dying in a variety of contexts. The experience of medical professionals regarding MAiD will likely look substantially different should the ongoing implementation follow its course toward further integration and normalization within the various Canadian healthcare systems, whether or not that implementation incorporates any of the currently disputed additional areas under consideration, and which of the above identified levels

(*Level 1* to *Level 5*) comes to most accurately describe the Canadian position within an international context.

Apart from involvement in the medical profession more broadly, each of the participants in this grouping maintain considerable palliative, hospice, and end-of-life care experience. Medical professionals in palliative care now encounter MAiD in Canada directly. They serve patients in Canada's North, in homes, in hospitals, in urban, medium and smaller population centres, in the community, and serve the homeless and street communities. They are witness to the initial integration of medical assistance in dying in Canada and simultaneously a transformation within palliative care. Within even the relatively small grouping of five medical professionals in this study, attitudes regarding MAiD, and thereby the relationship between MAiD and palliative care in Canada, were wide-ranging, unwittingly incorporating many of the forms identified by Gerson et al. (2020), derived from 16 studies focused on the relationship between assisted dying and palliative care in four international jurisdictions where assisted dying is legal: "supportive, neutral, coexisting, not mutually exclusive, integrated, synergistic, cooperative, collaborative, opposed, ambivalent, and conflicted" (pp. 1298-1299).[27] Notably, the attitudes of those participants within the medical professionals grouping concerning the relationship between MAiD and palliative care shifted from the inception of medical assistance in dying in Canada to the three to four years following. Overall, initial anxieties surrounding the rollout of the new regime lessened, whether those anxieties emanated from, on one hand, practical procedural concerns or, on the other hand, the compromising of the palliative care ethic, specifically around the hastening of death. Is it the relief of suffering short of the hastening of

[27] The 16 studies identified by Gerson et al. (2020) included a Canadian study by Wales et al. (2018) of the provision of MAiD within in a Toronto palliative care program.

death (even sometimes including palliative sedation), or the relief of suffering including (under prescribed circumstances) the hastening of death? Not a question Dame Cicely Saunders (1918-2005) confronted as starkly, upon her founding of the first modern hospice and early establishment of the palliative ethos, in 1967.

For nearly a half-century in Canada, the palliative care movement has worked tirelessly for recognition in the face of increased medical technology and medicalization. Since the introduction of MAiD in Canada, the palliative care movement faces additional challenges, seeking to establish its position anew. Well before the introduction of MAiD, palliative care in Canada was regularly unavailable or inaccessible to patients and their families. Though the eligibility criteria found in Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* (2016), requires the offering of palliative care as a means of relieving suffering, it appears as an afterthought.[28] A patient's shift to the palliative approach may feel like a concession, an acquiescence. Assisted dying for some may intervene to smooth over that shift, promoting a continuation of medicalization unto death. Though it remains early to suggest Canada is witnessing a fusion of assisted dying within palliative care, a lack of clear differentiation between the two inevitably impacts funding for palliative care, as bloated governments seek to curb healthcare spending.

Those Who Care for the Bereaved – MAiD and Disenfranchised Grief

The grouping represented by those who relate to and care for bereaved families revealed a depth of intimate connection to the community of the bereaved, and in particular those journeying forward preceding or following the medically-assisted death of a family member or

[28] It remains doubtful anyone seriously considered the instituting of assisted dying in Canada would finally elevate the palliative model to an equitable position, when the Honourable Jody Wilson-Raybould, then Minister of Justice, introduced Bill C-14 in the House of Commons, on April 14, 2016, or thereafter. The five-year review of Bill C-14 is to include a committee assessment of "the state of palliative care in Canada" (p. 14).

friend. Nicholas Wolterstorff in *Lament for a Son* (1987) revealed the isolating impact of grief following the death of his son and hinted at the need for those who provide bereavement care: "I must struggle so hard to regain life that I cannot reach out to you. Nor you to me. The one not grieving must touch us both" (p. 56). Those who care for the bereaved stand in that amorphous space between the decedent and a family. In many cases, grief surrounding MAiD may prove unique, deserving of its own consideration.

In this study, the Personal Support Worker's interfacing with the bereaved and those facing an assisted death seems to confirm the exclusive nature of medically-assisted dying, placing it more firmly in the arena of disenfranchised grief, at least as experienced in the initial years of assisted dying in Canada. The Personal Support Worker's internal angst emerged not as a result of bereavement as previously known (the Personal Support Worker regularly encountered death over the course of years in the workplace), but rather built up around the highly regulated, even seemingly secretive nature of MAiD's implementation. The potential exists not only for experiencing division within a family, as not all family members are on board with a patient's decision to pursue assisted dying, but additionally the Personal Support Worker expressed the isolating nature of MAiD among colleagues, as each Carefor Ottawa home health care staff person approaches MAiD from one's own conscience perspective. The Personal Support Worker cared less about the varying perspectives, differing perspectives, and more about the increased level of discretion, and feeling cut off. The Personal Support Worker may well recognize the need for the increased professional discretion around MAiD while at the same time remaining attuned to an internal anxiety, an anxiety not previously experienced, before palliative patients in their homes were given an option of pursuing a medically-assisted death.

Laurie Rail's experience speaks directly to the unique and disenfranchised nature of bereavement associated with medically-assisted dying. In the bereavement group setting, Rail learned of the alienation resulting from social stigma, or perceived social stigma, experienced by the bereaved whose family member chose to end life through MAiD. Rail's experience is in part consistent with the findings of Andriessen et al. (2019), yet the experiences around the known end date for the bereaved differed considerably. Rail observed the distressing impact on group members of the known, looming date for MAiD, while Andriessen's findings indicate a relative enhancing of bereavement resulting from the approaching date. The date, in Rail's experience, comes to haunt the bereaved. Andriessen et al. (2019) noted a potential positive with the known ending date, an impetus for tying up loose ends: "A sense of control both from the perspective of the bereaved and the dying family member, anticipating the death, the opportunity to 'finish business,' and the feeling of having honored the deceased's will were the main positive aspects reported" (Andriessen, p. 8).

Similar to findings in Andriessen et al. (2019), Rail also observed concerns over social stigma when a family member accessed MAiD, often coupled with the increased anxiety around the concrete date on the calendar, once the MAiD procedure is scheduled. In Rail's experience the prevalence of social stigma in the bereavement group setting necessitated the move toward a group designed exclusively for those individuals grieving a death, or anticipating a death, resulting from MAiD. Andriessen also noted the social stigma associated with assisted dying: "The main difficulties concerned moral or ethical conflicts, dealing with feelings of guilt and responsibility, dealing with authorities after the death, or coping with anticipated unfavorable

social perceptions or judgment regarding the death (Andriessen, p. 8)."[29] The apparent disconnect between significant support for medical assistance in dying in Canada and a stigmatizing impact on the bereaved following a MAiD death deserves greater attention as MAiD becomes increasingly integrated.

Studies by Gogolishvili and Globerman (2017) and Gamondi et al. (2015), which focus on bereaved families following assisted dying provide background for greater exploration of the Canadian bereavement experience following MAiD. The bereavement community continues to adjust to the initial introduction of MAiD as introduced through Bill C-14. Further changes to the existing regime will push the bereavement community further from meaningfully identifying with the varied grief experiences following MAiD. Should Canada move to *Level 2* or *Level 3* medically-assisted dying, for example, from its initial place at *Level 1* since 2016, a subsequent fallout will take place down the line as the bereaved come to absorb the isolating shock of a new form of dying, one not yet grounded in the surrounding societal experience.

Jennifer Mallmes interfaced with MAiD as end-of-life doulas began to gain increasing recognition in Canada. Perhaps not surprisingly, some came to assume end-of-life doulas were in some way involved in the early administration of medical assistance in dying. Correcting this misconception is indicative of the work end-of-life doulas offer individuals and families surrounding the journey toward death. Mallmes interacts with families who may not agree with a patient's decision to pursue MAiD, and often families uncomfortable in communicating generally. MAiD can present an additional hurdle for Mallmes in encouraging a family to open up around the pending death and encouraging the enhancing and preserving of memories

[29] Andriessen et al. (2019) findings come from 10 separate studies, focusing on either euthanasia or physician-assisted dying, spanning 23 years (1995 to 2018). The 10 studies focus exclusively on findings from Switzerland, the United States, and the Netherlands.

surrounding that death. With some family members opposing MAiD choosing to stay away at the time of the death, the potential for resentments and the disenfranchising of the family's grief experience begins.

As this study indicates, the recruitment and interviewing process of bereaved family members following medical assistance in dying requires a high degree of sensitivity. The *Tri-Council Policy Statement* (2018) emphasizes an important "mechanism for respecting participants' autonomy in research is the requirement to seek their free, informed and ongoing consent" (p. 6). Ongoing consent with the bereaved remains challenging due to the shapeless nature of grief. C.S. Lewis in *A Grief Observed* (1961), the now classic account of the death of Lewis's wife, Joy Davidman, movingly put down what many mourners experience arbitrarily and privately: "For in grief nothing 'stays put.' One keeps on emerging from a phase, but it always recurs. Round and round. Everything repeats. Am I going in circles, or dare I hope I am on a spiral?" (Lewis, p. 56). Research aimed specifically at the bereavement experience following MAiD in Canada deserves and demands a highly involved presence on the part of the researcher, even more considering the potential for disenfranchised grief and its alienating impact.

Community Actors – MAiD and the Never Compatible Group

The community actors grouping, made up of individuals both involved directly in the provision of MAiD, as is the case with Konia Trouton, and indirectly as commentators on the implementation and ethical and legal implications of MAiD, as in the cases of Sr Nuala Kenny and André Schutten, and all with a concern wider than their immediate responsibilities. The community actors look at broader implications for Canada's adoption of assisted dying as a means of ending life, looking at transformations within health care, implications for spiritual care

and community religious life, and jurisprudential and public policy considerations for Canadian society ongoing. The community actors in this study voice a full continuum of perspectives rife within Canadian society, from grave concern over the deeper implications of the instituting of assisted dying in Canada to prospects for the enhancement of personal autonomy and a revolution in the end-of-life experience. These perspectives remain sensitive to and profoundly influenced by Canadian law yet stretch beyond the law at any given time, aimed at greater adherence to the right ethical position.

Despite a voluminous chorus decrying the limitations placed on the Canadian implementation of assisted dying through Bill C-14, highlighting perceived insufficiencies and failings, the experience of the participants in this research study, even the foremost proponents of the benefits of MAiD for society, experienced some level of disruption, sometimes mitigated by preparation leading up to the introduction of MAiD, at *Level 1* medically-assisted dying. The very fact that Bill C-14 hesitated to introduce too quickly subsequent levels speaks to the importance of the gradations and the importance of a thoughtful approach to any additional access permitted under the MAiD umbrella in Canada. The *Never Compatible Group*, those opposed to assisted dying at any level, rested comfortably for the 22-years separating the SCC *Rodriguez* decision from the SCC decision in *Carter*. In a near total reversal since 2016, the *Never Compatible Group* stands outside looking in, no longer holding sway over the general Canadian public perspective on assisted dying. This transition corresponds with the baby boom generation beginning to reach retirement age. Consider, a boomer born in 1946 turned 70 the year of MAiD's legalization. The witnesses in this study highlight the practical reality of the systemic transformation necessary to allow for the implementation of MAiD in the first place.

Expansion of MAiD into *Level 2* or *Level 3*, or beyond, may have the unintended consequence of moving the theoretical beyond the practical if the public will for the expansion does not align as it did in 2016 when Bill C-14 achieved royal assent. With assisted dying dislodged from its mooring of competent adults experiencing imminent death (whatever the timeframe), a greater degree of inconsistency in the application of MAiD can be anticipated. A question remains whether enough medical professionals will offer their services to carry out the increased burden of additional procedures with the implementing of new levels of MAiD. Envision a nurse for example agreeing to provide assistance with a *Level 1* MAiD procedure, yet not any procedure beyond *Level 1*. If the MAiD procedure falls at *Level 2* or *Level 3*, the nurse may for conscience reasons decline to participate, and if the level of the MAiD procedure remains confidential up to the point of the procedure, some medical professionals otherwise predisposed to assisting at say *Level 1* MAiD may withdraw voluntary involvement in MAiD procedures across the board. Apart from the distinction between levels of MAiD, an increased number of MAiD procedures performed invites greater emotional strain on overly burdened health care professionals. Exploding health care budgets inevitably place increased pressure on those asserting conscience rights. As the provision of MAiD in Canada expands, so too the burden on those tasked with carrying it out.

Conclusion

For many of the participants, regardless of their grouping, the introduction of medical assistance in dying produced a heightened sense of awareness. It was generally experienced as highly significant. Whether one initially deemed the introduction of MAiD a perceived positive or negative development, or somewhere in between, a recognition of the momentous nature of the transition abounded. As with the cautious unveiling of Bill C-14, which did not go as far as

many had anticipated, the witnesses waited for a bang that for the most part sounded more like a whimper. During the three or four years following the introduction of MAiD in Canada, an evolution took place. For most of the witnesses, the slow and for the most part steady integration of MAiD encouraged its increasing normalization. The interviews with participants took place as the federal government entered into a new phase of evaluation of the existing MAiD regime. The interviews were heightened by capturing the initial manifestation of the regime, without the certainty of knowing which direction amendments to the existing legislation would go.

The interviews of participants preceded the prorogation of the First Session of the 43rd Parliament, beginning in August 2020, and consideration of the reinstated Bill C-7, *An Act to amend the Criminal Code* (*medical assistance in dying*), over the fall 2020 and winter 2021. Bill C-7 received royal assent on March 17, 2021. Translated into the terminology of this research study, the participants' experiencing of MAiD fell exclusively under *Level 1*, requiring both that death be deemed reasonably foreseeable and that patients maintain competency to give final consent at the time of the provision of MAiD. Though there was an awareness by participants of the likelihood of further changes to come, Bill C-7 did not factor directly into the interviewing of participants. Some participants maintained a broad awareness of the areas under consideration for inclusion in the existing legislation, while others reported they were aware more particularly, tracking developments following the September 2019 Superior Court of Québec ruling in *Truchon v. Canada (AG)*, for example. MAiD in Canada post Bill C-7 poses a rockier landscape. Despite much criticism following the initial rollout of MAiD through Bill C-14, purportedly betraying the essence of the SCC *Carter* decision, it offered Canadians (and MAiD's witnesses) relative clarity, whatever one's position. MAiD remained anchored to imminent death.

Allowing time for the integration of the MAiD *Levels* associated with Bill C-7, considered in the midst of a pandemic and taken up a second time following the prorogation of Parliament, will likely reveal a broader range of opinion among the majority of Canadians who at some level support an assisted-dying regime in Canada. Considering the gradations of MAiD and utilizing *Level 1* to *Level 5* can assist future research regarding the ongoing experience of various witnesses to MAiD, following the initial five-year review. With various gradations of MAiD conveyed through specific levels, it may mean a proponent of say *Level 1* and *Level 2* could find ethical departures at *Levels 3* and beyond too difficult to support. It must be kept in mind, Canada's various healthcare systems in 2021 and for the foreseeable future stretch further and further to meet ever-growing demands. It could well be the case though a level of MAiD is legal, it cannot be provided in keeping with the principles of the *Canada Health Act*, nor with buy-in from requisite medical associations and individual medical professionals. Fragmented public support, and the potential boomerang effect of latent bereavement experiences make the landscape rockier still. Consider, despite the inclusion of MAiD *Level 3* in Canada, what percentage of existing physicians and nurse practitioners providing MAiD willingly fulfill MAiD requests of a patient, no longer competent to consent, after a considerable period of time has passed? Some medical professionals may consider a substantial gap in time, between an individual initiating the MAiD process and the provision of MAiD, no longer in keeping with ethics around ongoing consent. The inclusion of *Level 5* in Canada broadly implicates the field of psychiatry, which today operates in perpetual crisis mode. Psychiatrists themselves may question their involvement both ethically and practically from the standpoint of a lack of availability. Would individuals requesting MAiD as a result of a mental health condition jump the queue? If not, MAiD at *Level 5* itself promotes another version of Gloria Taylor's "cruel

choice" described in *Carter* (2015, p. 349) between enduring suffering and the greater likelihood of a decision to suicide. With *Level 5*, however, suffering is not irremediable as it was for Gloria Taylor. As these and other debates take place, at the level of the provision of MAiD, reference to the gradations of MAiD through *Level 1* to *Level 5* provides a needed framework in the Canadian context.

This research study uncovered new perspectives on the grief process, in part surrounding the anticipation of the date and time of the MAiD procedure. This radically changes the context of dying, pointing to the potential for a different grief for close others of individuals who accessed MAiD. The Urban Physician's comment concerning a new conversation, with those patients who previous to 2016 would not likely have considered MAiD but now inquire, deserves further consideration. A question arises: Does MAiD open up access to more services or does this new access act as a coercive incentive for some patients? Several participants' change of mind (or values) concerning MAiD is a finding that also needs to be investigated more thoroughly. What is it about MAiD that was compelling enough to alter these participants' views? What are the factors: That it seemed to be applied without prejudice? Or the fears they had initially did not materialize? Or was it at its core a change of values for participants?

We continue to increase our collective understanding of the state's role in relieving suffering, nearly 100 years since the beginning of the Great Depression. The question is no longer, Does the state have a role in the relief of suffering? Now we ask: What level of suffering is the state relieved of responsibility from addressing? Is Canada, for example, responsible to carry out state-sanctioned assisted dying for citizens solely experiencing persistent mental illness (*Level 5*)? The question becomes difficult to answer in the affirmative considering the seismic shift within mental health care even since the initial introduction of the diagnosis Major

Depressive Disorder, published in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-III)* (1980), two years preceding the adoption of the *Canadian Charter of Rights and Freedoms*, still arguably in its infancy in 2021.

In a culture of growing agnosticism and uncertainty within Canada, fewer are comfortable aligning with an established belief system or faith tradition yet uncovering one's subjective experience often reveals a dynamism at the level of belief, meaning, or spirituality. We may feel comfortable to share our individual experience, recognizing no one else is implicated along with us. Often our beliefs, meaning, and the spiritual emerge alongside death and dying, even despite efforts to keep them at bay and however dormant they might have laid. It happens to us. The witnesses to medical assistance in dying in this study revealed great depth in their varied experiences at this level. Despite differing vantage points, all participants revealed a level of commitment to their vocation not easily divorced from the profound meaning ascribed to it.

From the clear acknowledgment of something lost to the momentum toward what amounts to a new way of conceiving of the ending of life, MAiD is not as much taking us to a new place as much as it serves to further reflect where we have arrived already. MAiD represents a manifestation of our societal progression, a new order: mechanistic, arranged, utilitarian. Medicine continues to rise on our priority list of importance to the human experience. We want to live well; we know that much. The pervasiveness of anxiety, continuing unabated since W. H. Auden characterized an epoch staggering out of world war, however, may indicate we may still not know what living well looks like. Current constructions of aging enhance the place of MAiD. Significant social change is afoot "when it comes to old age, illness, and death, little remains to us of common meaning or shared social rituals" (Davis, 2018, p. 20). Medical

assistance in dying may at first seem to contradict the impulse toward betterment, improvement, perfection, but rather MAiD falls on the extreme end of this continuum, representing a new level of autonomous decision making. The concern is our having lost touch with our estrangement.

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Appendix

Saint Paul University Research Ethics Board Ethics Certificate

UNIVERSITÉ
SAINT-PAUL
UNIVERSITY

26-02-2020
dd-mm-yyyy
Bureau de la recherche et de la déontologie
Office of Research and Ethics

Comité de la déontologie | Certificat d'éthique
Research Ethics Board | Ethics Certificate

REB File Number 1360.21/18

Last name	Name	Affiliation	Role
Walsh	**Charles**	**Faculty of Human Sciences**	**Student-Principal Investigator**
Guirguis-Younger	Manal	Faculty of Human Sciences	Thesis Supervisor

Type of project Doctoral Thesis

Title Witness to Medically Assisted Dying in Canada.

Approval date	Expiry Date	Decision
26-02-2020 (dd-mm-yyyy)	25-02-2021 (dd-mm-yyyy)	1 (Approved)

Committee comments

The Research Ethics Board (REB) approved the project.
The researcher is invited to use the reference number 1360.21/18 when recruiting participants.

1. In accordance with the [illegible], the Saint Paul University Research Ethics Board (REB) has examined and approved the application for an ethics certificate for this project for the period indicated and subject to the conditions listed above.

2. The research protocol may not be modified without prior written approval from the REB. This includes, among others, the extension of the research, additional recruitment for the inclusion of new participants, changes in location of the fieldwork, any stage where a research permit is required, such as work in schools. Minor administrative changes are allowed.

3. The REB must be notified of all changes or unanticipated circumstances that have a serious impact on the conduct of the research, that relate to the risk to participants and their safety.

4. Modifications to the project, information, consent and recruitment documentation must be submitted to the Office of Research and Ethics for approval by the REB.

5. The investigator must submit a report four weeks prior to the expiry date of the certificate stated above requesting an extension or that the file be closed.

6. Documents relating to publicity, recruitment and consent of participants should bear the file number of the certificate. They must also indicate the coordinates of the investigator should participants have questions related to the research project. In which case, the documents will refer to the Chair of the REB and provide the coordinates of the Office of Research and Ethics.

Louis Perron
Chair
Research Ethics Board

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