



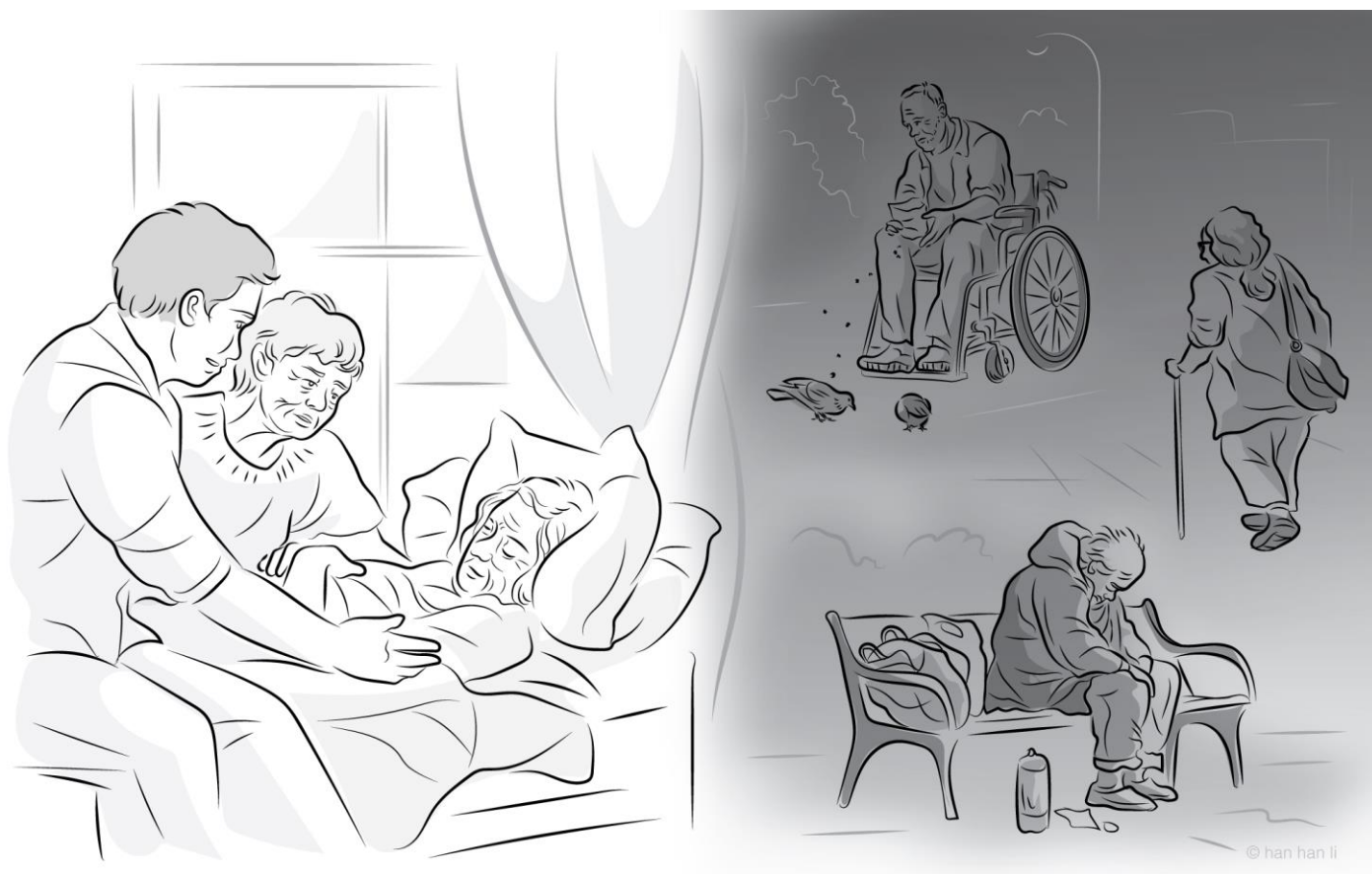
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ÉDITORIAL / EDITORIAL

MAiD in Canada: A Sober Second Look — Introduction and Overview

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Mots-clés

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Keywords

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In June of 2016 Canada's parliament enacted legislation to permit medical assistance in dying (MAiD). The measure has been widely embraced. In less than a decade, Canada has become one of the most prolific providers of medical assistance in dying in the world, with more than 15,000 MAiD deaths reported in 2023. Annually, almost 5% of all deaths in Canada are actively assisted by a physician or nurse practitioner. Quebec is now the most liberal MAiD regime in the world with over 7% of deaths resulting from MAiD (1).

Many view the expanding use of MAiD in Canada as evidence of the realization of a previously unmet need. Advocacy groups call for further expansion. Others are concerned that expansion has already been too rapid, that safeguards are inadequate to protect some vulnerable groups from feeling compelled to choose MAiD, and that further efforts to extend access should be curtailed.

It is this ongoing debate on whether and how to manage Canada's evolving MAiD regime that motivated us at the Centre for Bioethics at Memorial University to convene a symposium on MAiD in the fall of 2024. The title of the symposium was: *MAiD in Canada: A Sober Second Look*. A majority of the papers included in this special issue were presented initially at that symposium. In the spring of 2024, we issued a call for abstracts on any aspects of MAiD. The submitted abstracts went through blind review, and ten papers were accepted for presentation. We made the deliberate decision to keep the symposium small, and to avoid concurrent sessions, thus allowing all attendees to participate in every session.

In addition to ten accepted papers, we were pleased to have four invited keynote speakers, each of whom is an active contributor to the current MAiD debates. We were fortunate to host Isabel Grant (University of British Columbia Allard School of Law), Scott Kim (National Institutes of Health, Department of Bioethics, USA), Trudo Lemmens (University of Toronto Faculty of Law and Dalla Lana School of Public Health), and Wayne Sumner (University of Toronto Department of Philosophy). We thank each of our keynotes for their contributions but want to extend a special word of gratitude to Professor Sumner. When we first issued our call for papers, we'd already confirmed the other three keynotes, and we included information about their participation in that call. Each of those individuals is known to harbour reservations about aspects of Canada's current MAiD regime. Professor Sumner contacted us when he saw the call for papers, noting that our symposium might be viewed as an echo-chambre in which only those who shared negative perceptions of MAiD were given a voice. We took his concerns seriously and extended an invitation for him to join us as a fourth keynote. He graciously accepted. His contributions throughout the symposium did much to enhance the quality of the discussion and debate and his contribution to this issue serves as a counterpoint to several of the other papers.

Despite the at times passionate and animated discussion, a genuine sense of community emerged as interlocutors engaged in respectful dialog throughout the two days of our meeting. We were pleased that many participants commented later that the symposium provided a safe and constructive environment in which to discuss the issues.

This special issue is comprised of eleven papers, only eight of which were presented as part of the symposium at Memorial University. After consultation with the journal editorial team, the papers by Pesut et al. and Pullman were included to help round out this collection. The perspective piece by Trudo Lemmens, one of our invited keynotes, was not part of the symposium, but addresses concerns raised by the recent report from the Ontario 'MAiD Death Review Committee' which functions under the auspices of the Office of the Chief Coroner (2). The 2025 Report focuses on cases of MAiD for persons with dementia.

At the risk of doing a disservice to the careful scholarship evidenced in the papers included here, we have categorized them into four broad themes: 1) empirical explorations of some aspect of MAiD practice (empirical bioethics); 2) ideology, autonomy and the ethical probity of MAiD; 3) MAiD and disability; and 4) MAiD and mental illness. We acknowledge at the outset that

some authors may feel their paper does not fit neatly into one of these categories or that it may have fit better in another category. Nevertheless, for present purposes we have categorized the papers in this manner.

EMPIRICAL EXPLORATIONS OF SOME ASPECT OF MAID PRACTICE

Empirical bioethics is concerned primarily with the descriptive aspects of particular policies and practices and their effects on individuals or groups. It is less concerned initially with the normative implications of these observations, although the latter often figure in the discussion. The papers by Pesut et al (3) and de Bie et al (4) fall broadly into the category of empirical bioethics.

Barbara Pesut and her team have published extensively on various aspects of MAiD practice over the past number of years. In the current paper, they examine the perspectives of persons living with chronic illness who are potential candidates for Track 2 MAiD. One observation, based on this research, is that participants expressed concerns that a lack of adequate health and social care services might influence some to consider Track 2 MAiD.

Lee de Bie et al examine the role and contributions of peer supporters to MAiD in Canada. Peer support, as they describe it, involves people who share a common experience, meeting as equals to share skills, strengths and hope in order to learn from and support each other in coping, thriving and flourishing in their life situations. In this paper, they outline work their group is doing to develop tailored educational resources on MAiD for peer supporters, especially as it pertains to those suffering with mental health conditions.

IDEOLOGY, AUTONOMY AND THE ETHICAL PROBITY OF MAID

While MAiD is now well entrenched as an increasingly common end-of-life practice in Canada, the question of whether, when and how it is practiced continues to be debated. On the one hand some would argue that such ongoing debate should be encouraged. MAiD, after all, involves state sanctioned homicide whereby some individuals (medical professionals) are granted the power and authority to terminate the lives of others, albeit presumably with the latter's consent. This is a weighty matter, and as such, ongoing debate should be encouraged. On the other hand, some argue that there is nothing particularly unique about MAiD and it should be regarded much the same as any other commonly practiced medical procedure. Ongoing debate is thus a distraction at best; at worst, it represents ideologically driven attempts to subvert a legally sanctioned and apparently much needed medical intervention.

Philosopher Wayne Sumner (5) takes the latter view, arguing that concerns raised about MAiD in Canada are misplaced or disingenuous. He is particularly vexed by those who claim they are not opposed to MAiD in principle, but who nevertheless voice concerns about aspects of how the service is delivered, including ongoing efforts to expand it. Sumner systematically dismisses such concerns and suggests the fact he can do this so readily is reason to believe that opposition to MAiD must be ideologically motivated.

Ideology is also the focus of the contribution by physician/bioethicist Scott Kim (6). Kim argues that the rhetoric around MAiD, as practiced in Canada, makes it sound as if this is just another medical procedure. However, he argues, the language employed in these discussions gives novel meanings to common terms used in healthcare thus obfuscating the conversation by giving the impression that Canadian MAiD is about something medical. Instead, Kim argues that Canada's MAiD regime is an "autonomy only" model that demands "death on autonomous demand" As a result, it is ideology masquerading as medicine.

The contribution by bioethicist Timothy Christie (7) tends to support Kim's position. Christie argues that the ostensibly medical eligibility criteria for MAiD (incurability, irreversible decline, intolerable suffering) are not objective medical criteria but instead presuppose and enforce patient autonomy. MAiD assessments are thus reduced to procedural confirmations of autonomy rather than substantive medical assessments. He goes on to outline an ethics framework intended to guide the discretionary judgment of MAiD assessors.

In "MAiD and the Death of Dignity" (8), bioethicist Daryl Pullman attempts to clear up some of the ambiguity surrounding the notion of human dignity. While Dying with Dignity Canada (DWDC) is a vocal and aggressive proponent for expanding MAiD, Pullman argues that the notion of 'dignity' (lower case) which they promote presupposes a narrow and somewhat skewed conception of autonomy that is more akin to an aesthetic judgment than a moral notion per se. Such aesthetic judgments should be constrained, he argues, by the more fundamental moral notion of Human Dignity (upper case) that underwrites such treatises as the *Universal Declaration of Human Rights*. When aesthetic conceptions of dignity are untethered from this more fundamental notion, we risk the death of Dignity itself.

MAID AND DISABILITY

The papers by Janz (9) and Grant (10) each address concerns about MAiD raised by the disability community. Heidi Janz takes on the argument advanced by some bioethicists that MAiD should be considered a form of "harm reduction" for people living in "unjust circumstances" who are facing intolerable suffering. Janz uses a disability ethics framework to dismantle this argument, which she claims trades on the endemic ableism central to much of the medical and bioethical discussion of MAiD in Canada.

Legal scholar Isabel Grant argues that Track 2 MAiD is discriminatory against people with disabilities in general, and particularly so for women with disabilities. In her view, Track 2 MAiD poses heightened risks for those already disadvantaged by structural inequalities. Track 2 MAiD exceptionalizes the suffering associated with disability, Grant argues, treating it as different and inherently worse than other human suffering. Many of the factors motivating Track 2 requests for MAiD are social factors that are not unique to disability but are often exacerbated by it.

MAiD AND MENTAL HEALTH

Although the federal government has now deferred until 2027 the implementation of MAiD for those suffering from mental illness but with no other underlying medical condition, there are ongoing concerns raised about offering MAiD to this vulnerable population. Locky Butcher (11) takes on the notion of 'vulnerability' itself as he seeks to provide some clarity to this central but often poorly defined concept in the context of MAiD. He argues that a clarified notion of vulnerability suggests that current assurances that adequate safeguards are available for those suffering from mental illness are misguided.

Philosopher Kyle Barbour (12) questions whether those suffering from mental illness would have the capacity to provide a properly informed consent to receive MAiD. He argues that a mental disorder has the potential to affect one's values thereby impairing an individual's decision-making capacity. The high potential for invalid consent raises concerns on Barbour's part, about the ethical probity of extending MAiD to those suffering from mental illness in the first place.

Finally, Trudo Lemmens (13) raises concerns about providing MAiD for persons with dementia. He comments that current practice, as revealed in the recent report from the Ontario MAiD Death Review Committee (2), ignores legal restrictions and safeguards, often with impunity. In the context of Canada's aging population there is an urgent need for more stringent oversight of these practices.

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Conflicts of Interest

None to declare

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The editors follow the recommendations and procedures outlined in the COPE [Core Practices](#). Specifically, the editors will work to ensure the highest ethical standards of publication, including: the identification and management of conflicts of interest (for editors and for authors), the fair evaluation of manuscripts, and the publication of manuscripts that meet the journal's standards of excellence.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

A Life Disrupted: Perspectives on Track 2 MAID from Persons Living with Chronic Illness

Barbara Pesut^a, Sally Thorne^a, Caroline Variath^b, Margaret Hall^c, Catharine Schiller^d, Helen Sharp^a, Glendon Wiebe^a, W. David Robertson^e, Michael McKenzie^f, Laurel Plewes^g

Résumé

Contexte : En 2021, le Canada a étendu l'aide médicale à mourir (AMM) aux personnes dont le décès naturel n'est pas raisonnablement prévisible, ce qu'on appelle l'AMM de type 2. L'objectif de cette étude était de mieux comprendre les meilleures pratiques en matière d'AMM de type 2 du point de vue des personnes atteintes d'une maladie ou d'un handicap qui pourraient les rendre admissibles à l'AMM. **Méthodes :** Il s'agissait d'une étude qualitative basée sur des entretiens et utilisant les principes de la description interprétative. Sept participants ont été interrogés à trois reprises sur une période de 3 à 6 semaines. **Résultats :** Les participants ont décrit des trajectoires de maladie longues et complexes qui ont entraîné des souffrances liées à la perte, à la stigmatisation et aux dommages iatrogènes. L'expertise qu'ils ont acquise au fil des années passées à vivre avec leur maladie et les difficultés qu'ils ont rencontrées dans le domaine des soins de santé ont influencé leur point de vue sur les soins d'aide médicale à mourir. Les participants ont souligné l'expertise essentielle dont doivent disposer les évaluateurs de la voie 2 pour fournir des soins compatissants et tenant compte des traumatismes. Les participants ont reconnu la nécessité de disposer de temps pour acquérir une compréhension holistique de l'expérience de chaque demandeur, des souffrances qui en découlent, des tentatives pour soulager ces souffrances et pour se faire une idée du déclin au fil du temps. Les participants étaient troublés par la tension perçue entre l'autonomie et le rôle des déterminants sociaux de la santé dans la détermination de l'admissibilité à l'aide médicale à mourir. **Discussion :** Dans l'ensemble, les participants ont décrit la nécessité d'une approche partenariale pour l'évaluation de l'aide médicale à mourir dans le cadre de la voie 2. Bien que les participants aient considéré l'autonomie individuelle d'autrui comme plus importante que leurs opinions personnelles, ils ont exprimé de graves préoccupations quant à la possibilité que des systèmes de santé et d'aide sociale inadéquats influencent les demandes d'aide médicale à mourir.

Mots-clés

aide médicale à mourir, AMM, euthanasie, recherche qualitative, maladie chronique, handicap, expérience de vie

Abstract

Background: In 2021, Canada extended Medical Assistance in Dying (MAID) to persons whose natural death is not reasonably foreseeable, referred to as Track 2 MAID. The purpose of this study was to develop a better understanding of best practices for Track 2 MAID from the perspectives of those living with an illness, disease, or disability that could potentially make them eligible for MAID. **Methods:** This was a qualitative interview study using the principles of Interpretive Description. Seven participants were interviewed three times over a period of 3-6 weeks. **Findings:** Participants described prolonged and complex illness trajectories that resulted in suffering from loss, stigma, and iatrogenic harm. The expertise they had developed over years of living with their condition and the challenges they had experienced in healthcare informed their perspectives about MAID care. Participants highlighted essential expertise needed for Track 2 assessors to provide compassionate, trauma-informed care. Participants recognized the need for time to achieve a holistic understanding of each applicant's experience, consequent suffering, attempts to relieve that suffering, and to develop a picture of decline over time. Participants were troubled by perceived tension between autonomy and the role of the social determinants of health in determinations of eligibility for MAID. **Discussion:** Overall, participants described the necessity of a partnered approach to Track 2 MAID assessment. Although participants considered the individual autonomy of others as more important than their personal views, they expressed grave concerns about the potential for inadequate health and social care systems to influence requests for MAID.

Keywords

medical assistance in dying, MAID, euthanasia, qualitative research, chronic illness, disability, life experience

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INTRODUCTION

In 2021, Canada joined other countries such as Belgium and the Netherlands in allowing for Medical Assistance in Dying (MAID) in the absence of a reasonably foreseeable natural death (1,2). In Canada, this is referred to as Track 2 MAID. All applicants for MAID must meet the eligibility criteria and be 18 years of age or older; be eligible for publicly funded healthcare services; make a voluntary request; have the capacity to make healthcare decisions; provide informed consent; and be diagnosed with a grievous and irremediable medical condition (1). Grievous and irremediable conditions are defined as serious,

incurable, in an advanced state of irreversible decline, and accompanied by enduring physical and/or psychological suffering that cannot be relieved under conditions that the person deems acceptable (1). Additional safeguards are required for applicants whose natural death is not reasonably foreseeable (Track 2). These safeguards include a minimum 90-day assessment period between the time of the first assessment and the provision of MAID and require that assessors inform, discuss, and be satisfied that the applicant has given serious consideration to reasonable means to relieve their suffering (1).

In 2023, there were 662 Track 2 MAID deaths in Canada, which represented 4.1% of all MAID deaths (3). More women (58.5%) than men (41.5%) received MAID under Track 2 in contrast to a relatively equal distribution of women and men under Track 1 (3). The median age of persons receiving MAID under Track 2 was 75 in comparison to a median age of 78 years under Track 1; however, 11.2% of Track 2 cases were under the age of 55 in contrast to 3.5% of Track 1 deaths (3). In 2023, the most common health conditions among Track 2 MAID recipients were neurological disorders and other conditions such as diabetes, frailty, autoimmune conditions, and chronic pain (3).

There are few Canadian studies exploring Track 2 specifically, but studies to-date identify specific challenges for MAID assessors that differentiate Track 1 from Track 2 MAID care. An online mixed-method survey of 23 providers' experiences with 54 Track 2 applicants found that the most common diagnoses were complex conditions such as chronic pain, chronic fatigue, or myalgic encephalomyelitis and that 68.5% of Track 2 applicants had concurrent mental illness (4). The same study identified common challenges experienced by assessors including understanding the impact of vulnerability on the applicant's decision making about MAID (n=18), determining decisional capacity of the applicant (n=14), and evaluating whether serious consideration to the available means to relieve suffering had been given by the applicant (n=12) (4). A qualitative study by Pesut et al. with Canadian nurses (n=25) and nurse practitioners (n=10) revealed the moral complexities of Track 2. Nurses suggested that these deaths felt different because applicants often appeared well. Nurse practitioner assessors described their experience with applicants who carried stigmatizing diagnostic labels, lacked a primary care provider, and/or reported difficult living situations. Track 2 assessments were described as difficult, complex, and time-intensive (5). A recent qualitative study describes Track 2 applicants' experiences of prolonged suffering that was not always validated through their medical care. Among those studied, requests for MAID provided a measure of personal control over their circumstances and validation from medical professionals that their conditions and consequent suffering were real (6). In light of the paucity of first-person evidence, the purpose of this study was to develop a better understanding of best practices for MAID Track 2 from the perspectives of those living with an illness, disease, or disability that could potentially make them eligible for Track 2 MAID in future.

METHODS

Design and Setting

This was a qualitative interview study using Interpretive Descriptive (7) approaches conducted in the province of British Columbia.

Sample and Recruitment

Participants were recruited purposively through research team networks and from organizations that serve persons living with conditions common to Track 2 (e.g., pain, complex syndromes). Inclusion criteria included living with a serious condition that could at some point make them eligible for MAID under Track 2. There were no relevant exclusion criteria.

Data Collection and Analysis

Participants took part in three semi-structured interviews over a period of 3-6 weeks. Interviews were conducted by HS, BP, and GW. The first interview focused on understanding the participant's illness trajectory; the second on their experiences with, and perceptions of, MAID; and the third on their opinions regarding the eligibility criteria and safeguards. Interviews were conducted individually over Zoom or in person, audio-recorded, transcribed verbatim, and checked for accuracy. The analytic process followed steps of open-coding, developing themes using constant comparative analytic methods, and a narrative account. To ensure integrity of the findings, four team members read the data in its entirety, contributed to code generation, and constructed the themes. All authors provided feedback into the narrative account.

Ethics

The study was approved by the Behavioural Research Ethics Board of the University of British Columbia.

FINDINGS

Seven persons with lived experience of chronic illness, disease, and/or disability took part in the study. Participants' primary conditions included complex syndromes, chronic pain, mental illness, and neurological conditions. Most experienced a degree of disability as a result of those illnesses. Age of participants was gathered categorically and ranged from 25-34 years through 55-64 years. Study findings address participant experiences of living with their condition, experience of healthcare, and their reflections about Track 2 MAID as informed by their lived experiences.

Understanding the Complexity of Living with Serious Chronic Illness, Disease or Disability

All participants conveyed that living with a chronic health condition is inherently complex. Their accounts of the trajectories of illness, the nature of the suffering they had experienced, and strategies of illness management were fundamental to understanding their collective recommendations.

Illness Trajectories

Participants described illness trajectories that often had a triggering incident. For example, two participants could clearly recall the moment when their illnesses began. *"I was in a car accident and that's when all the big stuff started."* *"It was like the Big Bang. So, I got first symptoms on Monday, was in hospital by Thursday, and never really walked properly again."* Some recalled an assumption that their illness would be transitory and a perception that if they just pushed hard enough to keep going, they would return to normal. This view was reinforced in part by healthcare providers. In retrospect, one participant wondered whether "pushing through" had contributed to the development of their condition. *"I just pushed through, kept working, working, working. Sometimes when you have these conditions you blame yourself, like could I have done this differently?"* Another had difficulty getting help and so simply gave up. *"But I, I learned that I wasn't going to get help anyway, so I didn't pursue it. And I was younger and stupider then."* After the initial diagnosis or incident, several participants described a spiraling increase of symptoms and/or conditions (as many as 10 or more diagnoses) that developed over years to decades. Even though these were described as new conditions, participants often perceived them as all linked to one underlying problem. One participant had difficulty listing the many sequelae they had struggled with over the years. *"I'll randomly come up with new diagnoses that I've got that I didn't tell you before, because I don't remember."*

Receiving a diagnostic label was significant, but did not always happen. One participant described the experience of having a physician provide a name for their condition after they had struggled with mysterious symptoms for many years. *"I felt like I'd been punched in the gut because I was shocked. I didn't realize that I even had anything."* Another participant who had yet to have a name for their debilitating symptoms stated, *"It's not something that's recognized by doctors and, generally speaking, they'll just try and give me different pills."* This same participant spoke of the challenges of getting different diagnoses from specialists even with the same symptom profile. *"Some of them are geared to seeing things in a certain way. Like if you are a carpenter and know how to use a hammer you are going to see nails everywhere."*

Although some participants had diagnoses and others did not, what was common were the life-altering symptoms that had persisted for many years with varying degrees of intensity. The unpredictable nature and course of illness posed difficulties. One participant suggested that when they were younger, they thought they would have a limited life span as a result. *"I didn't see myself living beyond 25 years of age."* However, they also discussed how they had learned to live with new life realities. In some cases, participants described their quality of life as higher than what they had anticipated, in part, because they had learned to lay aside expectations. *"If you always internalize the message to keep fighting then there is a sense of failure and shame. But if you take that energy and put it into finding peace and space for life then you find a deeper peace."* Nevertheless, the cumulative effect of multiple illnesses and symptoms, some of which could not be diagnosed, resulted in a unique type of suffering.

The Nature of Suffering

Participants had endured a range of physical and/or mental health symptoms that caused suffering accompanied by psychosocial suffering. Psychosocial suffering was associated with personal and professional losses they experienced, social stigma, and difficult interactions with healthcare and social care systems including disability services and insurance. Participants had experienced profound changes in their life course as a result of their illness including loss of careers, partners, friends, or the ability to have a family. Participants described taking on a new identity as a person with a disability. *"I've had to learn different ways of thinking about myself. I'd never thought of myself as disabled or as having a disability. And that took a hell of a long time to wrap my head around."* Others acknowledged that it was really the social construction of the illness, rather than the illness itself, that contributed to suffering. *"I have a condition that I work with. That's the reality that I have to live with, but, in different times, I could have been seen as a spiritual leader, you know so it's really like the way we're thinking about illness."*

This social construction of illness and disability was associated with stigma. For those with a physical disability, infantilizing was particularly pernicious. One participant described that when their partner was present, others, including healthcare providers, would speak to their partner instead of to them as if they were not capable of engaging in the interaction. Another participant described assumptions that they would be unable to understand instructions: *"I've had a lot of judgment in the past around even being spoken to at the pharmacy when I'm picking up my medication, of like infantilizing."* A participant summarized how it took some time to realize that their social interactions had inherently changed as a result of their disability: *"I started to see the way that people actually speak to you and treat you and realized the privilege that I had enjoyed as an articulate, educated, upper middle-class woman was all undercut by becoming disabled."* Mobility aids were particularly significant. *"My wheelchair goes into any room before I do, people see it and they start to treat you in certain ways."* Mobility aids also contributed positive outcomes. *"The wheelchair is not this big scary thing. It's an amazing invention and a wonderful tool to allow you to save your energy and use it for the things that matter."* Users of mobility aids acknowledged potential benefits of having a "visible" aspect to their condition relative to others who live with "non-visible" health conditions.

For those with a non-visible illness or complex syndrome, stigma manifested within the healthcare system. Participants spoke of the challenges of negotiating illnesses that had little or no diagnostic proof in imaging or laboratory tests. *“Doctors will look at a series of blood tests, and that’s it, they ignore symptoms completely, and if nothing shows up on the bloodwork, they don’t have any other ideas. And they can’t think beyond that.”* Participants who were experiencing multiple symptoms affecting multiple body systems struggled in a healthcare system designed around primary care related to common diseases. *“I remember my physician saying to me, why do you always come here with 62 things? If he would have been informed about this syndrome, it would have made my journey decades shorter.”* Overly narrow areas of specialization required multiple appointments and searches for the provider with appropriate expertise.

It was common for participants to describe experiences with healthcare providers who assumed that they were misrepresenting or exaggerating their symptoms. Participants noted exacerbation of this experience within the disability, insurance, and/or legal systems within which healthcare providers were perceived as antagonistic and oriented to disprove their illness so that they would not qualify for benefits. *“It’s hard for me to distinguish between the professionals that I saw that were related to the insurance stuff and the legal stuff versus the professionals I saw just for me, like trying to get to where I needed to go. It can be extremely dehumanizing not to be believed.”* Worse, some physicians said or insinuated that the condition was purely psychological. *“He told me that I had a deep-seated psychological condition and until we dealt with that I would never improve. But if I dealt with that, I would be out of my wheelchair and life would be back to normal.”* Such iatrogenic suffering left some participants traumatized and reluctant to seek healthcare.

Expertise in Self-Management

Over the years, participants had become experts on their own care, and most had developed a carefully curated network of supportive healthcare providers, while some continued to search for healthcare providers they could trust. *“For the first time I had a nurse practitioner helping me and they got all this stuff rolling and diagnosed.”* Self-education, self-management, and self-advocacy were important to navigating their conditions. *“Do your research, get your education, have your knowledge, and then from that place, decide how you want to move forward on your own journey.”* Participants described the importance of healthcare providers who listened and facilitated access to the information they needed to make good choices. *“So, if you find something that works, fight like hell to keep it...if the medical appointments are causing you stress, they are making it worse. Don’t go. If your doctor is an [expletive], find a new doctor. Don’t waste your time.”* Ultimately, surrounding themselves with trusted, supportive healthcare professionals was integral to how they experienced their illness.

Participants described learning to present themselves in clinical contexts in ways to optimize the chance of building a positive relationship with healthcare providers so that they could get help. For example, a participant spoke of how they had learned to be a “good” patient. *“I was always trying to be the best patient, to present myself as together and believable because I had heard about how people talked about patients with my condition.”* Participants described the risks of being labelled by healthcare providers. Several participants were aware they had been labelled “a drug seeker” or as “exhibiting pain behaviours.” One participant found this label had been entered into the medical record after they sought treatment at a second, nearby emergency department when their pain was not resolved. Some participants perceived gender-biases in their care. A male participant spoke of the tension between his public and private faces. *“For the most part I have learned to put on a normal and untroubled face. But beneath that face I was really, really severely, not doing good, struggling quite a lot. But when I went to seek assistance, people would see that I was a normal dude who doesn’t appear to be struggling.”* Another participant described the challenges they experienced when they were misgendered in clinical settings and how that led to expectations about their behaviour. *“I think that comes into the [clinical] rooms a lot, like you shouldn’t be behaving like that just because you’re this gender or you’re that gender.”*

In summary, the health conditions described by these participants were often complex with multiple impacts on their life. Not only had they reconciled losses of identity, but they also endured public stigma and experienced biases within healthcare and social systems.

Implications of Lived Experience on Interpretations of MAID Track 2 Practice

Participants’ experiences over the course of their illness trajectory informed their thoughts about MAID Track 2 policy and practices. This included recommendations for the knowledge and skills needed by MAID assessors, ways to negotiate assessment of suffering, irremediability, and decline, and how MAID care could consider vulnerability and influences of social determinants of health.

Conducting Assessments

Participants’ familiarity with negotiating healthcare encounters informed their advice to healthcare providers engaged in MAID care. Participants hoped that an assessor would listen and take time to hear and accept their story. For example, a participant recommended an approach such as, *“What would you like me to know? Let them present first what they feel is important and there also has to be a little bit of patience or time with that.”* Another participant stated, *“I really hope that it’s a kind process. I hope that it is respectful, that it happens on the patient’s timeline in the context that they’re happy.”* Participants emphasized they would not want the assessment to feel like an interrogation. *“Historically in these medical environments they are more clinical and you have to hold back and not cry.”* Participants suggested that the assessor’s approach could influence whether applicants might consider alternatives to MAID. *“If the person is in a comfortable setting and feeling safe and secure, they might be open to listening to suggestions that the assessor might make. You know, it might be a last opportunity to get them*

actual help instead of just helping them end it.” In this way, participants saw the assessment as exploratory rather than a determinative process. *“It doesn’t mean just because you’re engaging in that assessment that you’re gonna go through with it. It just means you’re exploring it as an option — and it should be available to you to explore.”*

Participants wanted assessors to have a high degree of expertise in an applicant’s health condition. *“They should know their resources and if they don’t know, they should know where to go.”* Participants emphasized that this was particularly important for mental illness, citing frequent lack of knowledge or misinformation. *“I think physicians need much more training on just the basics of mental health and mental illnesses.”* A number of participants envisioned an interdisciplinary approach to Track 2 MAID assessments. *“I think just having a really robust network of people who come from different backgrounds can come together and do like those case reviews as a team and go, okay, we have all these different perspectives and we’re really covering this person’s world in a holistic sense.”*

Although participants suggested it would be a mark of respect for the assessor to have reviewed their medical records, they also recognized the risk of potential bias introduced through medical documentation. *“I think, for somebody to say they’ve read my history, that would certainly impress me, but I’d also be very worried about what the hell was in there. It’s like, you know, saying that you read War and Peace to prepare for a meeting, it’s a bit much.”* Participants acknowledged that medical records might yield an incomplete picture. For example, one participant stated that *“You know, my specialist sees me for 30 minutes once a year and writes these reports that have all kinds of bearing over the rest of my life, right?”* The potential for bias in the record was also a concern, and participants described a preference to engage in discussion with the assessor and to have the opportunity to contextualize what was in those records.

Finally, participants worried that the type of person conducting the assessment might be similar to providers they had frequently encountered in healthcare. *“There’s four types of doctors; ones that listen to you, ones that don’t, ones that are good at their job, and ones that aren’t.”* One participant had taken proactive steps to understand more about the providers who participate in MAID in their geographic area in case they did decide to apply for MAID in the future. Others raised questions about the training MAID assessors and providers undergo and the ethical requirements of decision-making.

Considering Social Determinants of Health

Participants spoke to the financial and social pressures of living with chronic illness and discussed whether and how assessors should give these factors consideration in MAID eligibility determinations. For those unable to work full time, finances were a constant and pressing concern. *“The fear of poverty that we face, not to mention the costs of being disabled are pretty fricking high. We can understand how that leads people into situations where they can’t get the care that they need.”* Another participant expressed concern that the public was unaware of the gaps in support in the system: *“The vast majority of the public believe that somehow disabled people are just taken care of — right? That they have somewhere to live and food to eat.”* Living with an illness or disability also took a toll on family members. For some participants, spouses and partners were supportive, but for others, it had led to a breakdown in their relationships, leaving them to face their illness alone. *“Many of the caregivers leave, because they just can’t handle it.”*

Participants indicated clear understanding that financial and social stability is a privilege that yields a measure of freedom that is simply not available to those who are alone and poor. However, participants were internally conflicted about whether or how individual circumstances such as poverty or social isolation should factor into MAID eligibility. One participant suggested that MAID could be an important fallback plan if their own living situation changed. *“Let’s say my [spouse] wasn’t here, let’s say my economic situation changed. And let’s say I couldn’t look after myself. Then I may consider it [MAID]. Right?”* Another participant suggested that we cannot hold an individual hostage to societal conditions that simply cannot be fixed. *“The really hard conversation to have is about what it means to live in poverty and whether poverty is curable...Are we going to fix the political systems of oppression right now? No, we’re not.”* Another had a similar reflection on barriers to MAID access on the basis of systemic social problems.

If all these things [poverty and isolation] are influencing the decision, then the problem is not that the person can’t live, the problem is that these things need to change. But unless the assessor has the ability to change those things then it doesn’t change that person’s circumstances. You are still leaving that person in suffering.

In summary, while recognizing the potential for poverty or lack of social supports to influence an applicant’s desire to keep living, participants expressed concern that if these factors were used to find someone ineligible, that would further marginalize them.

Negotiating the Irremediability of Suffering

Participants acknowledged the multi-faceted and subjective nature of suffering and the complexities of access and cost of interventions to relieve suffering as challenges for MAID assessors. These reflected their own experiences of seeking remedies for suffering, many of which had been traumatizing. One participant said: *“There’s so many different aspects to suffering: loneliness, not being able to participate in life, and the quality of life that you would like, trying everything and being exhausted. Having to subject yourself to things that don’t work, it all just accumulates.”* Participants explored the idea that intolerability could mean quite different things to different people. *“You’ll never get away from the fact that people have had different experiences in life. For example, someone who’s come from a background of being sexually trafficked is gonna have a different window of tolerance than someone who grew up without that kind of experience.”*

A concern among participants was having to negotiate with the assessor about whether their attempts to relieve suffering would meet the standard for eligibility. They worried that this could result in the same skepticism and disbelief they had experienced among healthcare providers. “Now I have to prove something again.” One participant suggested that if they were required to seek new remedies to relieve suffering, it could reopen the challenges to access they had already experienced. They emphasized the importance of having someone work alongside them to get additional help.

How are you supposed to figure it out how to navigate these things? There's 15 different places where you might potentially be able to get support, and all of them have different rules, and all of them have different criteria, and all of them have a different application process, and how the hell is one person supposed to figure it out?

After having worked so hard to establish trust with a supportive healthcare team, participants worried about the implications of being referred by a MAID assessor to an unknown person for additional treatment. Participants expressed the need for continued autonomy with such referrals. “If you agree to meet with another counsellor or psychiatrist then you have to have the capacity to withdraw if it's not a good fit.”

In reflecting upon how they would evaluate their own suffering, one participant drew a distinction between the perspective they had gained as they managed their symptoms and health over many years. “So an uneducated me, I would not know any better, and I would just be suffering 24/7 and constantly worrying about my symptoms, and constantly focusing on like, oh my God! I've got these issues! Have I got stomach cancer like, oh, my God! oh, my God! I have vertigo now.” In contrast, their now “educated self” would do the hard work of seeking approaches to alleviating suffering, while also acknowledging that there could be a threshold at which the suffering just becomes too much.

Finally, participants spoke to the financial barriers to relieving their suffering that went beyond the cost of being disabled. A number of the services that participants identified as helpful, such as specialized clinical counselling, were not covered or had limited coverage through provincial or supplemental healthcare benefits, leaving them without support if they were unable to pay out of pocket. Some treatments were prohibitively expensive. “Because when I get the [treatment], it's 300 bucks. It's not covered by MSP [Medical Services Plan].” Participants discussed their awareness of interventions that could relieve symptoms or suffering that they were simply not able to access because of financial or geographical constraints. “I think part of the challenge in a lot of these cases is the question of, is there anything that can be done? And the answer is — not within the current system.”

Understanding Decline

Participants acknowledged the difficulties assessors could have in determining whether they were in a state of irreversible decline, particularly for conditions or symptoms that fluctuate over time. They reflected on the impacts of the ups and downs of their condition. One participant described having a severe and prolonged period of disability for the first time and not knowing whether they would ever recover their capabilities. The experience of recovery provided hope for future episodes. “I learned a new term that was awesome ‘dynamic disability.’ It's the way that they're now describing disabilities that have flare ups.” Although this participant took comfort in having a term to describe their experience, these fluctuations took a toll psychologically. Participants described strategies to cope with uncertainty including fighting, giving up, reframing, and acceptance.

I remember having a conversation with my psychologist about I'm going to keep fighting, I'm going to track down every diagnosis, every issue, to try and pinpoint all of these problems and I'm not going to stop until I have answers. That was the approach I had then. Now years later and I don't know how many specialists later, I'm done. I am barely hanging on.

Another participant spoke of how they no longer use the term “recovery.”

Recovery is not a term that I use because two things kind of come to mind: one, the idea that I have an illness versus this is who I am, and you've labelled this term of illness upon me. So there's nothing I'm recovering from, really, I'm simply learning a new way to work with myself and to work around the barriers that society has put in front of me because disability is a social construct, right?

The cumulative effects of negotiating the healthcare system, social stigma and social constructs of disability, the uncertainties of illness, and rigorous self-management took a toll on participants. Some could envision future circumstances that could lead to seeking MAID, while others could not. Practically, this meant that the person with the lived experience of illness and disability would be the most appropriate to determine when their own decline in capability had reached the point where death through MAID was preferable to living. “A condition is terminal when the person who's suffering believes that they don't want to go on trying.” If MAID was not an option at this point, participants speculated that the only other option might be suicide. One participant recognized the inherent challenge this presented for MAID assessors. “How do we ensure that the person is in a state that can't be improved, or even thinking about how they are living with their condition...But the other half is worry about how long someone has to keep going before they choose suicide.”

In summary, participants expressed a desire for assessors who listen, are compassionate, knowledgeable, and open to a negotiated interpretation of their medical history and records. Participants acknowledged the inherent challenges of evaluating the impact of social determinants of health, negotiating the irremediability of suffering, and understanding irreversible decline when a person's natural death is not reasonably foreseeable.

Implications of Lived Experience on Interpretations of MAID Track 2 Policy

Participants provided important insights into aspects of Track 2 MAID that have policy implications. They offered recommendations for the 90-day assessment period, delineated the advantages of MAID as preferable to suicide, and spoke of the tensions between autonomy and vulnerabilities that exist within imperfect health and social care systems.

The 90-Day Assessment Period

Not all participants understood the purpose of the 90-day assessment period and there were concerns that this time requirement might be too long. *"It's important that the person not be abandoned during that stage because if their level of suffering is quite great then 90 days may be too long."* Another participant suggested that 90 days is nonsensical if *"people have been thinking about it for 10 years. What's 90 days going to do?"* Participants had recommendations about how to explain and manage the required assessment period. *"It should be framed in a way of curiosity — of I just need to do my due diligence. I don't mean to prolong your suffering but at the same time I want to make sure that I'm treating you in the best way that I can, and that means getting to know you and every part of your life."* Another participant suggested that this approach could have a therapeutic benefit for the person undergoing the assessment. *"There is hope, there is something that I can do. There is a doctor that I found that will actually listen to me, not gaslight me."*

The 90-day assessment minimum was also viewed as a time to improve the applicant's quality of life through interventions that might not have been tried or were perceived as higher risk.

Let's see what we can do. You've got 3 months. Live it. How do we make sure that you can be as happy and pain free as possible...It should be about making those 90 days as wonderful as they possibly can be and if that means permanent morphine, or whatever the good drugs are, then do it, because who cares? They're gonna die at the end, anyway.

Participants described perceived benefits of an interdisciplinary approach that could reduce suffering and encompass a holistic quality of life approach, inclusive of psychosocial and spiritual aspects of care alongside symptom management. While participants did not use the term "palliative care," what they described was consistent with a palliative care approach. From a policy standpoint, in many regions Track 2 applicants do not qualify for specialized palliative care. The participants in this study formed a cohesive argument for the applicability of palliative care services for Track 2 MAID applicants, both during the 90-day assessment period and after a finding of eligibility.

MAID versus Suicide

Participants all described clear and distinct differences between MAID and suicide and were in agreement that MAID would typically be preferable to suicide. They compared the trauma, secrecy, and isolation characteristic of suicide to a MAID process as a more open, thoughtful, and measured set of steps. Another participant spoke of the importance of the conversations that are necessary for a MAID application. *"MAID requires more thought and an open discussion. Having known several people who were suicidal, they don't discuss it. Whereas if you are going for MAID, you discuss it and that's positive."* Participants identified benefits of MAID for other people, particularly family and close friends. *"MAID means that I could be open and honest with my family about where I am at. They might still have trauma but it wouldn't be the same."* A participant spoke of the communal nature of a MAID death as compared to the isolation of a suicide death. *"Somebody can have a celebration of life while they're still alive and the family can be there and they can have food, memories, laugh and cry...that's a less isolated and lonely avenue to take."*

Participants spoke of the trauma of being reported and held against one's will if someone suspects you are suicidal. *"We are in this cycle of traumatizing people for simply struggling with a problem that we don't know how to treat well."* MAID was viewed as a possible way to break that cycle. *"If I tell people I have applied for MAID they can't really do anything about it. They can't report it because they have already reported themselves. It takes the onus off those around them and it doesn't leave people feeling bad for not having done something."* A participant suggested that we still know so little about chronic suicidal ideation. *"We don't have a good way to treat passive chronic suicidal ideation. It is an ailment all on its own that deserves time to research and study with support."* The same participant also suggested that, despite the fact that we do not know how to treat chronic suicidality, the ability to determine one's fate remains a fundamental human right.

Autonomy in an Imperfect System

Participants emphasized the importance of the availability of MAID to controlling their own life course. *"We are in our own choose your adventure book you know....and if someone is in pain or suffering and there's not enough known about how to help them, then let them go with dignity and on their own terms."* But participants also expressed significant concerns about MAID in the context of barriers to access and socioeconomic concerns. The most prevalent examples were inadequacies of care systems and the social safety net and whether these systems issues might influence people to apply for MAID. *"If I could say with confidence that our medical system was such that every option had been exhausted, I would be a lot more on board"*

with saying that MAID is a great idea.” “The social safety net...doesn’t exist or it’s grossly insufficient.” A participant who had experience working with disability communities suggested that, while in the beginning they had been comfortable with Track 2 MAID, they had become increasingly uncomfortable as they observed a shift in frequency of people with disabilities who described MAID as a fall-back plan if their life circumstances changed.

Participants often cited high profile media stories to illustrate the reasons for their concerns. Although the veracity of these media reports cannot be substantiated, they nevertheless affected participants’ perspectives about Track 2 MAID. They worried that healthcare providers might suggest MAID for persons with disabilities, even if only implied. “The very worst fear that disabled people have is that their healthcare provider will suggest MAID.... think a disabled life isn’t worth living. And if I say no to them, what kind of healthcare will I get going forward?” Even as participants struggled with the idea that some might choose MAID because of inadequate health and social care systems, they acknowledged that even perfect systems would not negate the need for MAID “Is it realistic to fix the healthcare system to the extent that someone wouldn’t want the option to have MAID? Even if it was amazing and perfect, which it will never be, it will still be an option for some people.”

DISCUSSION

Seven participants living with complex health conditions engaged in longitudinal interviews with the goal of informing best practices and policies in MAID Track 2 care. Participants described their experience with complex conditions and the impact of their condition on their lives. In addition to reconciling multiple losses related to their health conditions, participants had experienced substantial challenges in negotiating medical and disability systems together with social stigma in both public and healthcare settings. Participants’ descriptions were consistent with previous studies of those living with chronic pain and fatigue that reveal iatrogenic harm and inadequate treatment connected with disbelief on the part of healthcare providers (8,9). Participants identified important contributors to the quality of their healthcare, including development of expertise in self-management, identifying healthcare providers who listen and offer meaningful support, and developing a measure of acceptance of a reshaped identity and life course, all of which took time and considerable effort to achieve.

Limitations of the sample are that all participants identified as white and had at least some post-secondary education (43%) or a graduate degree (57%). As such, this group was well-educated and homogenous. The small sample size, lack of ethnic diversity, educational attainments, and the fact that the majority of participants were not considering MAID at the time of their participation, should be considered when evaluating generalizability. The longitudinal and in-depth data collection, diversity of illness and disability experiences, and richness of the participants’ reflections contribute to the quality of the findings.

Although the small and homogenous sample size precludes definitive policy or practice recommendations, it is important to interpret and understand the perspectives of people living with complex health conditions to inform healthcare providers engaged in Track 2 MAID assessments. These findings can also be interpreted in relation to the Model Practice Standards (MMPS) for Medical Assistance in Dying in Canada (10) and to current literature debates about voluntariness in requests for Track 2 MAID (11-13). The MMPS were developed by a task group convened by Health Canada in 2022 after the legislation change that defined Track 2 MAID (Bill C-7). Since the goal of MMPS is to support a consistent approach to MAID across Canada, they provide a context against which to evaluate the reflections of the participants in this study. One of the most heated debates in Canadian society around MAID after Bill C-7 is how to guard against vulnerabilities that could impact decision-making and reduce the voluntariness of requests for MAID. We will leverage the insights from this study in future studies to inform that debate. The following section addresses key insights arising from the interview data.

Serious Consideration of the Reasonable and Available Means to Relieve the Person’s Suffering

Participants’ reflections about how suffering should be assessed provide important insights for physicians and nurse practitioners who conduct MAID assessments. Namely, the need to approach a MAID assessment in a kind and compassionate manner and in a safe environment. Participants indicated a desire for assessors to adopt a spirit of curiosity and to work in partnership with each applicant. Several participants recommended an interdisciplinary collaborative approach, recognizing that this might be the last opportunity to identify and access treatments that could relieve an applicant’s suffering, either to obviate the need for MAID or to achieve comfort in the period leading to MAID. They also described the need for assessors to acknowledge previous difficulties in healthcare encounters, describing an approach consistent with trauma-informed care. This finding supports guidelines developed by the Canadian Association of MAID Assessors and Providers (14), that recognize the potential for applicants with chronic conditions to have been marginalized by the healthcare system.

Participants’ descriptions of multifaceted sources of suffering and recommendations related to the assessment of suffering also aligned with the guidance of the MMPS.

[Assessors] must ensure that the person has been informed of the means available to relieve their suffering, including, where appropriate, counselling services, mental health and disability support services, community services, and palliative care and has been offered consultation with relevant professionals who provide those services or that care. Community services must be interpreted as housing and income supports. Means available must be interpreted as available means that are reasonable and recognized. Serious consideration must be understood to mean: a) exercising capacity, not merely having it; b) exhibiting careful thought; and c) not being impulsive (10, p.17).

Must be of the opinion that it is the person's illness, disease, disability, or state of decline in capability that is the cause of the person's suffering (10, p.12).

Participants described the impacts of the trajectory of their experience of suffering over time. In coming to terms with new identities, participants described both positive and negative impacts of their illness trajectory on their quality of life. They uniformly described experiences of stigma and struggle associated with social constructs of illness and disability and experiences of suffering associated with system-level harms. The participants had become experts in their own care and described rigorous approaches to seeking help with their condition, typically over many years. As such, these participants were emblematic of having met the "serious consideration" clause in the MMPS.

Our findings highlight the difficulty for MAID assessors to differentiate distal from proximal causes of suffering described in the MMPS. For example, participants could imagine circumstances, such as changes to their support systems or financial status, that would have substantive negative impacts on their quality of life to a degree that they might no longer want to live. In this case, an assessor might conclude that an applicant's life circumstances were the most proximal cause of their suffering, rather than their illness. Nevertheless, participants suggested that these situations should not be disqualifiers for receiving MAID. Rather, they felt that it would be important for the assessor to understand the full trajectory of an individual's experience of illness, disease or disability and ways in which the compounding effects of life circumstances could compromise an individual's overall quality of life and experience of suffering.

Participants highlighted two important factors that frequently limit access to services and supports to relieve suffering. First, psychological and counselling services are not available to a large portion of the population because they are not covered by provincial health systems and many individuals with chronic health conditions lack supplemental benefits that might cover adequate access to such services. Out of pocket costs for non-covered services are often prohibitive. Second, persons may have disability benefits or financial support for specific services, but these may be insufficient to live on absent other sources of household income or social supports. In these cases, while reasonable means to relieve suffering may technically be available, they are not accessible or adequate. This leaves assessors in a difficult position of offering recommendations to relieve suffering, knowing that while the means may be reasonable and recognized, they are not accessible or adequate.

Advanced State of Irreversible Decline in Capability

The MMPS outlines three factors that need to be reconciled when assessing decline in capability: the severity of loss, its irreversibility, and its meaningfulness to the person.

Capability refers to a person's functioning (physical, social, occupational, or other important areas), not the symptoms of their condition. Function refers to the ability to undertake those activities that are meaningful to the person. Advanced state of decline means the reduction in function is severe. Irreversible means there are no reasonable interventions remaining where reasonable is determined by the clinician and person together exploring the recognized, available and potentially effective interventions in light of the person's overall state of health, beliefs, values, and goals of care (10, p.11-12).

A study of MAID assessors conducted prior to Bill C-7 described two contrasting approaches to assessing decline in capability. One approach is to evaluate the level of decline against the applicant's baseline. The other is for the assessor to evaluate the stage of the illness, disease, or disability (15). Participants in this study suggested that the focus on patient experience of decline should be central to the assessment. They described experiences of variability in severity of symptoms over time, and recognized that during a flare-up or period of worsening symptoms, it would be difficult to predict irremediability or impact on quality of life. Participants described the work, vigilance, and resources required to manage functional daily living and could hypothesize about circumstances that would be too much to manage. As one participant suggested, a person becomes terminal when they give up. As such, participants reflected the idea that capability is better assessed in reference to their own trajectories rather than to some objective or external standard. If an applicant no longer had the will to live, then death might be perceived as their only option and in that circumstance, MAID would be a preferable alternative to suicide.

Voluntary Request

The MMPS criteria for the assessment of voluntariness of a request for MAID limits consideration of coercive influences to that ascribed to other people.

Assessors and Providers must be satisfied that the person's decision to request MAID has been made freely, without undue influence (contemporaneous or past) from family members, healthcare providers, or others.
(10, p.12)

However, the participants described other specific vulnerabilities for people living with complex and/or chronic health conditions that could unduly influence people to seek MAID. Participants identified potential for social stigma, elevated risks for poverty, iatrogenic harm, and barriers to appropriate healthcare, psychological care, and/or social supports as contributing to an individual's decision to pursue MAID. They concurrently expressed concern that such factors might be used to unfairly strip applicants of their autonomy. These data provide support for the ongoing need for meaningful debate and discussion about whether and how factors such as barriers to care, poverty, stability of housing, and other social factors should be considered by MAID assessors in eligibility determinations.

Two recent articles take different perspectives on this question. Wiebe and Mullin (11) conclude that to refuse MAID to those living in oppressive conditions, except under conditions where it is clear that they have lost important internal autonomous capacities (e.g., self-trust, hope), is to further undermine applicants' autonomy, creating additional oppression. In contrast, Christie and Li (12) argue that autonomy alone is insufficient grounds for clinical judgments which must also consider issues of non-maleficence, beneficence, and justice. Similar to the MMPS, they would argue that the more distal the reason for intolerable suffering is from the primary illness experience, the more MAID should be questioned.

Lazin and Chandler (13) distill the debate down to two fundamental questions: Do we have a duty to protect vulnerable people from seeking certain procedures or do we have a duty to uphold their autonomy? Drawing upon a thorough review of the court cases and parliamentary debates leading up to the legalization of MAID, they distinguish between individual and collective vulnerability. It is not a person's identification with a particular group (a so-called vulnerable population) that renders them vulnerable to making a decision about MAID without a "rational and considered desire for death" (Carter, para 114); rather, each individual may be more or less vulnerable depending upon their individual capacities, characteristics, and circumstances. Lazin and Chandler suggest that the additional safeguards implemented for Track 2 MAID were designed to ensure that MAID does not become a default option for people with complex health conditions who experience poverty, homelessness, or other vulnerabilities, although they conclude that there will remain contention about whether these safeguards are sufficient.

Participants in this study expressed grave concerns about the potential for gaps in the accessibility of healthcare and the social safety net to compel people to apply for Track 2 MAID when they otherwise would not. Even though some expressed that they were grateful for the availability of MAID, should they seek it in future, they worried about how MAID might be used by others who felt they had few options to remediate their condition. They also worried that other people, particularly healthcare professionals, might suggest MAID for people living with complex, chronic conditions and disabilities and imply that their lives were not worth living. Despite some pessimism about whether oppressive systems could be changed or health and social care systems improved, participants expressed that it would be wrong to deny those who request MAID as a means to a peaceful and dignified death, on the basis of systems they cannot control. Participants' voiced support for autonomy and the right to choose balanced with a desire to ensure that applicants were not unduly influenced by external factors, which they interpreted to include both social and economic pressures. In essence, this articulate group of participants reflected the same tensions inherent in the public debate of trying to reconcile ideas of autonomy and vulnerability within a framework of justice.

CONCLUSION

The voices of those with lived experience are essential to informing policy and practice of MAID in Canada, particularly as it relates to Track 2 MAID in which natural death is not reasonably foreseeable. Participants explored the gravitas of a decision to seek MAID. Their perspectives highlight the essential role of applicants as partners in the Track 2 MAID assessment process and not merely as recipients of legislated approaches. Compassionate, trauma-informed, and expert assessors who take the time to understand the individual's experience of illness or disability, consequent suffering, attempts to alleviate that suffering, and the decline in capability in a holistic sense are central to ensuring the quality of Track 2 MAID care. Participants envisioned a comprehensive approach to the 90-day assessment period in which an interdisciplinary team would work alongside applicants to determine if anything further could be done to alleviate suffering, including trials of higher risk interventions, where indicated and of interest to the applicant. Participants also described interest in inclusion of psychosocial and spiritual supports that align with the philosophy of palliative and hospice care. Even with the best of treatment, some participants could imagine that there might come a time when the work of chronic illness management or the impact of substantive life changes could simply become too much and in such circumstances, such that MAID was viewed as a dignified alternative when compared with suicide. Participants reminded us of the importance of continuing to grapple with the challenges of balancing autonomy, vulnerability and justice for those seeking Track 2 MAID within imperfect systems.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

What's So Special About Medically Assisted Dying?

Wayne Sumner^a

Résumé

Les détracteurs du régime canadien actuel d'aide médicale à mourir (AMM) avancent généralement deux types d'arguments : 1) le nombre annuel de dispositions montre que le régime est hors de contrôle ou sur une pente glissante, et 2) il met les personnes handicapées en danger. Ces deux arguments commettent la même erreur fondamentale : ils traitent l'AMM comme une forme de traitement médical différente des autres, y compris les traitements de fin de vie.

Mots-clés

Canada, aide médicale à mourir, AMM, handicap

Abstract

Critics of Canada's current medical assistance in dying (MAiD) regime commonly employ two types of argument: 1) that the number of annual provisions shows that it is out of control or on a slippery slope, and 2) that it puts persons with disabilities at risk. Both arguments commit the same fundamental mistake: treating MAiD as different in kind from other forms of medical treatment, including end-of-life treatment.

Keywords

Canada, medical assistance in dying, MAiD, disability

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INTRODUCTION

Medical assistance in dying (MAiD) is now in its ninth year as a legal option in Canada. During its short life, it has gone through two stages: MAiD 1.0, as defined by Bill C-14, passed in June 2016, and then MAiD 2.0, as amended by Bill C-7, passed in March 2021. Since it is unlikely that further changes will happen anytime soon, it seems appropriate to take stock of how far we have come, and where we might go next.

MAiD 3.0 could incorporate any of three additional amendments: 1) extending eligibility to patients who present solely with a mental disorder, 2) extending eligibility to mature minors, and 3) allowing advance requests for patients with degenerative disorders like Alzheimer's disease who fear losing capacity before reaching the point at which they would wish to request MAiD. All three of these measures were recommended first by the 2015 Provincial-Territorial Expert Advisory Group and then repeatedly thereafter by the Special Joint Parliamentary Committee assigned to this file (1-3). For the record, I support all three. However, they are all contentious and I'm not going to discuss any of them.

Instead, I want to examine a view that has been advanced by some commentators: not merely that MAiD in Canada should not go farther, but that it has already gone too far. The critics of this persuasion are wont to say such things as: the current regime is much too permissive, we are currently sliding down a slippery slope, or MAiD in Canada is out of control (4-8). I'm interested in why they think this way.

As a preliminary, I'm going to draw a very simple distinction between two different kinds of objection to MAiD, which I will call principled v pragmatic. *Principled objections* usually take the form of contending that MAiD is just inherently wrong, or at least ethically problematic, by virtue of intentionally causing death or violating the sanctity of life (9-12). The Catholic Church provides an extreme version of this sort of opposition. *Pragmatic objections*, on the other hand, raise no ethical issue with MAiD itself, but are critical of the legal regime established to administer it: its eligibility criteria are too broadly drawn, or its procedures are too lax, or its safeguards are insufficiently stringent. It is objections of this latter sort with which I am here concerned. For the sake of the argument, I will assume that those who have voiced pragmatic objections to the current MAiD regime in Canada have no principled issue with the procedure itself¹, though I will later have reason to revisit this assumption.

Critics of Canada's current MAiD regime have raised a wide variety of objections. I am particularly interested in two lines of argument which, whatever their differences, share a common assumption, i.e., that among medical services in general, and end-of-life medical services in particular, there is something special about MAiD. I want to ask what that is.

The first line of argument starts with numbers — more particularly, the number of MAiD provisions in Canada. So let's take a look at the numbers that have so exercised the critics. In 2022, there were 13,241 MAiD provisions across the country, constituting 4.1% of all deaths in that year (14). According to the critics, both that total and that percentage were too high (6). The 2022 total was 31.2% higher than the previous year, in line with a 31% average annual growth rate for MAiD provisions in the three-year period from 2019 (14). According to these critics, that growth rate was also too high (6).

¹ Some critics, such as Daryl Pullman, say so explicitly: "While not in principle opposed to MAiD in all circumstances, I am nevertheless concerned about the rapid expansion of Canada's MAiD regime and the persistent pressure to extend it further" (13).

When these numbers are claimed to be too high, the obvious question is: too high relative to what? As far as I am aware, there is no Platonic ideal for the correct number of annual MAiD provisions for a given population size. MAiD is not like, say, immigration, where the government can set an annual intake target and then work toward hitting it. Instead, the annual number of MAiD provisions will be determined by the intersection of demand (the number of patients qualifying for the service and requesting it) and supply (the number of practitioners providing it). Since these are the factors driving the annual numbers in Canada, we should expect those numbers to continue to rise. The current legal regime for delivering MAiD is enormously popular among Canadians. In a 2023 Ipsos poll, 84% of respondents said that they supported the Supreme Court's 2015 decision in *Carter v. Canada* and 78% supported the Bill C-7 removal of the "reasonably foreseeable natural death" requirement (16). When a sample of Canadians was asked whether they would request MAiD if they were facing a long and painful death, just under 50% indicated that they either probably would or definitely would (17). That's a lot of potential demand, which we should expect to increase as the population ages. (The cohort of Canadians 65 years of age and older grows by about 3.5% annually.) In fact, the demand is already increasing: the annual growth rate in MAiD provisions is driven almost entirely by the annual growth rate in MAiD requests (14). On the supply side, the number of MAiD providers has also grown, with an average annual increase of 18% since 2019.

How high might the numbers go? One very speculative calculation projected that MAiD deaths might top out eventually at just over 10% of all annual deaths in Canada (17). While that projection cannot be dismissed out of hand, it does seem a little on the high side. In 2023, the annual growth rate declined by half to 15.8%, suggesting that the curve may be starting to flatten. In that year, MAiD provisions accounted for 4.7% of all deaths (15).

One way to demonstrate that the numbers are already too high would be to compare them with jurisdictions abroad that have their own assisted dying regimes. Currently, the comparator of choice for critics is California (6). On the surface at least, the comparison is apt: two jurisdictions with roughly equal populations, similar access to high-quality health care, and no substantial differences in the leading causes of death or overall death rates. And the disparity in the numbers is undeniably stark: in 2022 the 853 assisted deaths in California constituted just 0.27% of all deaths. We might therefore conclude, with the critics, that the Canadian numbers are too high. Or we might conclude that the California numbers are too low. At least at this point, both conclusions are equally in play.

So what explains the disparity? One obvious possibility is the different eligibility criteria in the two regimes: at least since the passage of C-7, Canada's criteria are more expansive than California's. In California, as in all US states that have legalized assisted dying, a diagnosis of a terminal condition is required, with death expected within six months. However, the authors of a recent side-by-side study of the two jurisdictions found that this difference does little to account for the numbers gap (17). Instead, they identified three principal factors: 1) Canadians are much more aware of MAiD and its availability than are their Californian counterparts; 2) Canada has many more MAiD providers than California; and 3) Canadian health care authorities and institutions provide robust support to members of the public seeking to access MAiD, support that is lacking in California. More awareness, more providers, more support — none of these sounds like a bad thing. Since just as many Californians as Canadians indicate that they would (probably or definitely) seek to access MAiD, were they facing a long and painful death (17), the appropriate conclusion would seem to be that they are being underserved by their current assisted dying regime. It's not that Canada is doing worse, but that California could be doing better.

However that may be, these differences between Canada and California make comparisons between the two regimes of questionable relevance. We get more reliable results when we look to jurisdictions with regimes more like ours in Canada. The nearest analogue is the Netherlands, where the 8,720 MAiD deaths in 2022 represented a 13.7% increase over the previous year and constituted 5.1% of all deaths during that year. Quite clearly, in this context Canada is not an outlier.

There is in any case something about this whole controversy over the numbers that I find puzzling. Suppose that we were talking, not about MAiD, but about some other medical service for which there is continuing, and growing, demand — such as joint replacements. In 2020-21, 110,585 hip and knee replacements were done in Canada (18). That total represented a decrease over the previous year, due to COVID-19, but, leaving that factor aside, the number of replacement procedures grew by an annual average of 10% during the previous two decades. Do we have any reason for thinking that either that total or that growth rate is too high? Should we not instead think it a good thing that increasing numbers of patients who need, and will benefit from, a joint replacement are getting one?

Or consider abortions. In 2022, 97,211 surgical abortions were performed across Canada, about 10,000 more than the previous year (19). Is either that total or the year-over-year increase too high? Abortion is equally legal in every part of the country, but access to it is notoriously uneven, with facilities much more restricted in some provinces than in others, and with poor and rural women disadvantaged by comparison with their more affluent urban sisters. If the number of abortions increases annually, either because barriers to access are removed or because new providers begin offering the service, shouldn't we think that a good thing, just because more women who want and need an abortion are getting one?

If we regard an increasing number of joint replacements or abortions as a success, with supply having risen to meet demand, why should we think that an increasing number of MAiD provisions is a failure, or somehow a problem? If more awareness, more providers, and more support are good things for these other services, why are they a bad thing for MAiD? Why should we think differently about MAiD than we do about other medical procedures? What's so special about MAiD?

I'll come back to that question, but first I want to consider another line of argument that begins in a different place but leads us to the same destination. The focus of this one is not on numbers but on disability. MAiD 2.0, initiated in 2021 by Bill C-7, is

defined principally by the two-track system it introduced, in which Track 1 is the pre-existing MAiD 1.0 (with minor modifications), while Track 2 imposes additional procedural safeguards for patients whose natural death is determined not to be reasonably foreseeable. To be clear, it is not the addition of Track 2 that is driving the growth in the MAiD numbers; in 2022, provisions in this category made up just 3.5% of the total (14). This change was widely reported as making MAiD available for the first time to persons with disabilities. But this was a misperception. Under the terms of the original Bill C-14, to qualify for MAiD a person had to have “a serious and incurable illness, disease or disability”. Persons with disabilities have therefore been eligible for MAiD ever since the inception of the program. The innovation of C-7 was to open up eligibility for those with a longer trajectory to their natural death.

As such, the bill was greeted with alarm by many disability rights advocates (20). Their concerns about the introduction of Track 2 were many and varied, but one theme tended to stand out. The critics make the point that Canadians with disabilities live in a society pervaded by ableism — the mindset that having a disability makes one less than fully human (8). As a result, they may seek an assisted death having internalized the ableist valuation that their lives are not worth living. As Anita Ho has put it: “...ableist ideology that treats a life with impairment as categorically worse off than one without impairment can impede some people’s capacity to form the self-trust and self-confidence that are essential to possessing and exercising autonomy...” (21, p.342). Under these oppressive circumstances, some have argued, persons with disabilities are unable to make a genuinely autonomous choice for MAiD, in which case it is wrong — because discriminatory and unjust — to offer them that option (8,22). It is worth noting that Ho does not herself endorse this conclusion (21). Nor is it so clear that autonomous decisions are impossible under conditions of oppression (23).

For various reasons, I find this line of argument odd. For one thing, from the outset the campaign to legalize assisted dying in Canada has been consistently led by persons with disabilities. Sue Rodriguez had amyotrophic lateral sclerosis (ALS). Austin Bastable, who advocated for legalization during the 1990s, was almost completely paralyzed by multiple sclerosis (MS). Steven Fletcher, the Conservative MP who in 2014 introduced two private Member’s bills to establish a legal regime for MAiD, had become paraplegic at the age of twenty-three as the result of an automobile accident. Gloria Taylor, one of the plaintiffs in *Carter v. Canada*, also suffered from ALS. Of the two plaintiffs whose challenge of the “reasonably foreseeable natural death” provision in Bill C-14 led to Bill C-7, Jean Truchon had had cerebral spastic paralysis from birth and later also developed spinal stenosis and necrosis of the spinal cord, while Nicole Gladu suffered from post-polio syndrome. Presumably none of these determined advocates shared the opinion that they were unable to make an autonomous choice for an assisted death.

That opinion also does not seem to be shared by most Canadians with disabilities. In a 2023 Ipsos poll, 83% of respondents who self-identified as having a disability supported the *Carter* decision. More to the point, 78% supported C-7’s removal of the “reasonably foreseeable natural death” requirement, exactly the same level of support found for respondents with no disability (15). So we seem to have somewhat of a disconnect between those disability activists who oppose MAiD, on the one hand, and the broader community of people with disabilities for whom they purport to speak, on the other.

However, what I find most perplexing about the ableism argument is its evident inconsistency. Anyone with a serious disability will frequently be called upon to make decisions about the course of their medical treatment, including very consequential ones where both benefit and risk are sizeable and uncertain. Sometimes those decisions will concern whether to continue treatment for their condition at all or, instead, opt for hospice or palliative care. Those who make the latter choice will have determined that their expected quality of life is no longer sufficient to justify continuing to prolong their life by every means possible. In the starkest cases they will be making a decision to die.

The woman known to the world only as Nancy B. had Guillain-Barré syndrome, an irreversible neurological disorder that left her completely immobilized and dependent on a ventilator. Her intellectual capacity was unaffected by her condition. In 1992, at the age of twenty-five, having been on respiratory support for two-and-a-half years, she requested its removal in order to escape the suffering caused by her immobility. With the ventilator, she could potentially have lived for a long time; without it, she would die quickly. While her decision was not opposed by her health care providers, or by the hospital in which she was resident, as a matter of law it was unclear whether disconnecting her from the ventilator would constitute either criminal negligence causing death (a culpable homicide) or assisting a suicide. Justice Jacques Dufour, who heard the case in the Quebec Superior Court, affirmed Nancy B.’s legal right to refuse continued use of the ventilator, even though such refusal would certainly precipitate her death (24). Five weeks after the judgment, her attending physician induced Nancy B. into a coma and removed the ventilator; she died comfortably in her sleep.

No one suggests that persons with disabilities lack the capacity to make autonomous decisions concerning the management of their medical condition, up to and including the decision to forego further life-sustaining treatment. Any such suggestion would be rightly dismissed as offensively paternalistic. Only in the case of MAiD is that capacity put in question. So I return to my earlier question: What’s so special about MAiD?

The answer to this question may seem obvious: alone among medical interventions, MAiD both causes death and is intended to do so. That makes it special enough to require a statutory exemption from the general legal prohibition of consensual homicide and assisting a suicide.

I believe, however, that this answer is seriously misleading; MAiD is not as special as it is commonly made out to be. To see why, we need to situate it within the broader context of end-of-life care. The question for each one of us is not whether we are going to die: that much is a certainty. The question, instead, is when and how. Many people are content to let nature determine the timing and manner of their death. But some, especially those with a serious and incurable medical condition, wish to have

some say in the matter, especially if there is a substantial likelihood that their natural end will be marked by serious suffering. Even before MAiD was legalized, those who were so disposed had available to them a number of ways of managing their exit from the world. If their condition required life-sustaining treatment — whether this took the form of technological support or surgical intervention or continuing medication — they could refuse further treatment and so hasten their death. If it did not require such treatment, they still had the option of seeking death by refusing food and water. Plus, of course, the time-honoured method of death by overdose of pharmaceuticals.

All of these methods were perfectly legal. The advent of legal MAiD provided a new way of hastening death, with considerable advantages over the previously available methods. Unlike refusal of treatment, it does not require dependence on life-sustaining treatment. Unlike refusal of food and water, it is quick and easy and can be arranged for a specified time so as to be able to share one's last moments with family and friends. Unlike overdosing, it is done under medical supervision and therefore guaranteed not to fail and leave the would-be suicide severely brain damaged. The fact that MAiD enables this kind of effective control over the timing and manner of one's death at least partly accounts for its enormous popularity.

Seen from this perspective, MAiD is not so special (except in a good way). It is not even unique in both causing death and being intended to do so: refusing food and water and overdosing on medication share both of these features. We could argue whether refusal of life-sustaining treatment causes death (I think it does), but it is clear that it will usually have the effect of hastening it. Whether it is intended to have this effect will vary from case to case; some patients may be very happy to find themselves living on without the treatment in question. But there are clear cases in which treatment is refused precisely in order to hasten death and avoid further suffering. Nancy B.'s case was one of them.

I have contended on a number of occasions that, all relevant factors being equal, there is no significant ethical difference between MAiD and other end-of-life treatment options that also have the effect of hastening death, such as cessation of life-sustaining treatment (25). One of those occasions was my affidavit in 2011 on behalf of the plaintiffs in *Carter v. Canada*. Similar testimony was submitted at that time by other expert witnesses. In her judgment, Madame Justice Lynn Smith reviewed the ethical evidence submitted by both sides and concluded as follows: "The preponderance of the evidence from ethicists is that there is no ethical distinction between physician-assisted death and other end-of-life practices whose outcome is highly likely to be death. I find the arguments put forward by those ethicists ... to be persuasive." (26, para 335)

Not everyone will agree with me, or with Justice Smith, on this contentious ethical issue. What is important is to note the ground on which we are now contending. In terms of the distinction I drew at the outset, we are here dealing with a principled issue about MAiD, not a pragmatic one. The point of contention is whether there is anything inherently problematic with it, or whether, ethically speaking, it is on a par with other end-of-life practices that can also hasten death. I earlier reported that critics of MAiD on pragmatic grounds seem not to, and sometimes explicitly claim not to, have any principled objection to it. I am now coming to doubt this.

Of all end-of-life treatment options, MAiD is by far the most closely scrutinized and most stringently regulated. I earlier mentioned the figure of 13,241 MAiD deaths for 2022. We have that figure because MAiD provisions are required to be reported to provincial and territorial authorities and the resulting data are published annually by Health Canada. Responsibility for monitoring MAiD cases, so to ensure compliance with the statutory requirements, also falls to the provinces and territories, each of which has set up a review process just for this purpose. There is no similar system of reporting and review of patient deaths that have been hastened by cessation, at the patient's request, of further life-sustaining treatment, despite the fact that the annual number of such deaths is vastly higher (many more patients with grievous and irremediable medical conditions choose hospice/palliative care rather than MAiD).

I cannot think of a single concern about MAiD and patient autonomy that does not apply equally to treatment refusal. But I also do not know of a single MAiD critic who raises similar concerns in this latter context. They all treat MAiD as special and in need of a higher level of scrutiny. I can think of no reason for this exclusive attention to MAiD except that they find the procedure itself to be peculiarly problematic and therefore in need of some kind of special justification. The principled critics of Canada's MAiD policy are open about this: they think that MAiD is inherently wrong, thus that the ideal number of annual MAiD provisions is zero. The pragmatic critics do not raise this issue, but I find it impossible to explain their concerns without attributing something like this view (maybe a weaker form of it) to them as well.

In this respect, the debate over abortion once again provides an illuminating parallel. Critics who argue that abortions are too easily accessed, or that either the annual total of abortions or the year-over-year rate of increase in these numbers is too high, or that in a society pervaded by sexism women are not capable of making autonomous decisions about their own reproduction, are really objecting to abortion itself on principled grounds. They believe that it is inherently wrong, and thus that the annual number of abortions should be zero, or close to it.

So, until a better explanation of what the critics find to be so special about MAiD comes along, my hypothesis will continue to be that their objection to it is, at bottom, principled rather than pragmatic. If I am right about this, then the ultimate issue for them is not the annual number of MAiD provisions or the annual growth rate of these numbers, and not the conditions of autonomous choice for persons with disabilities, but the ethical status of MAiD itself. If that is indeed the field on which the battle is to be fought, then I'm pretty confident I know who will be the winner.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Assisted Dying in Canada: Ideology Masquerading as Medicine?

Scott Y. H. Kim^a

Résumé

La loi canadienne sur l'aide médicale à mourir (AMM) est généralement considérée comme une loi sur l'euthanasie et/ou le suicide assisté (ESA) à caractère médical. Je soutiens qu'il s'agit plutôt d'un régime d'ESA fondé uniquement sur l'autonomie qui se fait passer pour tel. Les directives publiques sur les critères d'admissibilité généraux de la loi qui régissent la pratique actuelle donnent un sens nouveau à des termes familiers utilisés dans le domaine des soins de santé. Il en résulte que la loi donne l'impression que l'AMM canadienne est une question médicale, mais qu'en réalité, elle fonctionne comme un modèle fondé uniquement sur l'autonomie, c'est-à-dire « la mort sur demande autonome » déguisée en traitement médical. Les implications sont importantes. Cela permet de contourner les débats qu'un système fondé uniquement sur l'autonomie (qui n'est pas intrinsèquement médical) devrait aborder, tels que la question de savoir si l'ESA fondé uniquement sur l'autonomie est conforme à la morale commune, si et comment le système de santé devrait être impliqué, combien de ressources l'État devrait investir dans la promotion d'un système de mort sur demande, etc. La loi fausse également la pratique de la médecine en utilisant les préférences subjectives des patients (c'est-à-dire les préférences des patients) plutôt que la science et les preuves pour déterminer les normes médicales et définir des termes tels que « incurable ». Cette mascarade a été renforcée par les déclarations publiques des responsables canadiens. Il en résulte que le public canadien semble largement favorable à une loi qu'il ne comprend pas pleinement et qu'il désapprouverait probablement sous sa forme actuelle s'il la comprenait. La loi canadienne sur l'AMM est le produit d'une politique démocratique imparfaite.

Mots-clés

aide médicale à mourir, AMM, euthanasie, suicide assisté

Abstract

The Canadian medical assistance in dying (MAID) law is commonly understood as a type of medically-based euthanasia and/or assisted suicide (EAS) law. I argue it is instead an autonomy-only EAS regime masquerading as such. The public guidance on the law's broad eligibility criteria that direct current practice employs novel meanings to familiar terms used in healthcare. The result is that the law gives the impression that Canadian MAID is about something medical, but in reality operates as an autonomy-only model, i.e., “death on autonomous demand” clothed as medical treatment. The implications are significant. It allows bypassing the debates that an autonomy-only system (which is not inherently medical) would need to address, such as whether autonomy-only EAS comports with common morality, whether and how the health care system should be involved, how many resources the state should invest in promoting a death-on-request system, etc. The law also distorts the practice of medicine by using patients' subjective preference (i.e., patients' preference), rather than science and evidence, as determining medical standards and in defining terms such as ‘incurable.’ This masquerade has been reinforced by Canadian officials in their public statements. The result seems to be a Canadian public highly supportive of a law that they do not fully understand and indeed would likely disapprove of in its current form, if they did. The Canadian MAID law is a product of flawed democratic policymaking.

Keywords

medical assistance in dying, MAID, euthanasia, assisted suicide

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INTRODUCTION

Ideology conserves by camouflaging flawed social conditions, giving an illusory account of their rationale and role, in order to legitimate and win acceptance of them (1).

There are different strategies used to justify legalization of euthanasia and/or assisted suicide (EAS) in jurisdictions around the world. Canada's EAS regime, labelled “medical assistance in dying” (MAID), is unique, and uniquely problematic. It claims — in law, in statements of public officials, and in public documents — to be a kind of EAS regime based on medical criteria, but it is at bottom another kind, one that is based on “autonomy-only” criteria. By this I mean that on the surface, Canadian MAID law looks like a form of a “medical suffering” based EAS law found in places like the Netherlands. But this appearance is misleading. Although Canadian MAID is incorporated into and implemented as standard medicine/health care, the actual model underlying the law is tantamount to EAS justified only by an “autonomous request.” As I will argue, the result is an autonomy-only model of EAS that is misleadingly marketed and practiced as an inherently medical procedure, a result that is unique to Canada.

I begin by first comparing the Canadian system with the laws from other jurisdictions where EAS is legal. This will show how the Canadian system has the appearance of one type of regime (EAS justified on medical grounds), but actually is another kind of regime (EAS justified only by the autonomous request of the requestor). I then explain the divergence between how it

is marketed versus its reality, between the manifest justification and the actual regime in practice, by reviewing public documents from official sources on how the law is to be interpreted. I then discuss some of the implications and tensions created by this masquerade, i.e., a medical mask that obscures the true nature of the policy, especially how it enables bypassing certain types of public debate that one would expect in this context. After briefly explaining how public officials perpetuate and reinforce the masquerade, I examine some recent survey data which show that the public seems unaware of these implications of their MAID law. I end with some concluding reflections as to why all of this represents suboptimal policymaking.

For the purposes of this paper, I use the terms medical assistance in dying (MAID) to refer to the specific law and practice in Canada, and euthanasia and/or assisted suicide (EAS) to refer to the general concept, of which Canadian MAID is just one manifestation. This is necessary because the very name of Canadian EAS system ('medical' assistance in dying) is itself part of the issue I wish to address. Finally, I focus on EAS laws only insofar as they apply to competent requests, i.e., I put aside for now issues of nonvoluntary or involuntary EAS.

THE CANADIAN MAID REGIME AND ITS UNIQUE PLACE AMONG EAS REGIMES

To understand the uniqueness of Canadian MAID law, one needs to understand where it stands in the range of actual EAS laws.

In the United States, what is permitted is physician assisted suicide (PAS) for those with a terminal illness (6 months of expected life or less). There is no requirement of suffering, functional decline, or poor quality of life: it is an autonomy model within the context of a terminal illness. A doctor *may* participate, but no doctor is required to perform or make a referral. A clinic or hospital, without any need to invoke a conscience objection, may *prohibit* its doctors from participation, on pain of sanctions, even if it is legal for such doctors to participate in eligible cases (cf. the Oregon law (2)).

In Australian states and New Zealand, although there are some variations, generally the eligibility requirements are terminal medical illness, with 6 to 12 month life expectancy, "causing suffering to the person that cannot be relieved in a manner that the person considers tolerable" (example of law in Victoria, Australia) (3). The phrase "the patient considers tolerable" is a double-edged sword that needs comment, as it foreshadows some aspects of the Canadian MAID system that will be discussed below. If the phrase is applied with the understanding that "terminal illness" means only a condition that is medically irreversible *even with* current best standard of care — i.e., if we assume it applies only to palliative care interventions — then it may seem reasonable to include such a phrase since whether palliative measures are acceptable or not would be largely up to the patient's own experience of such interventions. Such an interpretation would be a natural one, and perhaps that accounts for its presence in the law. However, if the phrase is stretched to apply even to a situation where a patient refuses current best standards of care that would reverse the condition's progression to death (e.g., insulin dependent diabetes), then the effect would be to create a new and more expansive meaning of terminal illness — one that is largely determined by the "autonomous choice" of the requestor.

The Netherlands has a medical suffering-based EAS regime. Specifically, the legal basis is necessity: doctors with two perceived conflicting duties (preserve life vs relieve suffering) are not held liable for homicide (4). There is thus no terminal illness requirement, since suffering need not occur only at end of life. The criteria are that a doctor must be satisfied that the patient has a medical condition that causes intolerable and hopeless suffering, with no reasonable medical alternative — as determined by the doctor, with the patient. Of course, the patient can refuse even the "reasonable alternatives" that may exist (i.e., EAS would not be last medical resort) but by law the doctor would then find the person ineligible for EAS.

Canada also, at least on the surface, seems to have a medical suffering-based regime. The Canadian law requires the requestor to have a medical condition or disability, with no end-of-life requirement, whose intolerable suffering cannot be alleviated under conditions the patient considers acceptable. But as we will see in much greater detail below, the Canadian law is different from the Dutch medical-suffering based EAS law. In Canada, the health care practitioner need only discuss "reasonable and available means," and the patient can refuse them and still be eligible. Further, even if what would avert the request is a widely accepted standard of care intervention, a poor person without access to it would still be eligible.

Other jurisdictions allow EAS without a suffering justification, indeed, with only an autonomy justification. Let's call these "autonomy only" EAS regimes. The 2020 German Federal Constitutional Court ruling states that assisted suicide is protected by the principle of autonomy (as part of human dignity, enshrined in their Basic Law), and thus assisted suicide is a right that is: "...not limited to...serious or incurable illnesses, nor...certain stages of life or illness.... Restricting the scope of protection to specific causes or motives...of the person seeking to end their own life...is alien to the notion of freedom." Despite this unambiguous language about the autonomy-only basis for EAS, 5 years after the ruling there has yet to be any legislation implementing and regulating the practice. For our purposes, there is nothing inherently medical about this kind of assisted dying framework; indeed, as the court notes above, to require a medical illness condition is foreign to the overarching rule of autonomy as the basis for this right.

Switzerland also has an autonomy-only regime, not based on a constitutional principle but instead by legislation: 1937 law, Article 115, regulating assistance in suicide, with condition only on the motive of the assistor (it cannot be a selfish motive) (5).

Assisted suicide is largely managed by voluntary organizations and is not seen as an inherent part of medical practice. As the Swiss Academy of Medicine states:

The true role of physicians in the management of dying and death, however, involves relieving symptoms and supporting the patient. Their responsibilities do not include offering assisted suicide, nor are they obliged to perform it. *Assisted suicide is not a medical action to which patients could claim to be entitled, even if it is a legally permissible activity.* [My italics, See 6.2.1 of the SAM document (6)]

THE UNIQUELY MISLEADING NATURE OF CANADIAN MAID LAW

On the surface then, Canadian MAID law looks like a form of a “medical suffering” based EAS law. And in fact, great effort has been made to market and incorporate Canadian MAID as a medical treatment. But a close look at the law and at how it is to be interpreted (e.g., according to guidance documents from official sources) reveals the true nature of Canadian EAS regime as an autonomy-based model like the German or Swiss models. The result is an autonomy model of EAS misleadingly marketed and practiced as an inherently medical procedure.

Canadian MAID regime: marketed as medical, but the active ingredient is autonomy

Consider the following elements of the eligibility criterion that a person must have a “grievous and irremediable medical condition” (i.e., the criterion which makes Canadian EAS a “medical” procedure):

241.2(2) A person has a grievous and irremediable medical condition if

- (a) they have a serious and incurable illness, disease or disability;
- (b) they are in an advanced state of irreversible decline in capability;
- (c) that 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.* [italics added]

Now consider the following excerpt from German Federal Constitutional Court's ruling:

the individual's decision to end his/her own existence *according to his/her understanding of quality of life and meaning of his/her own existence* ought initially to be respected by the State and society as an act of autonomous self-determination... [italics added]

Although the italicized sections in the two texts clearly share the same idea of primacy of requestor's autonomous choice, the remaining parts of the Canadian law seem to create several additional restrictions on MAID eligibility, explicitly based on having “a grievous and irremediable medical condition” defined by the text in conditions a-c. These restrictions are, however, largely illusory.

Consider, first, that whether in an autonomy-only or a medical suffering-based regime, the pool of potential requestors of EAS will likely be the same. Happy and healthy people might be eligible for EAS in an autonomy-only regime, but they do not ask for EAS. The potential pool of EAS requestors in either type of regime will almost entirely consist of:

- Persons at the end of their life due to conditions like cancer, neurodegenerative disorders, end stage cardiovascular or pulmonary disease (7-10).
- Persons with psychiatric conditions with conditions such as (or some combination of) personality disorders, autism, chronic mood disorders, chronic psychoses, substance use disorders, eating disorders; there will be a preponderance of women (11,12).
- Persons with chronic illnesses or disabilities, especially when combined with destabilizing stressors such as: comorbid psychiatric conditions, poverty, social isolation, stigma, etc. (7,13).
- Elderly persons without terminal illness, with or without multiple conditions of old age, who may be isolated, lonely, or “tired of life” (14).

Second, the restriction of eligibility to only those with medical conditions is likely far outweighed by the practical reality of incorporating EAS as a standard medical procedure grafted into the machinery of a modern healthcare system as a delivery vehicle for EAS. That is, as the practice of EAS requires resources, integrating it into an existing public healthcare system is tantamount to a massive public investment promoting the practice¹ and that could far outweigh any theoretical restriction imposed by “medical suffering,” especially if that medical criterion is interpreted very flexibly (see below).

Still, it is hard to shake off the impression that the specific criteria in the Canadian MAID law seem to make access to MAID more restrictive than would be in an autonomy-only regime, where anyone who makes an informed competent choice qualifies. Surely having a “serious and incurable” condition and “advanced state of irreversible decline” creates a significant restriction

¹ Including making it part of routine information for persons entering nursing homes, EAS hotlines provided by the government, guidance documents claiming that bringing up the option of EAS unsolicited is in circumstances a professional obligation, etc.

to EAS access? Let's consider the criteria in turn. We can look to a document on an official Canadian government website (Health Canada) called *Model Practice Standard* (15).

The Standard gives guidance on incurability with the following:

9.5.1 ...the provider and assessor must be of the opinion that the person has a serious and incurable illness, disease, or disability.

9.5.2 'Incurable' means there are no reasonable treatments remaining where reasonable is determined by the clinician and person together exploring the recognized, available, and potentially effective treatments in light of the person's overall state of health, beliefs, values, and goals of care.

The first point is a mere repeat of the criterion itself, with the addition of "the provider and assessor must be of the opinion." Obviously, as a guide to how a clinician ought to arrive at such an opinion, it adds nothing.

The second point 9.5.2 says that "incurable" means there are no reasonable treatments remaining, which sounds right. But then "reasonable" is defined further. Two features of the definition seem especially pertinent, as they lead to a novel definition of an "incurable condition." First, reasonableness is something that is arrived at, not by an objective standard of medical science, but through an "exploration" by the clinician and the patient, "in light of" not just their health but also "beliefs, values, and goals of care." Second, the definition implies that even if a disease is medically curable, if it is not "available" to that individual, then it makes the condition incurable.

Whatever "incurable" means in ordinary medical practice, the definition in the Model Practice Standard is not it. When a patient is told that they have cancer that is incurable, our first thought is not, "the patient should ask whether this is consistent with the patient's beliefs, values, and goals of care."² Also, according to the Model Practice Standard, if your neighbour also has the same condition, but is cured by an intervention to which they have access, but you die because you couldn't afford it, then it turns out that your neighbor had a curable illness whereas you had an incurable one. At minimum, this is a very novel take on the meaning of incurable.

Next, what does "advanced state of irreversible decline in capability" mean? How should it be determined? Below, I quote the Model Practice Standard and comment on each point inside the brackets:

9.6.1 ...the provider and assessor must be of the opinion that the person is in an advanced state of irreversible decline in capability. [See above]

9.6.2 Capability refers to a person's functioning (physical, social, occupational, or other important areas), not the symptoms of their condition. Function refers to the ability to undertake those activities that are meaningful to the person. [Note that as qualified by the second sentence, capability is entirely defined by the perspective of the person. Again, it transforms the criterion into an individual subjective standard.]

9.6.3 'Advanced state of decline' means the reduction in function is severe. [No definition of 'severe' given. And since capability itself is subjectively defined, it is ultimately up to the requestor to determine the severity that defines 'advanced state of decline.']

9.6.4 'Irreversible' means there are no reasonable interventions remaining where reasonable is determined by the clinician and person together exploring the recognized, available, and potentially effective interventions in light of the person's overall state of health, beliefs, values, and goals of care. [Here, the same 'reasonableness' formula from the previous criterion is used, and will have the same implications in terms of 'availability' and personal 'values' defining the concept.]

Finally, we can deal with the criterion of "intolerable suffering that cannot be relieved under conditions that they consider acceptable" briefly since we've already discussed this criterion and the autonomy point is transparent in the legal criterion itself (rather than needing the convoluted reasoning provided by the Model Practice Standard).

Thus, according to official Canadian government documents, once a person requests MAID (recall the same pool of requestors as in autonomy-only regime) there are really no restrictions beyond autonomy — despite the appearance of medical language that suggests otherwise. The appearance of the "medical" is left intact, but under the surface are interpretations that do violence to the meaning of "medical".

This tendency toward an expansive definition of eligibility criteria by emphasizing or reinterpreting the criterion as a matter of preference or choice of the requestor is a common theme in MAID guidance documents in Canada. For example, for the

² In another Health Canada document, Advice to the Profession (16), we find this: "At the same time, a capable person cannot refuse all or most interventions and automatically render themselves incurable for the purposes of accessing MAID." This is another artfully worded constraint that gives an appearance of setting a genuine limit. But the combination of "all or most" with "automatically" renders the constraint practically meaningless. A person could refuse all or most treatments but as long as the pronouncement of incurability is not automatic — say, after an "exploration" of the person's refusals — that constraint is rendered moot.

definition of reasonably foreseeable death, the best-known MAID provider/assessor organization in Canada states that a person's natural death can be reasonably foreseeable "if they have demonstrated a clear and serious intent to take steps to make their natural death happen soon or to cause their death to be predictable. Examples might include... voluntarily cease eating and drinking." (17)³

Returning then to a comparison with the German (or Swiss) system of autonomy-only EAS regime, we can say the following. Both regimes are in practice autonomy-only systems of assisted death. In Germany, there is a single step of transparent stipulation that EAS is justified by autonomy. In Canada, there are two steps used: first, specifying pseudo-medical criteria that places MAID within medicine/healthcare system as a medically justified intervention, and second, interpreting those criteria to effect an autonomy-only regime that operates within the healthcare system.

PRACTICAL IMPLICATIONS OF AN AUTONOMY-BASED EAS CLOTHED AS A MEDICAL INTERVENTION

What is the significance of an autonomy-based EAS system packaged as a medical EAS system? There are several significant points to note.

First, we should ask what is gained by endorsing an autonomy-based EAS regime with the veneer of a medical suffering based system. Why not just adopt a transparent autonomy-only system? The obvious one is that it is much easier to convince the public of a medical-suffering based regime than an autonomy-only regime. Appealing to compassion (an emotion widely shared and idealized) is a more promising strategy than stirring up the inner libertarian in the average person. No one opposes "relieving suffering" but few would endorse "every individual can terminate their life for whatever reason they prefer." It's good marketing.

Second, by placing an autonomy-only EAS practice inside an already established, publicly funded healthcare system, it is possible to bypass a policy debate that will inevitably arise when an autonomy-only system is proposed, viz., who will perform EAS (should doctors be involved), with what safeguards and guidelines, and how much resources will be devoted to it from public funds, among other important policy questions. Such debates are hard debates. Note that the German high court ruling is now 5 years old, without clear signs of how to implement the ruling.

In Canada, the effect has been a massive public investment (without debate) in MAID. Indeed, the investment has been such that many find it more accessible (i.e., death is more accessible) than the standard treatments or resources they would rather have in the first place (13). It is difficult to think of a medical service that is so heavily defined by patient preference, that is so accessible, and whose consequences are so momentous and irreversible. All of this has occurred with no prior specific debate over resources because of the ideological nature of the Canadian MAID regime: as the true nature of the system is hidden under the veneer of medicine, important policy debates have been bypassed.

The final implication is that there are inevitable tensions and contradictions arising from a non-transparent implementation of an autonomy-only regime cloaked as a medical regime. Medical science and clinical standards can't be so plastic as to accommodate the ideologically driven regime. They will inevitably clash with the masquerade. To see this, consider the following cases:

P1 says she would rather have MAID than try a likely curative, but moderately burdensome, treatment that is available.

P2 with cancer is quite depressed, but cognitively intact, and requests MAID; she refuses recommended treatment for depression.

P3 requests MAID as a second choice as he would rather receive a known treatment that will likely work, but cannot afford it or lacks access to it even as more privileged persons next door, or in next province, have access, etc.

P4 has bipolar disorder that has been difficult to treat in recent years. She discontinued her standard antipsychotic medications abruptly, resulting in side effects that also cause a severe sense of restlessness and anxiety. Two specialists have told her that the side effects will disappear if she goes back on the drugs and then gradually tapers off. But she is insistent on seeking MAID for the somatic adverse reaction to medication, and finds a willing provider.

³ In the Model Practice Standard, the following quotes from a provincial court are provided:

- "... 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."
- "... in formulating an opinion, the physician need not opine about the specific length of time that the person requesting medical assistance in dying has remaining in his or her lifetime."

It is difficult to see how such artful legal quotes can provide clinical practice guidance. But they clearly do convey the point that there is to be a wide latitude in applying the concept *and* that it should be "person-specific." Since "person specific" can't mean the *object* of the prognosis is the person's disease — since that is obvious, there is no need to add 'person specific' in that sense, and thus it must imply another meaning. Is the point that the person determines their own prognosis? The logic here is by now familiar.

P3 is by now a familiar kind of case in Canada, with some bioethicists more concerned about defending EAS in such circumstances instead of trying to identify why a system that leads to such situations is problematic (18). P1 occurs too (19). P2 and P4 (20) are familiar in the sense that psychiatrists are well acquainted with patients whose conditions are treatable but which obscure the vision and desire of the patients themselves (hence the emphasis on suicide prevention); the only difference here is that these patients are seeking MAID as the means, and the Canadian law seems to protect providers who provide it.

The point to keep in mind is not what a reasonable health care practitioner *would* do in the above cases, but rather what such a doctor or a nurse practitioner would be legally permitted to do, using the interpretations provided by something like the Model Practice Standard or by organizations like CAMAP. So following the guidance provided by Health Canada we examined above, all of these hypothetical patients could be interpreted as eligible for MAID. But the cases are deeply problematic by ordinary medical standards — doctors do not opt for an amputation over an antibiotic just because that is the patient's preference. One would need to be in the grip of an ideology to think death is an appropriate *medical* response to an ameliorable medical condition.

But the Canadian law goes even further, at least according to Health Canada. As we saw above, a doctor's refusal to perform MAID in the above cases is consistent with, and would seem to be required by, ordinary standards of clinical medicine. Such a doctor may in fact perform MAID in other situations, but refuse to do so in these situations because they do not think MAID is *medically* indicated, *even if legal*. But consider this guidance from the Model Practice Standard:

Conscientious objection may be case specific. Some [physicians/nurse practitioners] are conscientiously opposed to all MAID. Some to only certain kinds of MAID (e.g., Track 2). Some to only specific cases given the specific circumstances. The same rules apply no matter the scope of objection — [physicians/nurse practitioners] cannot be compelled to participate but they must follow the steps laid out in 5.2 if they are unwilling to participate.

But following this guidance would result in compelling a doctor to refer a patient to another practitioner who will do what the doctor believes is *medically* contraindicated (not because of religious or philosophical objection). Nor does the guidance obligate the doctor to say, e.g., "You have effective medical alternatives that I recommend instead, in my medical judgment." Instead, according to the Model Standard, the Canadian law compels acting against a doctor's own best medical judgment.

HOW THIS UNIQUELY OPAQUE NATURE OF CANADIAN MAID LAW IS COMMUNICATED BY PUBLIC OFFICIALS: THE DEBATE OVER MAID WHERE MENTAL DISORDER IS THE SOLE UNDERLYING CONDITION (MD-SUMC)

Is the true nature of the Canadian EAS system transparently communicated by Canada's officials when they have the opportunity to do so? Two examples will suffice, from the debate over the legalization of MAID for persons with mental disorders as the basis⁴.

Canada's then Attorney General Lametti at one point stated, in arguing in favour of legalizing MAID for mental illness, that it would be granted only "where everything has been tried, where the person is an adult capable of making up their own mind and there is no remedy." (21) He did not, however, clarify that the true legal meaning (at least in Canada) of "no remedy" (i.e., incurability and irremediability as defined by the requestor) and of "where everything has been tried" (where "everything" does not include medically standard therapies if the person cannot afford it). The public therefore would have been misled about the true nature of the proposed expansion. The same goes for the Minister of Families, Children and Social Development, Ya'ara Saks's statement that the proposed expansion to mental illness will apply only to those "who have been presented treatment after treatment" and "have tried everything imaginable to address their suffering." (22)⁵

One might wonder why the ministers would say such inaccurate things in public. Are they statements of intentional misdirection or are the ministers themselves confused? My speculation is they have the correct political sense that if they made truly transparent statements, their cause of expanding MAID even further would face pushback from the public. This is especially so since they did not propose any additional protections or safeguards for this uniquely vulnerable population.

This leads to another observation about the so-called debate over MAID for MD-SUMC (mental disorder as sole underlying medical condition) in Canada. It is a uniquely Canadian way of framing the issue. In anticipation of legalizing MAID for mental illness, the government created an Expert Panel to recommend "safeguards, protocols and guidance" to structure the practice of MAID for persons with mental illnesses." (23) This made sense given the controversial nature of MAID for psychiatric disorders. Surprisingly, the Expert Panel charged with the task felt that there was no need for a special set of safeguards. The reason given is something that can only be described as Orwellian — there is no need for special safeguards for MAID for

⁴ The term used by the government is MAID where the sole underlying condition is a mental condition, or MAID SUMC. The Canadian conception of psychiatric EAS is unique, and this is often lost in the discourse. Because of the way it is phrased, a person who is seeking MAID for mental disorders but who also has a chronic medical condition could qualify for MAID even now — that is, using the flexible guidance of the Model Practice Standard. See below how this loophole is used as a justification for downplaying the unique concerns associated with psychiatric EAS.

⁵ Of course, some people seeking psychiatric MAID might fall under such a description, but clearly the context of the statement is that anyone seeking it would fit that description. Even by low standards of veracity in political speech, these comments are rather disturbing.

MD-SUMC because MAID for mental illness is already legal and occurring in Canada, and MAID for mental illness with physical illness is not that different from MAID for MD-SUMC.

The Panel's *unstated* premise is that if it is happening under current law, there is no need to worry about adding special safeguards since the *current process is fine as it is*. This amounts to denying the rationale for the Panel itself. But surely the question is whether such a practice is in fact fine as it is. Again, without argument or debate, the Canadian policy guidance process bypasses necessary debate by a sleight of hand reasoning. This is in contrast to jurisdictions, such as the Netherlands and Belgium (which allow psychiatric euthanasia), that acknowledge the need for additional protections in their guidance discussions and standards (24-26). In countries like Belgium and the Netherlands, what matters — what needs scrutiny in order to determine whether special protections are needed — is the idea that EAS is being given for mental illness (regardless of whether the person has another illness).

If one asked the average Canadian whether MAID for mental illness is legal, they would likely say no. Indeed, even bioethicists not specializing in MAID would likely say no. That the Canadian MAID law *makes it appear that somehow MAID for mental illness is not yet legal* is yet another example of the mismatch between how it is marketed and how it is practiced⁶.

IS THE CANADIAN PUBLIC AWARE OF THE IMPLICATIONS OF THEIR MAID LAW?

In a survey conducted in August of 2023 (27), after informing them of the Canadian legal criteria for MAID, we asked 2140 Canadian adults if they supported MAID if all conditions for eligibility in the current law were met. As in other previous surveys (28), a clear majority (73%) said they supported MAID. Further, when asked about whether certain situations met the necessary “grievous and irremediable” criterion for MAID eligibility, 78% and 71% respectively answered correctly that the patient must have a “serious and incurable illness, disease, or disability” and that “the patient must be in an advanced state of irreversible decline in capability.” Thus, our respondents were typical of Canadians in supporting the MAID law, and, further, they seemed to at least recognize two of the key eligibility criteria. But when we examined their understanding of the actual implications of the current eligibility criteria, only 19% correctly answered that terminal illness is not an eligibility condition and only 21% correctly answered that refusal of effective treatment is compatible with eligibility. The public know and support the fact that MAID is legal, but they do not fully understand for whom it is legal.

This lack of awareness of the full implications of the law was further confirmed when they were given scenarios depicting situations that are compatible with MAID eligibility (they were modelled on media reports of known MAID cases — namely, refusal of effective intervention or lack of access to standard resources that would ameliorate the condition). Only 23-32% (depending on scenario) correctly answered that such situations are compatible with Canadian MAID eligibility criteria. Notably, a similarly low proportion felt the persons portrayed in the scenarios should be able to receive MAID⁷.

How does one explain the fact that Canadians are strongly supportive of their MAID law and are able to recognize at least two key eligibility criteria when presented with the law's wording, but be so wrong about the implications of that law? Although causation cannot be inferred from observational data, the data are nevertheless consistent with the obfuscating effect of the Canadian MAID law: the Canadian public seems to be in the dark about what their law really implies and how it actually applies in practice, because the law is not what it seems, and that is reinforced by statements of public officials. It is important to again note that most Canadians seem to think that their country's MAID law prohibits some types of MAID that are in fact legal.

CONCLUDING REFLECTIONS

The current monitoring and safeguard system presumably assumes that MAID is a medical procedure. But if the Canadian MAID system is actually an autonomy-only EAS regime, it is worth asking whether there are adequate protections and monitoring of such a system. It is, after all, a framework that gives doctors and, uniquely, nurse practitioners, plenty of signals to flexibly interpret the law toward a pure autonomy model.

In this regard, the pattern of uptake in practice by Canadian health practitioners is notable, as it suggests that MAID is heavily driven by a small minority of highly active practitioners, rather than by a widespread adoption by the healthcare community (7). There were 2,200 unique providers of MAID in 2023. Of the 15,343 MAID deaths in 2023, only 361 providers accounted for 10,138 (66%) of those deaths. Remarkably, a subgroup of 89 providers accounted for 5,345 deaths, or 35% of all Canadian MAID deaths in 2023; on average these providers performed MAID more than once a week. It is difficult to see these numbers as reflecting a broad willingness to provide MAID among health care providers. Further, all of this is consistent with few doctors publicly stating they have performed hundreds of cases of MAID (29-31) and some even adopting it as their primary or only medical activity (7)⁸. Of course, without individual level data (i.e., of individual MAID cases), it is difficult to evaluate the full

⁶ There is currently no legal barrier to MAID even if a person seeks it primarily because of their major depressive disorder. The person could still meet MAID criteria because the law as written does not require that the medical condition (the basis for MAID) be the cause of, for instance, meeting other criteria, such as being in state of advanced decline, etc. Recall that according to the dominant interpretive framework in Canada, a person whose death is not reasonably foreseeable can become so by the act of not eating or drinking, independent of the justifying medical condition.

⁷ Respondents who were older, with higher income and more education, were less religious, and identified as white tended to support MAID law in general, in higher proportions. However, we found that when answering questions about persons seeking MAID under conditions of treatment refusal or lack of access to needed resources, those characteristics were either not correlated or were correlated with lower support for MAID.

⁸ Based solely on the high number of cases performed per provider, Health Canada attributes “focused expertise” to the prolific providers (7, p.53). Given that virtually anyone who asks for MAID in Canada is found eligible and given that the procedure itself is hardly complex, it is unclear what kind of expertise is meant.

significance of a tiny number of clinicians accounting for such high proportions (and absolute numbers) of MAID deaths in Canada. It also means we cannot rule out the possibility that MAID practice reflects the work of a small number of activist clinicians driven by an ideology whose implications are at odds with the values of most Canadians.⁹

The way that Canadian MAID policy has evolved and is publicly guided do not seem like a good way of making and implementing policy in a pluralistic democratic society, especially regarding a policy about life and death decisions. It is concerning that the ideological nature of Canadian law could be keeping the public in the dark. It does not seem respectful to its citizens that the law borrows familiar terms used in medicine, but the public guidance on interpreting it relies on novel meanings, and the country's public officials (intentionally or ignorantly) perpetuate that obfuscation — especially given that the hidden implications are likely contrary to the values of most citizens. The ideological structure of the law also means that important policy debates have been bypassed. The Canadian MAID law is a product of flawed democratic policymaking.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

The Moral Permissibility of Providing Medical Assistance in Dying in Canada: An Ethical Framework for Professional Practice

Timothy Christie^{a,b}

Résumé

Bien que l'aide médicale à mourir (AMM) soit légalement autorisée au Canada dans des conditions légales bien définies, ce cadre juridique ne détermine pas quand il est moralement acceptable pour un professionnel de la santé de fournir une AMM. Cet article examine explicitement la distinction normative entre la pratique légale et éthique de l'AMM. Il soutient que les critères d'admissibilité liés à la médecine, tels que l'incurabilité, le déclin irréversible et la souffrance intolérable, ne fonctionnent pas comme des critères médicaux objectifs, mais présupposent et renforcent plutôt l'autonomie du patient. En conséquence, les évaluations de l'AMM sont souvent réduites à des confirmations procédurales de l'autonomie plutôt qu'à des évaluations médicales substantielles. Ainsi, l'autonomie est devenue la justification *de facto* de la prestation de l'AMM, même si la loi canadienne ne considère pas l'autonomie seule comme une condition suffisante. Cet article examine la structure discrétionnaire de la pratique de l'aide médicale à mourir et démontre que chaque décision de fournir une aide médicale à mourir implique un jugement normatif de la part du professionnel de la santé. Afin d'orienter ce jugement, un cadre éthique fondé sur les obligations fiduciaires des professionnels de la santé est proposé. S'appuyant sur les quatre principes fondamentaux de l'éthique des soins de santé, ce cadre stipule qu'il est moralement acceptable pour un professionnel de la santé de pratiquer l'aide médicale à mourir uniquement lorsque : 1) le patient est autonome, en termes de capacité, de volontariat et de consentement éclairé; 2) l'intervention satisfait aux principes de bienfaisance et de non-malfaisance; et 3) la demande découle d'un contexte de justice, dans lequel un état médical rend le patient incapable d'agir selon son souhait autonome de mourir sans assistance.

Mots-clés

aide médicale à mourir, AMM, euthanasie volontaire, suicide assisté, obligations fiduciaires, choix cruel, droits de réclamation, droits privilégiés

Abstract

Although medical assistance in dying (MAiD) is legally permitted in Canada under defined statutory conditions, this legal framework does not determine when it is morally permissible for a healthcare professional to provide MAiD. This paper explicitly examines the normative distinction between legal and ethical MAiD practice. It argues that the medically related eligibility criteria, such as incurability, irreversible decline, and intolerable suffering, do not function as objective medical criteria but instead presuppose and reinforce patient autonomy. As a result, MAiD assessments are often reduced to procedural confirmations of autonomy rather than substantive medical assessments. Thus, autonomy has become the *de facto* justification for the provision of MAiD, even though Canadian law does not regard autonomy alone as a sufficient condition. This paper examines the discretionary structure of MAiD practice and demonstrates that every decision to provide MAiD involves a normative judgment on the part of the healthcare professional. To guide that judgment, an ethics framework grounded in the fiduciary duties of healthcare professionals is proposed. Using the four core principles of healthcare ethics, this framework holds that it is morally permissible for a healthcare professional to provide MAiD only when: 1) the patient is autonomous, understood in terms of capacity, voluntariness, and informed consent; 2) the intervention satisfies the principles of beneficence and nonmaleficence; and 3) the request arises from a context of justice, in which a medical condition renders the patient unable to act on their autonomous wish to die without assistance.

Keywords

medical assistance in dying, MAiD, voluntary euthanasia, assisted suicide, fiduciary duties, cruel choice, claim rights, privilege rights

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INTRODUCTION

This paper investigates when it is morally permissible for a healthcare professional to provide Medical Assistance in Dying (MAiD) in Canada. While MAiD is legally permitted under defined statutory conditions, the legality of an act does not establish that it is morally permissible. The ethical question at the heart of this paper is under what conditions are healthcare professionals morally permitted to provide MAiD. This is particularly relevant for Canada, where the Supreme Court of Canada (the Court) envisaged MAiD as a carefully monitored exception to the criminal prohibitions on assisted dying, permitted only in clearly defined circumstances with stringent safeguards (1). In reality, however, the legal eligibility criteria are sufficiently broad and subject to such discretionary interpretation that nearly any autonomous patient with a serious illness, disease, or disability may qualify for MAiD, particularly if they are assessed by a healthcare professional predisposed to endorsing requests on the basis of respect for patient autonomy (2).

It is important to clarify that most MAiD procedures in Canada involve patients living with serious, chronic, or terminal conditions, such as cancer, neurodegenerative disorders, or advanced cardiovascular disease (3). Many of the healthcare

professionals involved with these patients see their role as one of compassion, ethical responsibility, and responsiveness to patient suffering (4). This paper does not claim that MAiD is routinely provided inappropriately or that those receiving it are ineligible. The concern is not with individual decisions but with the legal structure itself, which requires healthcare professionals to exercise normative discretion while presenting those decisions as if they are purely legal or procedural. In doing so, the law conceals the ethical nature of these judgments, allowing them to proceed without explicit ethical justification. In the absence of a principled ethical framework, legal compliance cannot ensure that decisions to provide MAiD meet the ethical standard of moral permissibility.

To address this gap, this paper develops an ethics framework grounded in the fiduciary duties that structure the healthcare professional–patient relationship. These duties arise from the patient's vulnerability and the discretionary authority exercised by healthcare professionals. They require that discretionary decisions be guided by obligations of trust, loyalty, and the patient's best interests, not merely by legal permissibility. Although fiduciary duties remain part of the common law, they are not meaningfully engaged by the legal framework governing MAiD, which is situated within the criminal law. Because MAiD is structured as an exception to the prohibitions on culpable homicide and assisted suicide, legal compliance protects healthcare professionals from prosecution but does not require that fiduciary duties be fulfilled. The presumption of innocence and the burden of proof beyond a reasonable doubt further limit the ability of the legal system to evaluate whether a discretionary decision to provide MAiD was ethically permissible. In practice, a healthcare professional who can demonstrate compliance with the procedural requirements for MAiD (including the eligibility criteria and safeguards) may be able to establish reasonable doubt, even if those requirements were met through highly permissive interpretations or in a manner that is ethically questionable. As a result, decisions that satisfy legal criteria may still fall short of the ethical standards expected from healthcare professionals.

This paper proceeds in three parts. First, it demonstrates that legal eligibility for the provision of MAiD does not logically entail moral permissibility. Second, it argues that MAiD constitutes a legal privilege rather than a claim right, rendering the decision to provide it a matter of discretionary judgment. Third, it develops an ethics framework grounded in the four principles of healthcare ethics: respect for autonomy, beneficence, nonmaleficence, and justice. This framework is not a supplement to legal compliance but a necessary condition for determining when the provision of MAiD is morally permissible. Without such a framework, the provision of MAiD risks being reduced to a procedural affirmation of patient autonomy rather than a substantive ethical decision.

DEFINITIONS AND LEGAL CONTEXT

MAiD refers to an intervention where a medical or nurse practitioner (healthcare professional) either administers a lethal substance to a patient upon their request to cause the patient's death or prescribes the substance for the patient to self-administer to cause their own death (5). These practices have historically been referred to as “voluntary euthanasia” and “assisted suicide.” (6-9) However, this terminology is contentious. Some critics argue that the acronym MAiD sanitizes and obscures the nature of the act of killing, while proponents contend that it more accurately captures the medical and compassionate context in which the practice occurs (10). The term MAiD was introduced into federal legislation with the passage of Bill C-14 in 2016, but its origin lies in the earlier legislative process in Quebec, which deliberately sought to frame assisted dying as another end-of-life medical procedure rather than as an exception to criminal law.

Quebec began exploring assisted dying in 2009, when the Collège des médecins du Québec released a discussion paper suggesting that physician-assisted death could be considered part of appropriate end-of-life care (11). This led to the creation of the Select Committee on Dying with Dignity, which in 2012 recommended that “medical aid in dying” be legally recognized as another end-of-life option, alongside existing practices such as withdrawal of treatment, palliative care, and continuous palliative sedation (12). In 2014, the Quebec National Assembly enacted Bill 52, *An Act Respecting End-of-Life Care*, which established a legal regime for “medical aid in dying” within the provincial healthcare system (13). This legislation framed assisted dying as a matter of healthcare provision under provincial jurisdiction and did not rely on federal criminal law exemptions.

Importantly, the term “medical aid in dying” was introduced to replace “euthanasia” and “assisted suicide,” which the Select Committee found to be emotionally charged and poorly suited to the legislative goals. The choice of terminology was deliberately euphemistic (14). By framing the intervention as a form of medical care, the Quebec framework situated MAiD within a model of clinical decision-making, thereby distancing it from its roots in criminal law. This terminology was later adopted at the federal level, though within a distinct legal structure that treats MAiD as an exception to criminal prohibitions rather than as a healthcare service.

While Quebec was implementing its legislation, the Supreme Court was adjudicating *Carter v Canada* (2015), which held that the blanket prohibition on assisted dying violated section 7 of the *Canadian Charter of Rights and Freedoms* (the Charter). The Court found that competent adults suffering intolerably from a grievous and irremediable condition should have the option of seeking assistance in dying, provided the request was voluntary and informed. In response, Parliament enacted Bill C-14 in 2016 (amended by Bill C-7 in 2021), which created an exemption from the Criminal Code provisions on culpable homicide, consenting to death, and assisted suicide (15-17). This federal legislation established a distinct criminal law framework for MAiD, grounded in the constitutional division of powers, where criminal law remains a federal responsibility and healthcare a matter of provincial jurisdiction.

Law and Ethics in the MAiD Legislation

Although MAiD emerged from distinct federal and provincial legislative processes, both frameworks share a common feature, namely, that they establish the conditions under which MAiD is legally permitted. However, while the law defines when the provision of MAiD is legal, it does not determine whether it is morally permissible for a healthcare professional to provide it. This distinction is important, because the legal framework prescribes eligibility and procedural safeguards but does not address the ethical responsibilities of those who perform the procedure. To assess these responsibilities, it is necessary to distinguish law from ethics.

Law and ethics are conceptually distinct domains. Law refers to rules and standards established through governmental processes, such as legislation, regulation, or judicial rulings. These rules carry legal authority and are enforceable through courts, regulators, and law enforcement. In Canada, federal laws are enacted through a formal legislative process that includes the introduction of a bill, debate and revision in both the House of Commons and the Senate, and final approval through Royal Assent (18). These processes produce legally binding legislation.

Ethics, by contrast, is concerned with what individuals and institutions ought to do, based on normative reasoning. Ethical principles are not enacted by vote, nor are they enforced by courts, or law enforcement. Rather, they are grounded in values such as respect for persons, beneficence, nonmaleficence, and justice, and are justified through argument, reflection, and deliberation (19,20). Whereas legal reasoning determines what is permitted or prohibited within a legal system, ethical reasoning evaluates the ethical probity of actions regardless of their legal status. In some cases, law and ethics may align, but this alignment is neither automatic nor guaranteed. A law may prohibit actions that are morally required or permit actions that are morally prohibited. For example, the forced attendance of Indigenous children in residential schools was legally required but constituted a fundamental violation of morality (21). The legality of an action, therefore, cannot be assumed to determine its morality.

One of the objectives of an ethical analysis is to determine whether an act is morally required, morally prohibited, or morally permitted. These categories are foundational to normative reasoning, particularly in applied ethics. An action is morally required if an agent has a duty to perform it, morally prohibited if there is a duty not to perform it, and morally permissible if there is no duty either to perform or to avoid it. Therefore, morally permitted actions are those for which agents have no moral obligation either to act or to refrain. They fall within the scope of moral discretion.

In the Canadian context, MAiD is legally permitted under specific conditions, but it is not legally required. Section 241.2(1) of the Criminal Code states that a person “may” receive MAiD if all legal eligibility criteria and procedural safeguards are met. The use of the word “may” is legally significant because it confers a legal privilege to provide MAiD but does not impose a legal duty to do so (22). Even when all criteria are satisfied, no healthcare professional is under a legal obligation to perform the procedure.

The ethical analysis parallels this legal structure. While the provision of MAiD may be morally permissible in some circumstances and morally prohibited in others, it is unlikely that any circumstance could give rise to a duty to provide MAiD. The *prima facie* duty not to cause death, introduced later in this paper, stands in tension with the claim that MAiD could ever be morally required. Although this *prima facie* duty may be overridden by other moral considerations, its presence precludes any claim that professionals have a general duty to provide MAiD. This view is also unsupported by the Canadian legal framework, which permits but does not require the provision of MAiD. Accordingly, this paper does not address cases in which MAiD might be morally obligatory or categorically prohibited. Rather, it examines the specific conditions under which providing MAiD may be morally permissible, understood as a discretionary act that must be ethically justified in each case.

COMPARATIVE ETHICAL FRAMEWORKS FOR MAiD — CLARIFYING THE CANADIAN MODEL

Justifications for the provision of MAiD are typically structured around two conditions. First, the individual must make a voluntary, competent, and informed request. Second, the individual must be experiencing a medical condition that warrants assistance in dying. This second condition is often framed in terms of either a terminal prognosis, intolerable suffering, or both. Together, these two conditions form what is often referred to in the literature as the joint view (23,24). On this model, both autonomy and welfare are necessary, but individually insufficient. The autonomy condition ensures that the request reflects a voluntary and informed decision by a competent individual. The welfare condition requires that the individual's medical circumstances be sufficiently grave to justify the intervention. While jurisdictions differ in how they define the welfare condition, for example, some require a terminal diagnosis while others require intolerable suffering, the joint view maintains that neither autonomy nor medical condition alone is enough to ethically justify the provision of MAiD.

A contrasting model, sometimes referred to as the autonomy-only view, holds that an autonomous request is sufficient to justify the provision of MAiD (25,26). On this view, suffering may be a relevant subjective motivation, but it is not a necessary condition of eligibility. The ethical permissibility of MAiD, on this account, derives solely from the individual's autonomous decision-making authority. So long as the person has capacity, acts voluntarily, and provides informed consent, the professional's role is to facilitate the person's autonomous choice.

The Canadian legal framework purports to adopt the joint view model. The Criminal Code sets out eligibility criteria that include administrative requirements, autonomy-related requirements, and the presence of a grievous and irremediable medical condition. Judicial interpretations have reinforced this model. In *Carter*, the Supreme Court held that MAiD should be permitted only for competent individuals who are affected by a grievous and irremediable medical condition that causes intolerable suffering. These legal and jurisprudential elements reflect a formal commitment to both autonomy and welfare, consistent with the joint view.

Despite this formal structure, the legislation permits interpretations of the eligibility criteria that may render the medically related requirements difficult to distinguish from the patient's autonomous request. The statutory elements that define a grievous and irremediable medical condition (which include incurability, advanced decline, enduring suffering) are not formulated in a way that clearly separates them from the patient's autonomous request for MAiD. As a result, the assessment of these criteria may, in practice, rest primarily on the patient's own account of their condition's incurability, the extent of their irreversible decline, the severity of their suffering, and their expressed desire to receive MAiD. While the law appears to endorse the joint view, in which both autonomy and a qualifying medical condition are both necessary, the interpretive flexibility built into the statutory language raises the question of whether the legal framework consistently maintains this dual structure or whether it permits practices that approximate the autonomy-only model.

The ethical framework proposed in this paper does not begin with a rejection of the autonomy-only view. Rather, it begins with the observation that the Canadian legal framework explicitly rejects that model and claims to adopt the joint view. The concern, therefore, is not that the autonomy-only model is necessarily incoherent. Jurisdictions such as Germany (27) and Estonia (28) have adopted autonomy-only approaches that treat suicide and assisted suicide as a matter of individual choice rather than as a medical act. These models are internally consistent because they do not frame assisted suicide as a form of healthcare, they do not impose medical eligibility criteria, and they do not require the involvement of healthcare professionals. By contrast, Canada situates MAiD within a healthcare framework while, in practice, relying almost exclusively on patient autonomy to justify it. The aim of this paper is to clarify what would be required to make the Canadian model internally coherent, given its explicit adoption of a joint view structure.

MAiD ELIGIBILITY CRITERIA

MAiD exists as an exception to the Criminal Code's prohibitions on consenting to death, culpable homicide, and assisting suicide. The legislation establishes legal eligibility criteria and procedural safeguards for its provision. If these conditions are not met, or if the act of causing a person's death or assisting in their suicide is carried out by someone not authorized by law, the act (of MAiD) would constitute a serious criminal offence. To receive MAiD, a patient must satisfy legal eligibility criteria and adhere to one of two procedural pathways, known as Track 1 and Track 2. The eligibility criteria can be divided into three categories: administrative, autonomy-related, and medically related criteria. The administrative criteria encompass age and residency requirements, although the exclusion of individuals under 18 appears to be an arbitrary restriction without a clear logical justification. The autonomy-related criteria include capacity, voluntariness, and informed consent, which aim to ensure that a patient's decision to pursue MAiD is genuinely autonomous. However, a closer examination suggests that these criteria create internal inconsistencies within the legislation that verge on logical contradictions. The medically related criteria, which require that a patient have a grievous and irremediable medical condition, ostensibly set independent medical limits on access to MAiD. However, these criteria ultimately collapse into autonomy-based considerations, as their application is primarily guided by the patient's preferences, values, and goals rather than by objective medical criteria (25). Track 1 applies when the patient's natural death is reasonably foreseeable (RFND), while Track 2 applies when it is not, thereby including individuals with chronic diseases and disabilities rather than only terminal conditions. However, since RFND is undefined in the legislation, its application relies entirely on professional discretion, without an objective medical basis to guide its determination.

In evaluating the ethical coherence of the MAiD eligibility criteria, this paper adopts the standards of healthcare practice established in Canadian common law as its normative basis. These include the fiduciary duties of healthcare professionals and the common law doctrine of informed consent. In standard healthcare contexts, these principles require professionals to act in the patient's best interests, provide professional recommendations, disclose material risks and alternatives, answer questions, and assess the patient's decision in relation to the standard of care. Informed consent in common law also requires disclosure of the information that a reasonable person in the patient's position would want to know. Although these duties formally remain in place, the shift from a civil law framework to one grounded in criminal law has functionally displaced them. The legal structure governing MAiD functions primarily to protect professionals from prosecution, rather than to ensure that fiduciary obligations are fulfilled or that vulnerable patients are protected. Unlike other areas of healthcare, there is no requirement to assess the best interests of the patient, no duty to recommend for or against the intervention, and no obligation to disclose information that is tailored to the specific circumstances of the patient. Accordingly, this paper compares the MAiD legislation to common law standards in order to identify conceptual inconsistencies and normative gaps that are not addressed by the criminal law framework.

Administrative Eligibility Criteria

The administrative eligibility criteria establish basic restrictions on who can access MAiD. These criteria require that individuals be at least 18 years old and eligible for publicly funded healthcare services by a Canadian government. The age restriction arbitrarily excludes mature minors (individuals under 18 who possess the capacity to make informed medical decisions) from

seeking MAiD (29). In contrast, other jurisdictions, such as Belgium (30) and the Netherlands (31), allow minors to access assisted dying under specific conditions. The residency requirement ensures that only Canadian residents can access MAiD, preventing non-residents from traveling to Canada solely for this purpose. This distinguishes Canada from jurisdictions like Switzerland, where assisted suicide is permitted for non-residents (32).

Informed Consent — Descriptive Analysis

The Criminal Code mandates that before proceeding with MAiD, a healthcare professional must ensure that the patient has given informed consent after being informed of the means available to relieve their suffering, including palliative care. The Model Practice Standard (33) and Advice to the Profession (34) documents elaborate on this requirement, outlining the specific information that must be disclosed and the procedural steps involved in obtaining informed consent. The healthcare professional must obtain informed consent directly from the patient because substitute decision-makers are not permitted to consent to MAiD on behalf of incapable persons. Additionally, the patient must be informed that they may withdraw their request at any time and will be given an opportunity to withdraw consent immediately before the procedure, unless they have signed a waiver of final consent.

The Model Practice Standard specifies that informed consent requires the healthcare professional to discuss all reasonable, accepted, and available treatment options with the patient, including their benefits, risks, and side effects. This includes informing the patient of palliative care options and, for Track 2 patients, additional supports such as counselling services, mental health services, disability support services, and community services. The healthcare professional must also offer consultations with relevant professionals who provide these services, but the patient does not have to access them. For patients choosing self-administered MAiD, the professional must inform them of potential complications, including the possibility that death may not occur. Patients who prefer self-administration must be informed that if the procedure fails or is prolonged, the healthcare professional will not be able to intervene and complete the process unless the patient retains capacity and can provide consent, or they have a written arrangement providing advance consent for healthcare professional administered MAiD.

Informed Consent Normative Analysis

While informed consent is a fundamental requirement in both MAiD and traditional healthcare decision-making, its function in MAiD is fundamentally different. In standard medical practice, informed consent operates within a fiduciary relationship that requires healthcare professionals to act in the patient's best interest (35). Healthcare professionals are required to engage in a deliberative process that includes providing a professional recommendation, disclosing material risks and benefits, exploring reasonable alternatives, and answering any questions the patient may have (36). In addition, traditional informed consent is guided by the standard of "reasonable person in the patient's position," which legally requires healthcare professionals to consider what information a reasonable person with the patient's specific circumstances would want to know before deciding whether to consent (37). This standard emphasizes the importance of tailoring information disclosure based on the patient's unique situation, which reinforces the fiduciary obligation to act in the patient's best interest. By contrast, informed consent in MAiD functions primarily as a procedural safeguard designed to verify compliance with legal requirements rather than to facilitate a deliberative process that serves the patient's best interests. The MAiD legislation requires only that the patient be informed of the legally mandated information, like the means to relieve their suffering and the option of palliative care, without reference to the reasonable person standard or the patient's specific circumstances. This approach shifts the healthcare professional's role from guiding the decision-making process to merely confirming that the patient's request meets the statutory requirements.

This distinction gives rise to three fundamental differences between informed consent in MAiD and traditional medical contexts. First, informed consent in MAiD does not involve a professional recommendation. In standard medical decision-making, informed consent typically involves the disclosure of material risks, benefits, and alternatives within the context of a professional recommended treatment plan. The fiduciary duty of the healthcare professional requires them to apply their medical expertise to assess the patient's condition and guide them toward a decision aligned with their best interest. While the patient retains the authority to accept or reject a recommended treatment (38), the professional's role is active and involves a deliberative process that includes professional judgment. In MAiD, however, the process is fundamentally different. The patient initiates the request for MAiD, and the healthcare professional's role is to assess eligibility and ensure the disclosure of legally required information, not to determine whether MAiD is in the patient's best interest.

Second, there are no material risks to disclose in MAiD. In conventional healthcare, the duty of disclosure is central to informed consent, requiring the professional to disclose any material risks, which are risks that a reasonable person in the patient's position would want to know before providing or withholding consent to treatment (36,37). Legal disputes over informed consent typically arise when a patient was not warned about a material risk, experienced harm as a result, and argues that they would have made a different decision had they been properly informed. In MAiD, however, the procedure does not involve the same kind of risk disclosure because the intended outcome is death. While there may be procedural risks associated with the administration of MAiD, these do not constitute material risks in the legal sense established by *Hopp v Lepp* (36). This distinction underscores that the disclosure requirement in MAiD is limited to informing the patient about the legal eligibility criteria, alternative means to relieve suffering, palliative care, and procedural details, rather than a deliberative assessment of material risks and the potential risks and benefits of the recommended procedure and alternatives.

Third, MAiD exists as an exception to the criminal prohibition on assisting suicide or culpable homicide. Unlike other medical decisions, where informed consent serves as a means of respecting patient autonomy within the framework of a fiduciary relationship, MAiD required a legislative amendment to the Criminal Code to permit healthcare professionals to engage in an act that would otherwise constitute a criminal offense. If the legal framework governing MAiD were not followed, the very same act, administering or prescribing a substance to cause a person's death, would be classified as culpable homicide. The specific classification would depend on the circumstances, ranging from first-degree or second-degree murder, to manslaughter, or criminal negligence causing death (39). This distinction reinforces that informed consent in MAiD is not a medical requirement but a legal safeguard, designed to ensure that the procedure remains within the narrow confines of the law. In contrast, informed consent in traditional healthcare is governed by civil negligence law, where disputes focus on whether the professional provided an adequate standard of care, rather than whether their actions constituted a criminal offense.

Capacity

The Criminal Code specifies that to be eligible for MAiD, a person must be “capable of making decisions with respect to their health.” In standard medical practice, capacity is a necessary condition for informed consent, meaning that without capacity, a patient cannot meaningfully provide or withhold consent (40). Capacity assessments ensure that a patient's decisions genuinely reflect their values and preferences, based on their ability to understand, appreciate, reason, and communicate their choices (41,42). However, the treatment of capacity in MAiD diverges from its role in other areas of medicine in ways that create conceptual inconsistencies and weaken the legislation's intended protections.

In standard healthcare, capacity is embedded within informed consent, which means that a patient who lacks capacity cannot legally provide informed consent. MAiD legislation, however, lists capacity and informed consent as separate eligibility criteria, which creates a logical inconsistency. This separation suggests that a patient could satisfy the requirement for informed consent without having capacity, which is logically incoherent. While in practice, a patient lacking capacity is ineligible for MAiD, the presentation of capacity as a stand-alone criterion creates the illusion of additional protection that does not seem to exist.

Additionally, in most areas of healthcare, capacity is presumed unless there is evidence to the contrary (40). The burden is on the healthcare professional to establish incapacity if it is in doubt. In MAiD, however, capacity must be affirmatively established through an assessment, yet there is no standardized method or tool for making this determination within the MAiD context (43). This lack of standardized capacity assessments raises concerns about consistency and reliability (44). The requirement to establish capacity, combined with the absence of clear evaluation criteria, once again, risk creating the appearance of heightened scrutiny without ensuring substantive protection.

Another major deviation from standard healthcare practice is the exclusion of substitute decision-makers in MAiD. In most areas of medicine, if a patient loses capacity, substitute decision-makers are authorized to make decisions on their behalf, either by following previously expressed wishes or, in their absence, by making best-interest decisions (45,46). This aligns with the fiduciary nature of healthcare, in which professionals must balance autonomy with their fiduciary duties. However, in MAiD, substitute decision-makers are not permitted, and outside of Quebec (47), advance directives for MAiD are prohibited. While a narrow legal exception exists in the form of a waiver of final consent (which is applicable only if the patient was already assessed and found eligible before losing capacity) this provision does not allow for new decisions based on prior wishes or substitute judgment. If a patient loses capacity before the procedure, their prior expressed wishes are legally irrelevant, and MAiD cannot proceed. The exclusion of substitute decision-makers and the inability to rely on prior wishes reinforce that MAiD is fundamentally structured as an act of protecting the healthcare professional from prosecution rather than as a treatment decision governed by fiduciary duties.

The decision-making task required of a MAiD patient varies significantly between Track 1 and Track 2 patients. Track 1 patients, whose natural deaths are deemed reasonably foreseeable, must have the capacity to decide when and how to die, but not whether to die. The decision primarily concerns the timing and manner of death, rather than an existential judgment about the value of continued life. Track 2 patients, by contrast, must decide whether death is preferable to continued life. Their decision involves a complex value judgment about suffering and quality of life, which makes this decision qualitatively different from the decision required of Track 1 patients.

The legislation acknowledges this difference implicitly by imposing an additional protection for Track 2 patients, because they must have given serious consideration to alternative means of relieving suffering. The Advice to the Profession document (34) clarifies that this requirement is distinct from capacity itself. It mandates that the patient must have actively engaged in the process of considering alternatives, rather than merely possessing the ability to do so. The requirement of “serious consideration” implies that Track 2 decisions demand a higher level of deliberation than Track 1 decisions. This distinction raises an important concern because if Track 2 decisions require a more complex evaluative process, then should the capacity standard for these patients be different? Unlike Track 1, where the decision is about controlling the manner and timing of an inevitable death, Track 2 patients must justify why continued existence itself is no longer preferable. This qualitative difference suggests that capacity assessments should logically differ for the two Tracks, yet the legislation does not explicitly account for this disparity.

The distinction between Track 1 and Track 2 patients is further complicated by the ambiguity of “reasonably foreseeable natural death” (RFND). The legislation does not define RFND, leaving its interpretation entirely to professional discretion. In practice,

most MAiD cases fall under Track 1, but it is unclear whether this classification is based on the patient actively dying or merely on an assessor's judgment that death is foreseeable at some indeterminate point in the future (3). For example, some providers have interpreted RFND to include cases where a patient is not actively dying but is expected to follow a predictable trajectory toward death based on age, frailty, or progressive illness (48). This demonstrates that there are some patients assigned to Track 1 who may, in reality, be making Track 2 type decisions, deciding whether to die, rather than when. However, because they are classified under Track 1, they are not subject to the heightened "serious consideration" requirement imposed on Track 2 patients. This analysis suggests that this effectively eliminates any meaningful distinction between Track 1 and 2.

Taken together, these concerns suggest that the treatment of capacity in the MAiD legal framework lacks logical coherence and consistency. The separation of capacity from informed consent creates an eligibility criterion that does not enhance substantive protections. The exclusion of substitute decision-makers and advance directives has no logical basis. The Track 1 versus Track 2 distinction implies that capacity should be assessed differently, but the legislation does not acknowledge this disparity. The ambiguity surrounding RFND allows for broad discretionary interpretations that weaken the consistency of capacity evaluations. Ultimately, the lack of a coherent capacity framework in MAiD risks undermining the integrity of informed consent. By failing to distinguish between different levels of decision-making complexity and by structuring MAiD exclusively around autonomy, the legislation introduces internal contradictions that are absent in other areas of healthcare.

Voluntariness

Voluntariness, like capacity, is a separate eligibility criterion for MAiD. The legislation requires that the patient must have "made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure." In most areas of healthcare, voluntariness is a necessary condition for valid informed consent; if consent is not voluntary, it cannot be valid. As with the analysis of capacity, presenting voluntariness as an independent eligibility criterion creates a conceptual inconsistency. By listing voluntariness separately, the legislation creates the appearance of a more rigorous standard without providing any additional protection. This approach raises concerns about the internal coherence of the eligibility criteria.

The legislation requires that a request for MAiD must be voluntary and not the result of external pressure. This requirement differs fundamentally from traditional healthcare contexts, where it is the consent to a treatment that must be voluntary rather than the request itself. In traditional healthcare, a patient's consent is typically a response to a professional recommendation and must be free from coercion, undue influence, and misrepresentation to be valid (49). The focus is on ensuring that the patient's decision to accept or refuse a recommended treatment reflects their autonomous will, following a deliberative process guided by a healthcare professional's recommendation. By contrast, in MAiD, it is the request that must satisfy the criteria of voluntariness and freedom from external pressure, independently of informed consent. This distinction suggests a fundamental conceptual difference in how voluntariness is understood in MAiD compared to traditional healthcare. Since the request must be voluntary and free from external pressure, it is unclear what additional role informed consent plays beyond the procedural disclosure of legally required information.

Next, the legislation's requirement that a MAiD request must not result from external pressure introduces a further conceptual difference. In most areas of healthcare, the voluntariness of a patient's consent requires the absence of coercion, undue influence, and misrepresentation. If these conditions are already implied by the requirement of voluntariness, then the additional stipulation that the request must be free from external pressure logically implies that external pressure must encompass something beyond these forms of influence. However, the legislation does not define what constitutes external pressure, leaving its meaning undefined rather than merely unclear. The Model Practice Standard (33) and Advice to the Profession (34) documents reinforce that MAiD requests must be made freely and without undue influence from family members, healthcare providers, or others. However, these documents do not clarify what external pressure might entail beyond interpersonal forms of coercion or influence. The Advice to the Profession document, for instance, briefly addresses the impact of social determinants of health but does not provide a substantive explanation of how these factors might constitute external pressure. The absence of a clear definition of external pressure risks making this requirement an empty criterion that lacks substantive meaning.

One possible interpretation is that external pressure may include unjust social conditions that influence a patient's decision to request MAiD. Reports of patients seeking MAiD due to factors such as homelessness, economic hardship, inadequate access to medical care, social isolation, or fear of becoming a burden on others suggest that such conditions may function as a form of external pressure (50-52). If these factors significantly influence a patient's request, it raises a significant ethical concern about whether such requests can be genuinely considered voluntary. If external pressure is understood to include social and economic pressures, then many requests for MAiD might fail to meet the voluntariness requirement. Conversely, if social and economic pressures are not recognized as threats to voluntariness, the current legal framework may allow MAiD to function as a response to social inequities rather than solely to medical suffering. This raises a profound ethical dilemma. A patient may meet all the legal requirements for MAiD but the request is primarily because of intolerable social conditions rather than from a medical condition. Does society want MAiD to be a viable option for them?

The treatment of voluntariness in the MAiD legal framework diverges fundamentally from its treatment in traditional healthcare contexts. By separating voluntariness from informed consent and introducing the undefined concept of external pressure, the legislation creates a conceptual ambiguity that raises significant concerns about the coherence and adequacy of the eligibility criteria. They present the appearance of rigorous criteria intended to protect the vulnerable but lack the necessary conceptual clarity and definitional precision to ensure that voluntariness is meaningfully assessed and safeguarded.

Grievous and Irremediable Medical Condition

In addition to the administrative and the autonomy-related criteria, there are the medically related eligibility criteria. The legislation requires that a patient have a grievous and irremediable medical condition, which is defined as meeting three conditions: 1) a serious and incurable illness, disease, or disability; 2) an advanced state of irreversible decline in capability; and 3) physical or psychological suffering that is intolerable to the patient and cannot be relieved under conditions the patient considers acceptable. These criteria ostensibly impose a medical threshold that must be satisfied before MAiD is permitted. However, a closer analysis reveals that these terms lack independent medical definitions and instead defer to the subjective preferences, values, and goals of the patient. As a result, the requirement that a person have a grievous and irremediable medical condition functions as a validation of patient autonomy rather than as an independent medical standard.

Incurability

The term “incurable” appears to impose a medical requirement by implying that only those with a condition that cannot be treated are eligible for MAiD. However, the Model Practice Standard and Advice to the Profession documents explain that incurability means “no reasonable treatments remaining,” where reasonableness is determined through a collaborative discussion between the patient and professional. This means that incurability is not based on an objective clinical determination of medical futility, but rather on whether the patient subjectively deems available treatments acceptable. Furthermore, patients are not required to attempt available treatments before being considered incurable. While a professional must confirm that “recognized, available, and potentially effective treatments” exist, the assessment of whether they are reasonable depends on the patient’s subjective preferences, values, and goals. The patient’s subjective interpretation of what constitutes an acceptable treatment ultimately determines whether a condition is “incurable.” If a patient refuses treatments that a provider might consider effective, they can still be considered to have an incurable medical condition.

Irreversible Decline

The requirement that a person be in an advanced state of irreversible decline in capability also appears to introduce a medical standard. However, the Model Practice Standard and Advice to the Profession documents specify that “capability” refers to the ability to undertake activities that are meaningful to the person. The definition of “irreversible decline” depends on whether a person’s ability to function in ways that matter to them has been severely reduced. This means that decline is assessed in relation to the patient’s personal values and expectations about their life. A patient may have a stable condition with minimal change in physical health but may still be considered to have experienced an irreversible decline if they perceive their ability to engage in meaningful activities to be significantly diminished. The criterion for irreversible decline thus shifts from a clinical determination to a value-based interpretation of function. Because of this subjectivity, there is no fixed medical standard for what qualifies as an “advanced state of irreversible decline.” The same condition might be deemed irreversible for one patient but not for another, depending on how the individual interprets their own functional capabilities.

Intolerable Suffering

The third element of a grievous and irremediable medical condition is physical or psychological suffering that is intolerable to the patient and cannot be relieved under conditions they consider acceptable. The phrase “intolerable to them” makes clear that the patient’s assessment alone is decisive. Unlike incurability or irreversible decline, which at least involve some degree of medical interpretation, intolerable suffering has no external validation requirement whatsoever. A patient does not need to demonstrate suffering through any objective measure. A professional does not assess whether the suffering is medically unmanageable. Instead, the only relevant question is whether the patient states that their suffering is intolerable.

Summary of the Grievous and Irremediable Medical Condition Criterion

Taken together, the three components of the grievous and irremediable medical condition criterion are defined and assessed in ways that rely heavily on the patient’s own account of their illness, decline, and suffering. Each element requires a professional to confirm the presence of a condition but ultimately defers to the patient’s preferences, values, and goals in determining whether it qualifies. While this approach may be ethically appropriate in many cases and may reflect good clinical practice, it carries an important conceptual consequence, namely that the medically related eligibility criteria become extensions of the patient’s autonomous request, rather than objective medical criteria. The result is that Canada’s MAiD framework, while formally adopting the joint view that requires both autonomy and a medical condition, in practice permits interpretations that closely resemble the autonomy-only model. This observation is not a critique of individual decisions but a clarification of how the structure of the law functions in practice.

Summary of the MAiD Eligibility Criteria

The MAiD eligibility criteria appear to impose distinct legal requirements, but a closer analysis reveals significant conceptual and structural inconsistencies. The separation of voluntariness and capacity from informed consent creates the illusion of enhanced safeguards, despite the fact that these conditions are logically inseparable from consent itself. The informed consent requirement is reduced to a procedural formality focused on legal compliance, rather than a deliberative process grounded in fiduciary obligations. The medically related criteria, while ostensibly establishing objective clinical standards, are ultimately determined by the patient’s subjective interpretation of incurability, decline, and suffering. As a result, the legal framework collapses into a model that affirms autonomous requests rather than constraining them through objective medical standards. These features create the appearance of rigour without ensuring substantive protection, particularly for vulnerable individuals. While the law formally adopts a joint model that combines autonomy with medical criteria, in practice it permits applications

that align more closely with an autonomy-only model. This gap raises serious ethical concerns about whether the eligibility criteria can fulfill the Supreme Court's requirement that MAiD be accompanied by stringent and well-enforced safeguards to protect the vulnerable. Given these structural and conceptual deficiencies, the fact that a patient meets the legal eligibility criteria cannot, on its own, establish that it is morally permissible for a healthcare professional to provide MAiD.

MAiD AND PROFESSIONAL DISCRETION

The provision of MAiD is not a legal duty but a legal privilege, a distinction that has significant implications for when it is ethically justifiable for a healthcare professional to provide MAiD (53). In legal theory, a claim right imposes a corresponding duty on another party. A competent patient's right to refuse medical treatment, for example, creates a legal obligation for healthcare professionals to respect that decision, even if they believe it is not in the patient's best interest. This duty is rooted in the concept of bodily integrity. A healthcare professional may not touch a patient without consent, which puts them under a legal obligation to obtain consent. Otherwise, they could be liable for the tort of battery. In contrast, a privilege permits an action, but the action is not a requirement. MAiD falls into this category, it is legally permitted under specific conditions, but no healthcare professional is legally required to provide it.

This distinction is explicitly reflected in section 241.2(1) of the Criminal Code, which states that "A person may receive medical assistance in dying only if they meet all of the following criteria." In legal terms, "may" means that an action is permitted but not obligatory (54). If the law intended to impose a duty to provide MAiD, it would have used the word "must." The permissive wording makes clear that the decision to provide MAiD remains at the discretion of the healthcare professional. Unlike a competent patient's right to refuse treatment, which creates a legal duty to comply, even if a patient meets all the eligibility criteria for MAiD, the healthcare professional does not have a corresponding duty to perform the procedure.

The discretionary nature of MAiD is not an unintended consequence of legislative wording but a necessary structural feature of the law. The Supreme Court, in the *Carter* decision (1), recognized that MAiD must operate within a system of stringent limits and scrupulous monitoring. This requirement necessarily involves the professional judgment of healthcare professionals, who must determine whether those limits have been met in each case. Additionally, the MAiD legislation creates a narrowly controlled legal exception to the prohibition on culpable homicide. This reinforces that MAiD is a permissible but restricted act. The discretionary nature of MAiD is further demonstrated by variability in its application. Some providers adopt a more restrictive interpretation of the eligibility criteria, while others take a more permissive approach. Doctor shopping has emerged as an observable phenomenon, where some patients seek out high-volume MAiD providers known for their more flexible interpretations of eligibility (55).

Since every decision to provide MAiD involves professional discretion, ethical practice requires that this discretion be exercised in a manner that is transparent, accountable, and guided by principled ethical reasoning. Some professionals may argue that once a patient meets the legal eligibility criteria and safeguards, MAiD should be provided as a matter of course (56). However, such a position is neither a legal requirement nor a medical determination. Rather, it is a normative stance that defers entirely to the principle of respect for patient autonomy. Every decision to provide MAiD is a normative judgment about whether providing MAiD is appropriate in a given case. The next section will develop an ethical framework to structure this discretion, outlining the conditions that must be satisfied for it to be morally permissible for a healthcare professional to provide MAiD.

ETHICS FRAMEWORK

The need for an ethics framework for MAiD arises from a fundamental gap in Canadian public policy and legislation. While the legislation sets out conditions under which a patient may be eligible for MAiD, there is little guidance in Canada to help determine when it is morally permissible for a healthcare professional to administer this procedure. This paper proposes an ethics framework grounded in the fiduciary obligations of healthcare professionals and structured around the four core principles of healthcare ethics: autonomy, beneficence, nonmaleficence, and justice. The framework recognizes that every decision to provide MAiD involves a normative judgment, and that such judgments must be guided by professional duties to respect patient autonomy (autonomy), to promote the patient's best interests (beneficence), avoid harm (nonmaleficence), and ensure that the request arises in a context justice (justice). On this account, it is morally permissible for a healthcare professional to provide MAiD only when the patient is autonomous (understood in terms of capacity, voluntariness, and informed consent), when the intervention aligns with beneficence and nonmaleficence, and when the request arises from a situation of injustice or cruel choice that renders the patient unable to act on their autonomous wish to die without assistance.

Moral Foundation of the Ethics Framework

The term "Medical Assistance in Dying" (MAiD) was deliberately created to replace more emotionally charged terms like "voluntary euthanasia" and "assisted suicide." (11-14) This linguistic shift was not merely semantic but a deliberate effort to frame MAiD as an ordinary end-of-life option, comparable to palliative care or the withdrawal of life-sustaining treatment. The goal was to present MAiD as a neutral and medically legitimate option for patients at the end-of-life. However, this framing overlooks the ethical concern that MAiD involves the deliberate act of killing. Since killing is *prima facie* morally wrong, it requires a compelling justification to be considered morally permissible. Recognizing this reality is the starting point for the ethics framework, which contends that there is a *prima facie* duty not to cause death.

According to W.D. Ross's moral theory, a *prima facie* duty is a moral obligation that holds unless overridden by a compelling justification (20). The duty not to kill, therefore, creates a strong presumption against the provision of MAiD, which can be set aside only if there are sufficiently strong ethical reasons. The fact that MAiD is legally permitted does not, in itself, provide such a justification. The ethical question is not merely whether MAiD can be legally provided but under what conditions it can be morally permissible for a healthcare professional to provide it. Ross's distinction between the right and the good is particularly useful in this context. Even if a specific act of killing could be justified for morally good reasons, such as relieving intolerable suffering, it remains a *prima facie* wrong act. The duty not to kill is not negated by the presence of good reasons but must be weighed against them. This distinction underscores that the act of causing death is not rendered ethically neutral simply because it is pursued for compassionate reasons or aligns with a patient's autonomous choice.

The distinction between legal eligibility and moral permissibility is crucial because moral permissibility depends on individual circumstances rather than being a member of a category or group of people. Legal eligibility for MAiD establishes a class of individuals who may access the procedure, but it does not follow that MAiD is morally permissible for every member of that class. The law determines eligibility by setting broad criteria, but ethical reasoning requires a case-by-case evaluation to determine whether it is justifiable for a healthcare professional to provide MAiD in a given instance. The *prima facie* duty not to kill remains in effect unless specific ethical conditions are met that justify overriding it. Therefore, even if a patient meets the legal eligibility criteria, the provision of MAiD is not automatically morally permissible. The ethical permissibility of providing MAiD must be assessed in each case by evaluating whether the healthcare professional's decision aligns with the principles of autonomy, beneficence, nonmaleficence, and justice, understood within the fiduciary obligations of clinical practice.

Informed Consent, Capacity, and Voluntariness

The ethical analysis of informed consent in MAiD must begin by acknowledging its deficiencies in the current legislative framework. While the legislation presents informed consent as an eligibility criterion, it emphasizes the disclosure of legally mandated information but does not sufficiently address the deliberative process that characterizes informed consent in traditional healthcare contexts. In contrast, outside of MAiD, informed consent is a fiduciary obligation that extends beyond mere disclosure of information; it requires healthcare professionals to engage in a meaningful exchange of information, assess the patient's capacity and voluntariness, and support autonomous decision-making within the professional's duty to act in the patient's best interest.

The inherent power imbalance between patients and healthcare professionals necessarily entails a fiduciary relationship (57). A fiduciary relationship is one that imposes legal and ethical obligations on healthcare professionals to act with loyalty, honesty, and good faith towards their patients. Fiduciary duties include the positive duty to act in the patient's best interest (beneficence), the negative duty to do no harm (nonmaleficence), as well as duties to provide accurate information, and to exercise independent judgment that balances professional expertise with the patient's preferences. Thus, respecting autonomy in the context of MAiD requires more than merely disclosing legally required information; it requires fulfilling fiduciary duties to genuinely attempt to compensate for the patient's vulnerabilities.

One of the fundamental deficiencies of the current legislative framework is the separation of capacity and voluntariness as independent eligibility criteria. This separation is both illogical and misleading because capacity and voluntariness are necessary conditions for valid informed consent. If a patient lacks capacity or if their consent is not voluntary, then the consent itself is invalid, regardless of whether it meets the legislative criteria. By treating these elements separately, the legislation creates the appearance of additional safeguards while adding no substantive protection beyond what informed consent already requires. To address this conceptual inconsistency, the ethics framework reintegrates capacity and voluntariness as inherent components of informed consent.

The current legislative standard for capacity in MAiD, which requires that patients be "capable of making decisions with respect to their health," mischaracterizes the nature of the decision involved in MAiD. The decision a patient must make is not a general decision with respect to their health but about when and how to die (Track 1) or whether death is preferable to continued life (Track 2). Framing this decision as a decision about healthcare in general fails to capture its distinct ethical dimensions. The ethics framework contends that capacity in the context of MAiD must involve a comprehensive assessment of the patient's understanding, appreciation, reasoning, and ability to express a choice, directly related to the decision to request MAiD, not to healthcare decisions in general. For Track 1 patients, the decision primarily concerns the timing and manner of death. Therefore, the capacity assessment must focus on the patient's understanding and appreciation of the implications of this decision, including the available alternatives and the foreseeable consequences. For Track 2 patients, who are not facing imminent death, the decision is fundamentally different. It involves evaluating whether death is preferable to continued life. This type of decision requires a more rigorous assessment of the patient's understanding, appreciation, and reasoning capabilities, as it entails a complex value judgment about the patient's quality of life and why it is so poor that death is the preferable alternative. In both tracks, the ethics framework requires that capacity be assessed concerning the specific decision facing the patient in their specific track, not as an ability to make healthcare decisions in general.

Voluntariness and capacity are necessary conditions for informed consent, and their significance lies in ensuring that the patient's consent to MAiD is autonomous. While there is no objection to ensuring that the request for MAiD is made voluntarily, the ethically decisive issue is whether the patient provides informed consent to undergo MAiD while they still have capacity and that they do so voluntarily. The focus must be on the validity of consent, rather than merely on the voluntariness at the

time of the initial request. The legislation, however, separates voluntariness and capacity as independent eligibility criteria, creating the misleading impression that voluntariness applies specifically to the request, while capacity is reassessed at the time of the MAiD procedure. This separation fails to enhance patient protection and instead introduces a structural inconsistency. Since a MAiD request is written, signed, and witnessed without a healthcare professional present, the professional cannot assess voluntariness at that time. What is logically and ethically more relevant is that the patient has capacity and gives voluntary consent to undergo MAiD at the time of providing consent, not necessarily at the time of the request.

The legislation imposes an additional requirement that the patient have capacity at the time of the procedure, but this does not reflect the fundamental principle of informed consent in medical ethics. Informed consent is a process, not a singular event, and its validity hinges on the patient's capacity and voluntariness at the time of providing consent, not at the time of the procedure. The critical issue is whether the patient had capacity and provided consent voluntarily, not whether they retain them at the time of the procedure. Applying this standard to MAiD would mean that if a patient had capacity at the time of providing informed and voluntary consent, then requiring a final capacity assessment at the moment of the procedure would be an arbitrary requirement that does not offer any additional ethical protection. The legislation's separation of capacity and voluntariness from informed consent creates an illusion of rigour while undermining the ethical coherence of the decision-making process.

Beneficence, and Nonmaleficence

In the beneficence and nonmaleficence analysis of this framework, the healthcare professional's task is to make an independent, professional determination of whether providing MAiD meets the ethical requirements for professional involvement. This determination must be made independently of the patient's personal preferences, values, and goals, which are addressed separately in the autonomy analysis. It is analogous to the process in ordinary clinical practice where, after diagnosis, the professional identifies the standard of care and the range of clinically reasonable alternatives before engaging in shared decision-making with the patient. In this framework, the standard of care refers to the course of action that a reasonably prudent practitioner — with comparable skill, knowledge, and expertise — would judge to be appropriate in similar circumstances, based on an assessment of the patient's condition and the available evidence (58).

Beneficence requires that the professional act in the patient's best interest. This involves an objective, evidence-based determination that MAiD meets the standard of care and would serve the patient's best interest better than any other available option, including palliative care, medical interventions, or psychosocial supports. The principle is not satisfied by simply affirming the patient's own assessment of their best interest. If beneficence is not met, the provision of MAiD is not ethically defensible, regardless of the patient's autonomy.

Nonmaleficence requires that the professional avoid causing harm. In this framework, death and killing are treated as harms, and the *prima facie* duty not to kill establishes a strong *prima facie* duty that MAiD should not be provided if a less harmful option exists. The professional must therefore determine, from among all clinically reasonable alternatives, whether any option can relieve the patient's suffering with less harm than causing death. This includes considering medical, palliative, and psychosocial interventions. Nonmaleficence is satisfied only if violating the duty not to kill is the least harmful course of action available. If another option offers equal or greater relief with less harm, MAiD must not be provided.

For Track 1 patients, who are approaching natural death, the assessment focuses on whether an earlier death, chosen and controlled by the patient, is both in their best interest and the least harmful option. For Track 2 patients, who are not facing imminent death, the assessment is more demanding. It must be shown that death itself is in the patient's best interest and that MAiD remains the least harmful option after all other reasonable interventions have been considered and exhausted.

The principles of beneficence and nonmaleficence require the healthcare professional to determine the standard of care and assess all clinically reasonable alternatives independently of patient preferences. (Patient preferences are already addressed via the autonomy analysis of the previous section as well as the cruel choice section.) Under this framework, MAiD is ethically permissible only if it meets the standard of care, serves the patient's best interest, and is the least harmful available option. Assessing these principles as independent, objective determinations ensures that professional judgment plays a substantive role in the ethics analysis. If either principle is applied with reference to patient preferences at this stage, it becomes a restatement of autonomy, which collapses the joint view into an autonomy-only model.

The Cruel Choice is Necessary for the Provision of MAiD

A major part of the ethical justification for MAiD has its origins in what the Supreme Court, in the *Carter* decision (1), referred to as the cruel choice. The Court identified this dilemma as arising when individuals, due to the natural history of a medical condition, foresee a future in which their quality of life will become unacceptable to them. When they reach this point, they anticipate that they will no longer have the physical ability to end their life without assistance. Before MAiD was legalized, the prohibition on assisted suicide and consenting to death forced individuals facing this cruel choice to decide between ending their life prematurely while still physically capable of doing it on their own (which means that they will miss out on a quality of life that they find acceptable) or continuing to live until their suffering becomes intolerable, at which point they would be unable to end their life without assistance. This dilemma was central to the Court's ruling in *Carter* and illustrates a structural injustice. It imposes a disadvantage on those whose medical condition impairs their ability to act on their autonomous wish to die. In this

respect, the cruel choice is not merely a legal concept, but an instance of a broader ethical concern grounded in the principle of justice.

Accordingly, this ethics framework treats the justice considerations like the cruel choice as a necessary component of the ethical permissibility of MAiD. In the absence of this condition, MAiD risks being reduced to a mere accommodation of patient preference rather than a professional response to a legitimate medical need. Canadian law does not prohibit individuals from ending their lives without assistance (i.e., suicide). What requires ethical justification is the involvement of a healthcare professional. That justification must rest on more than a patient's autonomous request; it must include a reason for professional intervention. A core function of medicine is to assist individuals whose illnesses impair their ability to act on their autonomous decisions. When a medical condition renders a person physically incapable of ending their life unaided, the need for professional involvement arises not to fulfill a preference, but to address a medical limitation that constitutes a form of structural injustice. It is in this sense that the cruel choice transforms MAiD from an expression of autonomy into a response to a medical and ethical dilemma that justifies professional involvement under the principle of justice.

There are three necessary elements that when taken together constitute the cruel choice. All three conditions are necessary. First, the patient must be able to provide informed consent as outlined in the previous section. This guarantees that the pursuit of MAiD is truly autonomous. Second, the patient must determine that their quality of life is unacceptable. This is a purely subjective determination, meaning it is entirely up to the individual to decide when their quality of life has become intolerable. The Supreme Court in *Carter* and, before that, in *Rodriguez* (59), made it clear that the standard was when the person finds their quality of life intolerable to them, in their own judgment. There is no requirement that the person be experiencing physical suffering. They may consider their quality of life unacceptable for any reason that is significant to them. Third, the patient must be incapable of ending their life without medical assistance. This condition makes professional involvement a matter of justice (60) — in the sense that it helps those who are the worst off — rather than patient preference, which ensures that MAiD remains a response to a medical dilemma rather than an accommodation of patient autonomy. The mere presence of an illness, disease, or disability does not justify a healthcare professional's active role in assisting suicide or causing death. Instead, the patient's physical functioning must be such that they are unable to act on their autonomous decision without medical assistance.

Assisted Suicide and Voluntary Euthanasia

A crucial aspect of the ethics framework is the distinction between assisted suicide and voluntary euthanasia, a distinction that the current legislative framework for MAiD in Canada does not use fully. Assisted suicide involves a healthcare professional providing a patient with the means to end their own life, such as a prescription for a lethal substance that the patient self-administers. In this case, the act of ending life remains the patient's own. Voluntary euthanasia, by contrast, involves a healthcare professional actively administering a substance that causes the patient's death, making the professional the direct agent of death. This distinction is morally significant because it shifts the ethical burden. Assisted suicide respects patient autonomy while minimizing the professional's direct role in causing death, whereas voluntary euthanasia makes the professional the agent of death.

The case of Sue Rodriguez illustrates this distinction. Diagnosed with ALS, Rodriguez argued before the Supreme Court for the right to receive assistance to end her life once she decided that her quality of life was no longer acceptable but could no longer end it herself without assistance. Importantly, Rodriguez did not seek voluntary euthanasia but only the assistance of a qualified medical practitioner to set up the technological means for her to self-administer a lethal substance, by her own hand. Her case emphasized the ethical justification for assisted suicide, which is maintaining patient autonomy without making the healthcare professional the direct agent of death. While the Court ultimately rejected her appeal, her case laid the groundwork for the subsequent *Carter* decision.

This distinction is not merely theoretical. A number of jurisdictions that permit assisted death explicitly allow assisted suicide but prohibit voluntary euthanasia. In the United States, assisted suicide is legal in more than eleven states, none of which permit voluntary euthanasia. For example, states such as Oregon (61), Washington (62), and California (63) have legalized assisted suicide under *Death with Dignity Acts* but prohibit healthcare professionals from performing euthanasia. Similarly, Switzerland permits assisted suicide if the act is not motivated by self-interest yet bans euthanasia outright. These practices reflect a widely recognized ethical and legal principle that actively causing death carries a heavier moral burden than providing the means for a patient to end their own life. In Canada, however, over 99.9% of MAiD procedures have been voluntary euthanasia, a statistic that raises significant ethical concerns about whether the current practice adequately distinguishes between those who need professional assistance due to physical incapacity and those who do not (3,64-67).

In both Track 1 and Track 2 cases, the cruel choice framework applies equally. The ethical justification for professional involvement arises only when a patient's medical condition will make them physically incapable of ending their life without assistance (i.e., suicide). Where a patient retains the physical ability to self-administer, assisted suicide should be the preferred option, with voluntary euthanasia ethically reserved for those who cannot self-administer even an oral medication. The case of Sue Rodriguez illustrates this principle. She sought to preserve the ability to end her life by her own hand at the point when ALS would make this physically impossible, requesting professional assistance only to set up the means for self-administration. This reflects the ethical distinction between respecting autonomy through assisted suicide and making the professional the direct agent of death through euthanasia. Without such incapacity, the mere presence of illness, disease or disability does not, on its own, justify a professional actively ending a patient's life.

Summary of the Ethics Framework

The ethics framework establishes that the *prima facie* duty not to kill can only be overridden under specific conditions. These conditions require that the patient provide informed consent, which necessitates capacity and voluntariness, and that the healthcare professional independently determine that MAiD is in the patient's best interest and represents the least harmful option. Additionally, the patient must be facing a situation where they find their quality of life unacceptable and are physically incapable of ending their life without medical assistance. When these conditions are not met, the *prima facie* duty not to kill remains in force.

The logical implication of a patient not meeting the ethical standards for MAiD is that other, less harmful interventions remain available, or the patient does not need the assistance of a healthcare professional to achieve their autonomous desires. This does not amount to abandonment or a denial of care but rather affirms the principle that professional participation in MAiD is only ethically permissible when no better alternative exists. Patients who do not satisfy the conditions outlined in the ethics framework retain access to treatments and supports that better serve their interests and mitigate harm. The ethical significance of this conclusion is that healthcare professionals cannot justifiably provide MAiD when these alternatives remain viable. The ethics framework does not prescribe what a patient must do; rather, it delineates when it is morally permissible for a healthcare professional to provide MAiD. Upholding this ethical boundary ensures that MAiD remains a response to a legitimate medical need rather than a mechanism for accommodating patient preference.

An important implication of this framework is that when a patient remains physically capable of ending their life without assistance, the justice-based rationale for professional involvement in MAiD does not apply. Suicide has been decriminalized in Canada since 1972, so the question is not whether individuals may end their lives, but when is it morally permissible for a healthcare professional to assist. The *Truchon* decision distinguishes suicide from MAiD partly on the basis that professional involvement may spare loved ones the trauma often associated with suicide (68). Empirical studies have explored how individuals and families experience this distinction, including perspectives from those with complex chronic conditions and from people living with mental illness as a sole underlying condition (69,70). While such accounts shed light on the emotional and relational dimensions of these decisions, they do not in themselves establish a principled ethical basis for professional involvement in an autonomy-only model. Other jurisdictions, such as Germany and Estonia, address such concerns outside the healthcare system. Within this framework, a necessary condition of morally permissible professional participation is when it addresses a medical limitation that prevents the patient from acting on their autonomous decision without assistance, thereby making MAiD a matter of justice.

This framework sets out the minimum ethical conditions that must be met for the provision of MAiD to be ethically defensible. Any critique of this framework, aside from a categorical rejection of MAiD as inherently unethical, must challenge one of two (or both) necessary conditions: either 1) the conception of informed consent incorporating fiduciary duties of beneficence and nonmaleficence, or 2) the justice condition. However, rejecting the fiduciary model of informed consent reduces any alternative position to an autonomy-only model, where professional judgment plays no substantive role. Likewise, if one rejects the justice condition, then no medical basis remains to justify healthcare professional involvement, again collapsing into an autonomy-only model. This demonstrates that any alternative position must ultimately rely on the claim that patient autonomy alone is sufficient to justify the provision of MAiD by a healthcare professional. Neither the Courts nor Parliament envisioned an autonomy-only model for MAiD, yet by failing to define substantive ethical and medical criteria, the legal framework has effectively allowed an autonomy-only model to emerge under the guise of legal eligibility criteria and procedural safeguards.

CONCLUSION

This paper has critically examined the ethical foundation of MAiD in Canada. It demonstrates that the legal framework establishes the conditions under which a patient is considered eligible for MAiD but there is little guidance to help healthcare professionals determine when it is morally permissible to provide MAiD. A fundamental flaw in the current system is that it treats professional participation as a matter of procedural compliance rather than substantive ethical judgment. By focusing primarily on patient values, goals, and preferences, the legal criteria collapse into a verification of patient autonomy rather than an independent medical determination of a grievous and irremediable medical condition. This approach fails to recognize that professional participation in MAiD, demands an explicit ethical justification beyond mere legal eligibility.

To address this gap, this paper proposes an ethics framework grounded in the fiduciary duties of healthcare professionals and structured by the four core principles of healthcare ethics: respect for autonomy, beneficence, nonmaleficence, and justice. The framework holds that providing MAiD is morally permissible only when the patient is autonomous, understood in terms of informed consent, voluntariness, and capacity; when the intervention aligns with the duties of beneficence and nonmaleficence, requiring the professional to exercise independent clinical judgment; and when the request arises from a context of justice, exemplified by the cruel choice, in which a medical condition impairs the patient's ability to act on their autonomous wish to die without assistance. This approach ensures that MAiD is not merely a discretionary affirmation of patient autonomy but a medically and ethically permitted intervention grounded in professional fiduciary duties.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Why Track 2 MAiD is Discriminatory

Isabel Grant^a

Résumé

Cet article soutient que le régime canadien d'aide médicale à mourir (AMM) de type « Track 2 » est discriminatoire envers les personnes handicapées, ayant un impact disproportionné sur les femmes handicapées. Il est important de mettre en lumière les lacunes critiques dans la défense de l'AMM, qui occultent la manière dont la marginalisation systémique façonne l'accès à l'aide médicale à mourir. Fondé sur un modèle médical du handicap qui considère la souffrance liée au handicap comme exceptionnellement intolérable, le régime d'aide médicale à mourir de deuxième voie présente des risques accrus pour les personnes déjà défavorisées par les inégalités structurelles. En présentant la mort comme un traitement médical, la loi renforce les préjugés discriminatoires qui considèrent que les personnes handicapées seraient mieux mortes plutôt que de leur fournir l'accès à des aides essentielles. Ces inégalités sociales sont exacerbées pour les femmes handicapées qui sont victimes de taux alarmants de violence masculine, de l'intersection entre le capacitisme médical et le sexisme, ainsi que de l'idée préconçue selon laquelle les femmes devraient être des aidantes et non des personnes ayant besoin de soins.

Mots-clés

aide médicale à mourir, AMM, euthanasie, discrimination fondée sur le handicap, capacitisme, sexisme

Abstract

This paper argues that Canada's Track 2 Medical Assistance in Dying (MAiD) regime is discriminatory against people with disabilities, and has a disproportionate impact on women with disabilities. It is important to expose critical gaps in pro-MAiD advocacy, which obscures how systemic marginalization shapes access to assisted death. Premised on a medical model of disability which exceptionalizes disability-related suffering as uniquely intolerable, Track 2 MAiD poses heightened risks for those already disadvantaged by structural inequalities. By framing death as a medical treatment, the law reinforces ableist assumptions that portray people with disabilities as better off dead instead of providing access to essential supports. These social inequalities are heightened for disabled women who experience alarming rates of male violence, the intersection of medical ableism and sexism, as well as the assumption that women should be caregivers and not those needing care.

Keywords

medical assistance in dying, MAiD, euthanasia, disability discrimination, ableism, sexism

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INTRODUCTION

In this paper, I make two basic claims about Canada's regime of medical assistance in dying for people who do not have a reasonably foreseeable natural death (Track 2 MAiD) (1)¹. First, that Track 2 MAiD is discriminatory against people with disabilities generally, and second, that it has a disproportionate, indirect impact on women with disabilities such that it also constitutes sex discrimination. It is important to unpack why women may be disproportionately at risk of having their lives ended under Track 2.

Both Track 1 and Track 2 MAiD require that the individual have a grievous and irremediable medical condition. This is comprised of a serious and incurable illness, disease or disability, an advanced state of irreversible decline in capability, and physical or psychological suffering that is intolerable to the individual and that cannot be remediated by means that are acceptable to that individual. The difference between these two tracks lies primarily in the fact that under Track 1, a reasonably foreseeable natural death is required whereas for Track 2, the individual need be nowhere near death. There are some additional safeguards associated with Track 2, such as a 90-day assessment period, but eager providers have learned how to circumvent many of those safeguards. An individual must be told what means are available to alleviate their suffering, but those means need not be provided, funded or made accessible to the individual. In other words, there is no legal obligation to attempt to alleviate the suffering of an individual accessing Track 2 other than through the provision of death.

While I am focusing on Track 2 as being discriminatory, I must start with an important caveat. While Track 1 and Track 2 are different in principle, we are increasingly learning that they blur in practice. The principle that differentiates them, of course, is that under Track 1 the person is *supposed* to be already dying (2). Track 1 was intended to deal with the suffering of a difficult death. Track 2, by contrast, deals with the suffering of a difficult life. In both contexts, death is put forward as the solution and presented as a form of medical treatment.

However, in Canada reasonably foreseeable natural death has been interpreted by some medical practitioners as only requiring that death be predictable from the irremediable medical condition, which, if correct, means that some individuals may

¹ I use Medical Assistance in Dying (MAiD) in this paper for convenience. However, I agree with other scholars that this term must be contested, especially in the context of Track 2 where individuals may be nowhere near the end of their lives and those lives are being ended by physicians and nurse practitioners.

have years left to live but nonetheless can be classified as Track 1 (2)². Furthermore, some practitioners are willing to provide Track 1 on the basis that the individual has demonstrated a serious intent to stop eating or to refuse routine medical treatment like antibiotics (3). Thus, while we may have a principled difference between the two tracks, there are ways to circumvent what was intended as a safeguard but has been characterized by proponents as a barrier to access (4).

Before looking at the substance of section 15 of the *Charter*, Canada's equality guarantee, there are two preliminary points that are important to understanding why Track 2 MAiD is discriminatory.

First, and this point is central to understanding the discrimination argument, every person who accesses Track 2 MAiD (as well as Track 1) has a disability in the eyes of the law. While not everyone who has a disability will qualify for Track 2, everyone who has a grievous and irremediable medical condition — which by definition involves a serious and incurable illness, disease or disability, an advanced state of irreversible decline in capability and intolerable physical or psychological suffering — is disabled in the eyes of the law. While there is no universal definition of disability in Canadian law, if one looks at definitions in human rights statutes (5-6)³, the *UN Convention on the Rights of Persons with Disabilities* (7)⁴, and other federal statutes (8,9), one will see that a grievous and irremediable medical condition satisfies every relevant legal definition of disability. This is true whether or not the person self-identifies as being disabled. Self-identification as disabled is complex in light of the stigmatization associated with the label of disability and the degree to which internalized ableism may prevent many people from attributing that label to themselves (10,11). But Canadian law does not distinguish between illnesses, diseases and other forms of disability. All of these come within the umbrella term of disability, especially when coupled with an irreversible decline in capability and intolerable suffering. From a legal perspective, everyone who qualifies for MAiD is disabled regardless of whether one identifies as such. This point is important because if everyone who accesses Track 2 MAiD is disabled, and no one who is not disabled can access it, then it becomes clear that the law draws a distinction based on disability — a prohibited ground of discrimination under section 15 of the *Charter*.

The second preliminary point is that MAiD is largely premised on a medical model of disability that constructs disability as a medical shortcoming or a flaw, a deviation from what is normal — something that medicine seeks to fix or eliminate (12). MAiD becomes an option when there are no other medical solutions available. It is notable that the General Comment No. 6 on Equality and Discrimination on the *UN Convention on the Rights of Persons with Disabilities* (7) starts by observing that a medical model of disability is incompatible with the Convention because “persons with disabilities are not recognized as rights holders but are instead ‘reduced’ to their impairments.” (13, p.2, para 8)

While there might be good reasons to have medical practitioners administering MAiD, and perhaps diagnosing whether a condition is irremediable, it is not apparent why doctors and nurse practitioners are the sole gatekeepers for MAiD. In fact, deciding whose suffering warrants a response of death is fundamentally not a medical decision but a normative one about whose lives may be worse than death. Doctors and nurse practitioners have no particular expertise in making this assessment. It is the medicalization of suffering, and the assumption that the suffering experienced by people with disabilities is caused primarily by that disability and is intrinsically different and worse than other human suffering, that leads one to believe that death might be preferable to life with a disability. But suffering is far more complex than simply the symptoms that may or may not accompany a particular disability. One's access to the social determinants of health, for example, may well influence one's ability to live a tolerable life with those symptoms.

This medical construction of human suffering may obscure the social factors that often contribute to and shape one's perception of suffering. Those who can afford adequate home care (14), an accessible and even comfortable place to live (15), and have strong social connections (16-18), are more likely to perceive their suffering as tolerable and may be less likely to perceive themselves as a financial or emotional burden on others (17,18). This reality is compounded by the fact that studies suggest that doctors evaluate the quality of the lives of people with disabilities considerably lower than those individuals rate their own lives (19,20). This is the ableist lens through which people with disabilities interact with the medical profession, a framing that is only exacerbated by the intersections with racism and sexism within the medical profession (21-23).

DISCRIMINATION AGAINST PERSONS WITH DISABILITIES

Section 15 of the *Charter* reads:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability (24).

² Catherine Frazee has documented the story of Julia Lamb, who initiated litigation to extend Track 1 to those who were not dying only to drop her case when she was told by an expert witness that she could qualify for Track 1.

³ The Ontario Human Rights Code includes in its definition of disability “any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness”, “a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language” and “a mental disorder”.

⁴ The purpose of the Convention states that “[p]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

There are two steps to a discrimination analysis under section 15. First, it must be shown that the distinction made by the law is based on one of the enumerated (or analogous) grounds protected by section 15, like mental or physical disability. The second, and most important, step in the MAiD context is to show that that distinction is discriminatory against people with disabilities. I have already shown that everyone who qualifies for MAiD has a disability as that term is understood in law. The intolerable suffering of people with disabilities may be responded to with the option of death whereas that is not the case for the intolerable suffering of any person without a disability. But the law often makes distinctions on the basis of disability — for example, the law might provide financial benefits for people with disabilities that are not available to others. Equality in fact may require us to make distinctions based on disability that are necessary to level the playing field. Thus, the key question is whether the distinction drawn on the basis of disability is discriminatory.

The answer to the discrimination question depends on whether MAiD is properly constructed as a benefit to people with disabilities or a detriment, a subject on which there is considerable debate. Those who support MAiD argue that death may be a benefit to people who are suffering intolerably because it allows them to escape that suffering when other solutions to the suffering have failed (25-27). Those who are concerned about MAiD argue that death is generally conceived of as a detriment and that to posit death as a benefit, but only for people whose suffering can be linked to disability, is itself an ableist premise that is inconsistent with equality for persons with disabilities (2).

The Supreme Court of Canada has observed that people with disabilities have historically faced disadvantages that have been shaped and perpetuated by the notion that disability is an abnormality or flaw:

As a result, disabled persons have not generally been afforded the “equal concern, respect and consideration” that s. 15(1) of the *Charter* demands. Instead, they have been subjected to paternalistic attitudes of pity and charity, and their entrance into the social mainstream has been conditional upon their emulation of able-bodied norms (28, para 56).

This conception of disability as a flaw or abnormality is very much grounded in the medical model of disability. Disability is construed as a flaw that demands a medical response. And we assume that the suffering associated with disability is a medical phenomenon rather than a social one. The final step is to distort death into a form of medical treatment used to ‘cure’ the suffering of disability. But death does not cure suffering; it eliminates the sufferer. So, this s. 15 analysis requires us to assess whether Track 2 MAiD perpetuates or remediates the historical disadvantage of people with disabilities.

The Supreme Court has also explained that laws which widen the gap between the historically disadvantaged group and the rest of society are discriminatory (29). Track 2 MAiD widens the gap between how we respond to the suffering of people with disabilities and how we respond to the suffering of others. That distinction lies at the core of the problem with Track 2. If your suffering is based even in part on an irremediable illness, disease or disability, death may be an appropriate solution to all your suffering, regardless of the role of social factors in that suffering. The fact that the *Criminal Code* is clear that intolerable psychological suffering alone is a sufficient basis for Track 2 MAiD clearly demonstrates that Track 2 is not necessarily about the physical suffering that may be associated with some disabilities. Psychological suffering is not limited to people with disabilities and yet access to MAiD is.

The law against murder makes an unequivocal statement that intentionally ending someone’s life is a harm regardless of whether the victim consents to the death. An Ontario man who allegedly used the Internet to sell suicide drugs to people who wanted to end their lives has been charged with multiple counts of first-degree murder (30-32)⁵. His victims wanted the drugs and voluntarily chose to consume them. Some, if not all, of those victims were almost certainly suffering in ways they perceived as intolerable. Yet, no one is suggesting that we should prioritize the victims’ autonomy and choice to die. Instead, we believe their suffering should have been responded to with suicide prevention in the broadest sense of that term. But if you are disabled, suicide prevention may fall off the table and your death can be funded by the state as well as encouraged, facilitated and caused by healthcare practitioners. Peters has noted that Track 2 MAiD has created a “killable class” (33). There is simply no way that such a “killable class” does not widen the gap between people with disabilities and the rest of society. It is profoundly stigmatizing to suggest that some people with disabilities might be better off dead.

Track 2 MAiD also fundamentally alters the relationship between persons with disabilities and their medical practitioners. Doctors are allowed to offer patients MAiD even where the patient has not raised it or suggested that death is an option they are considering. A medical practitioner suggesting MAiD is a signal that the practitioner has lost hope and an acknowledgement that they believe the person might be better off dead. Some people with disabilities may be deterred from seeing a physician, or from going to the emergency room where they fear being offered MAiD (33). The media is replete with stories of people being offered MAiD on their way into surgery for a mastectomy (34), or upon being diagnosed with cancer (35). In the recently filed constitutional challenge to Track 2 MAiD, the applicants argue that Track 2 MAiD may actually narrow choices:

⁵ At the time of writing there is some dispute about whether Kenneth Law should have been charged with murder or aiding suicide because his victims actually consumed the drugs themselves. The Supreme Court of Canada has heard an appeal in *R v BF*, 2024 ONCA 511 which may resolve this question. There is no dispute, however, that had Mr. Law injected those drugs into his victims, as is done in the overwhelming majority of MAiD cases, first degree murder would have been the appropriate charge.

A health-care provider communicating to a person with a disability that the person could or should consider MAiD, and that death is an option for their suffering, can shape that person's perceptions of their value, dignity and the degree to which they are, or are perceived to be, a burden. An offer of MAiD also communicates that their circumstances are hopeless and that the health care and other systems do not value their lives, and cannot be relied upon to save or support them. MAiD Track 2 thus narrows the range of options that are available, or that persons with disabilities may perceive as available, for dealing with suffering they are finding intolerable (36).

One could argue that the same logic applies to Track 1 MAiD which is almost certainly constitutional, given the decision of the Supreme Court of Canada in *Carter v Canada* (37). Everyone who accesses Track 1 MAiD is also disabled and being offered death. However, Track 1 does not distinguish on the basis of disability in the same way that Track 2 does. The fundamental distinction made by Track 1 is whether the individual has a reasonably foreseeable natural death. The distinction is made between how we treat people who are suffering in the process of dying and those who are suffering in the process of living. Death for Track 1 individuals is presumably inevitable and cannot be avoided, and the question is whether they can be eased into death with less suffering. Track 2 MAiD, by contrast, makes a distinction based on the cause of your intolerable suffering; the distinction is whether you are disabled or not. MAiD to deal with the suffering of life is different than MAiD to deal with the suffering of death⁶. I am not asserting that social suffering never contributes to MAiD deaths under Track 1. Rather, as Frazee explains: “[w]hen the threshold for MAiD was suffering from a medical condition at the end-of-life, the discriminatory effects of the regime had been neutralized, with eligibility contingent upon one's place along the trajectory of life, rather than one's medical or disability status.” (2, p.55) I recognize that this distinction is fragile, however, if MAiD providers are willing to shift Track 2 patients to Track 1 if they refuse food and drink or decline basic medical care.

Another possible response to my discrimination argument is that no one is forced to access Track 2 MAiD — only those who choose it will receive it. If you feel threatened or harmed by Track 2 MAiD, just avoid it; just say no. However, the fact that Track 2 MAiD is contingent on the choice of the recipient does not necessarily insulate the law from s. 15 scrutiny. Choice must be assessed through the lens of ableism and sexism that shape both the choices available to people with disabilities and the choice made. The Supreme Court has consistently held that differential treatment can be discriminatory even if it is based on choices made by the individual — particularly where those choices are constrained by the kinds of systemic inequalities facing people with disabilities. As the Supreme Court said in the *Fraser* decision, you have to look at the social and economic environment in which choices play out to understand whether choice negates discrimination (38). We know that people with disabilities disproportionately live in poverty, and face unemployment and other forms of disadvantage that contribute to them being unable to remediate their social suffering (39-41).

Justice Abella stressed that the structural conditions in which people exist mean that some choices are made more often by people with “particular ‘personal characteristics’.” (38, para 90 [emphasis removed]) That is especially true of Track 2 MAiD where it is a response to intolerable suffering only for those who are disabled. What we are seeing with Track 2 is a choice disproportionately being made by those who are marginalized and those who are women. This should be a huge red flag for those concerned about social justice and yet it has been ignored and obscured by pro-MAiD rhetoric about choice.

Choice in the abstract is simply not a sufficient answer to the discrimination allegation. Those who promote choice as a justification for Track 2 fail to explain why this is a choice only available to people with disabilities. If MAiD is really about ending intolerable suffering, why is it not available to everyone who is suffering intolerably? And if choice is central to the analysis, why do we not prioritize choices that people with disabilities make to continue living or the choices of those who want to commit suicide for reasons unrelated to disability (39-41)⁷. Where choices are driven by state-sanctioned poverty, social isolation, a history of trauma, loneliness, or perceiving oneself to be a burden on others, it is problematic to construct state inflicted death as an autonomous choice. It may be a person's only available choice but that does not make it an autonomous one.

Where the state has deliberately curtailed the range of life-affirming choices open to people with disabilities, a choice between intolerable suffering and death — as Frazee has explained — is a choice between what is bad and what is worse, and that is not an exercise of true autonomy (43, p.66-71). Of the people who received Track 2 MAiD in 2023, 49.2% cited being a burden to their loved ones or caregivers as one of the causes of their intolerable suffering and 47.1% cited loneliness or isolation (18). An alarming 70.4% of Track 2 recipients cited a loss of dignity (18). Track 2 MAiD recipients are disproportionately living lonely and isolated lives which they perceive to be undignified. None of that is inherent to disability. As Benedet has observed, “some choices have such profound consequences, and take place in the context of such inequality, that we ought to preclude them.” (43, p.50)

The focus on choice also obscures the harms caused by Track 2 to people with disabilities who are not seeking MAiD. These individuals are now forced to live in a country whose laws exempt the deaths of some people with disabilities from the crimes of murder and aiding suicide as long as those deaths are carried out by medical practitioners under the MAiD regime. People with irremediable disabilities are now required to engage with medical professionals and others who may believe they are better off dead. It is no longer taken for granted that all people with disabilities who do not have a reasonably foreseeable

⁶ It is again important to refer to the caveat here that the scope of Track 1 has been interpreted so broadly that the differences between the Tracks may eventually have less significance.

⁷ According to 2023 Statistics Canada data, individuals with disabilities experience roughly twice the rates of poverty and unemployment that individuals without disabilities experience. Individuals with disabilities, especially women with disabilities, also experience disproportionate rates of homelessness.

death should continue to live and that their lives are worthy of saving; Track 2 MAiD may lead those who are suffering to reassess whether their own lives are worth living. Briscoe (44) explains why it is harmful to lose the benefit of a default position that one's life should continue.

[E]ven if they never face the overt inquiry from others, [the person] must nevertheless settle the matter in their own mind: why am I still trying to live? Can I come up with sufficient reasons? Is society helping me find a reason to live? The mere offer—even the existence—of [MAiD] forces them out of default territory. Now they *must* choose.

For many, this so-called choice exacerbates suffering rather than relieves it. It adds to the burdens of those who already perceive themselves to be a burden (44).

In March 2025 the United Nations Committee reviewing Canada's performance under the *Convention on the Rights of Persons with Disabilities*, comprised of international experts on disability, in its concluding observations, urged Canada to repeal Track 2 MAiD and not extend Track 1 any further. It confronted the choice issue directly highlighting Canada's refusal to provide access to good choices:

[T]he concept of 'choice' creates a false dichotomy, setting up the premise that if persons with disabilities are suffering, it is valid for the State Party to enable their death without providing safeguards that guarantee the provision of support, and on the basis of ableist assumptions that de-emphasize the myriad of support options that could allow persons with disabilities to live dignified lives, and about the systemic failure of the State Party to address the social determinants of health and well-being with regard to poverty alleviation, access to healthcare, accessible housing, prevention of homelessness, prevention of gender-based violence, and the provision of community-based mental health support and employment support (41, para 19(b)).

These observations have thus far gone unanswered by Canada.

DISCRIMINATION AGAINST WOMEN

The most obvious discrimination caused by Track 2 MAiD is what lawyers refer to as "direct discrimination", i.e., the very purpose of the law is discriminatory. The purpose of the law is to make death available as a means to respond to the intolerable suffering of some people with disabilities. Here the assertion of discrimination refers to a form of direct discrimination. But there is another type of discrimination in law referred to as "adverse impact" or "indirect discrimination" that applies where a law has a disproportionate impact on a protected group, even though that was not the purpose of the law (38). In other words, this discrimination may be completely unintentional but if the impact is adverse on a protected group under s.15, then the law may be discriminatory. Thus, I argue that Track 2 MAiD has had an adverse impact on women with disabilities. This reality of Track 2 MAiD has been largely ignored by Canadian feminist organizations (43)⁸, and obscured in public debate by reliance on numbers of MAiD deaths from Track 1. MAiD proponents focus on the fact that women may be more likely to suffer from MAiD-able chronic illnesses, which I do not dispute. However, the relevant question is why women are more likely to be suffering intolerably from these conditions. I make this argument not because I think this is the basis on which the law is likely to be invalidated. Rather, I use this argument as a device for confronting the particular dangers this law presents to women with disabilities who live at the intersection of ableism, ageism and sexism and often experience other intersecting forms of disadvantage.

Many more people die from Track 1 MAiD than from Track 2 and thus, when looking at overall MAiD numbers, the Track 1 numbers will always overwhelm the Track 2 numbers (18). Track 1 appears to have roughly equal numbers of men and women with slightly more men accessing it (18). It is important to stress, however, that numbers do not tell the whole story, nor even the most important part of the story. If women are disproportionately at risk of accessing Track 1 because of their history of trauma, because they perceive themselves to be a burden, or because they are socially isolated, that is cause for concern (43).

The Track 2 numbers, by contrast, make clear that Track 2 is more obviously gendered than Track 1. For instance, 59% of those who died from Track 2 in 2023 in Canada were women (18). The Ontario Coroner's report comes in with 61% of Ontario Track 2 deaths as women (42).

These numbers are especially troubling in light of what we know about gender and euthanasia for mental illness from other jurisdictions. Nicolini, Gastmans and Kim found that, in Belgium and the Netherlands, 69 to 77% of those who received euthanasia based on a psychiatric condition were women (45). They note that the numbers on the gender breakdown for MAiD for mental illness map almost perfectly to the gender breakdown for attempted suicide. We know that at least in the Western world, roughly two thirds of those who attempt suicide are women even though men are more likely to die by suicide. This gender paradox is explained in part by the fact that women are likely to choose less violent methods of suicide and thus are less likely to succeed in bringing about their own deaths. Thus, the suggestion is that MAiD is providing women with a

⁸ Two exceptions of note are the Disabled Women's Network (DAWN) who has actively opposed Track 2 and the Feminist Alliance for International Action (FAFIA) who made a submission to the UN CRPD Committee in Geneva arguing that Track 2 MAiD is discriminatory against disabled women.

nonviolent means of committing suicide that is 100% effective. While that study relates to mental illness, 62% of those dying from euthanasia for mental illness also had one or more physical comorbidities (46), meaning that they might well have been eligible under Track 2 MAiD.

Once reasonably foreseeable natural death is eliminated from MAiD, the result is a law that makes it easier for disabled people to die by suicide. The idea that we can somehow differentiate people who are suicidal from people who have a settled intention to access Track 2 MAiD is problematic. Wanting to commit suicide because one is disabled does not transform death from suicide into some form of beneficent medical treatment. Kim has accurately described labelling Track 2 MAiD as treatment as “an especially cruel form of gaslighting.” (47) As Peters describes, the MAiD regime has created a form of socially acceptable suicide which may itself act as a source of social pressure encouraging a disabled person to apply for MAiD and serving as “a façade entryway to respectability and middle-class-sanctioned dignity” (48, p.214).

I acknowledge that this view is premised on a belief that suicide is something we should, as a society, try to prevent or at least minimize. In other words, I view suicide generally as a harm to be avoided and suicide prevention as an important social good (49,50). Others may disagree and see some suicide as a rational response to life circumstances (51,52). Whether one sees assisted suicide as harmful or beneficial, however, does not change the fact that receiving a fatal prescription and ending one’s life or giving a doctor permission to end one’s life through lethal injection is a form of suicide, if not a form of homicide, whatever the motivation. This is precisely why the MAiD regime is built around explicit *Criminal Code* exemptions from the crimes of murder and aiding suicide.

The important question is: What drives the fact that more women are accessing Track 2? This is a complex question that probably has many contributing factors and cannot be answered with certainty without much better data. However, we cannot ignore the possible role of the widespread systemic inequality that is still experienced by women in Canada, and especially by women with disabilities, in almost every aspect of social, political and economic life. In the following section, I briefly raise three factors that may well put women at heightened risk from Track 2 MAiD.

Violence Against Women

It is well known that the types of violence women experience are different than that experienced by men. Overwhelmingly, violence against women and girls is perpetrated by men with whom they are in close personal relationships: a father, a brother, and most often for adult women, an intimate partner. And there is an important link between disability and male violence, with women and girls with disabilities facing higher rates of intimate partner violence (IPV) and higher rates of sexual violence throughout their lives (53,54).

An alarming 30 to 40% of women experience intimate partner violence in Canada, depending on how it is defined. The Government of Canada reports that among women who have been in intimate partner relationships, 44% — or about 6.2 million women aged 15 and over — reported experiencing some kind of psychological, physical, or sexual abuse (55). Women and girls are overrepresented among victims of IPV, with rates nearly four times higher than for men and boys (56)⁹. A history of intimate violence greatly increases the risk of suicide attempts. In one global study using evidence from the WHO multi-country study on women’s health and domestic violence, the authors found that IPV was significantly associated with suicide attempts in every location studied (57). Childhood sexual abuse and having a mother who had experienced IPV also increased the risk of suicide attempts considerably (57).

A recent English study by McManus found that women who have experienced domestic abuse were four times more likely to have attempted suicide and three times more likely to have done so in the past year (58). McManus analyzed the most recent edition of the Adult Psychiatric Morbidity Survey, which asked 7,000 people aged 16 and over in detail about their mental health. Among women who had attempted suicide in the past year, over half had experienced IPV in their lifetime, and a third had experienced it in the past year (58). Those who had experienced sexual abuse within a relationship had an even higher risk of suicide, and were seven times more likely to have attempted to end their life (58). McManus also observed — and this is important in the MAiD context — that women living in poverty, or who were unemployed, or could not work because of sickness or disability, were at a heightened risk of IPV (59).

Not only do women with disabilities face higher risks of male violence, but male violence is also disabling for women. This is both in the sense of causing physical injuries like traumatic brain injury and chronic pain, for example, but also psychiatric conditions like complex PTSD and depression (60)¹⁰. In one systematic review, observational data made clear that persistent pain is one of the most frequently reported health consequences of IPV (61). Chronic pain is also listed as one of the most common “other conditions” cited by 65% of all Track 2 MAiD recipients (18). We know that Indigenous women face alarming rates of physical and sexual violence and that immigrant women or those who are socially isolated for other reasons may also be particularly at risk (62,63). Being disabled makes people more susceptible to IPV which in turn is disabling, and IPV makes

⁹ In this report, IPV included “physical and sexual assault, harassment, uttering threats and other forms of violence that reach the criminal threshold.”

¹⁰ The authors found that “[o]f those who experience physical IPV, up to 92% may suffer a brain injury (BI) as a result of trauma to the head or hypoxia via strangulation. BI ranges in severity from mild trauma (mTBI) or concussion, characterized by transient symptoms affecting mental processes such as memory and executive function, to moderate and severe BI resulting in disorders of consciousness lasting days to years. IPV-BI is often complicated by neurologic and mental health comorbidities, including depression, anxiety, post-traumatic stress disorder, and substance use disorder.”

it more likely that a woman will attempt suicide. And now, in Canada, disability resulting from IPV may make one eligible for MAiD.

In Canada, at least until March 2027, a person cannot access MAiD on the sole basis of PTSD or depression — there must be some corresponding physical disability. But once there is a physical disability, we have no hesitation ending the lives of people with comorbid mental illness. A high number of women with PTSD and or depression have physical comorbidities (64,65).

Escaping male violence is also particularly difficult for women with disabilities. It may be much more challenging for women with disabilities to extricate themselves from a violent relationship, particularly where the abuser is in a caregiving role. Women with disabilities may have fewer financial resources, they may be less likely to be believed by professionals when they seek help, and disability may make it more difficult to defend oneself in a physical confrontation. A coercively controlling man can manipulate these physical and economic realities, making a woman feel all the more entrapped (66,67).

A majority of women who experience physical and/or sexual violence do not report that violence (68), so it is unlikely that they will report it to their MAiD assessor who may have no ongoing relationship with the woman involved. Of course, MAiD proponents will say that if a woman who has suffered IPV wants to die because of her resulting disability and intolerable suffering, we should let her — ending her life, we are told, enhances her autonomy (69). But if we understand male violence against women as an issue of systemic inequality in which the state is complicit, we are more likely to understand that offering state-facilitated death as a solution to state-facilitated inequality only compounds the inequality.

Sexism Within the Medical Profession

Another systemic factor that is deeply worrying about gender and Track 2 MAiD is the well-established sexism within the medical profession. Sexism, combined with ableism, is a dangerous combination for disabled women. This intersection is evident on a variety of dimensions.

For example, the conditions from which women are disproportionately likely to suffer have historically been much less studied than conditions predominantly affecting men (70). Endometriosis, fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivities, and migraines — all of which are disproportionately experienced by women — have struggled for research dollars (23). Where a condition or disorder is predominantly experienced by women, funding is comparably lower: “[t]he disparity between actual funding and the disease burden by sex is nearly twice as large for diseases more prevalent in females versus those more prevalent in males.” (71, p.5) Further, studies on more gender-neutral conditions like cardiac and stroke risk have tended to focus on male subjects, thus, making it more difficult to diagnose these conditions adequately in women and so they are more likely to go undiagnosed (72).

Women’s pain is also consistently undertreated. When women complain of the same symptoms as men for conditions like diabetes, cancer, coronary artery disease, stroke orthopedics and other conditions, they are less likely to be admitted to the ICU than men, they are less likely to be given pain medication in the emergency room, and they are more likely to be given psychotropic medication for the same symptoms as men (73-75). The opioid crisis has heightened the barriers to seeking adequate pain control, making opioid pain medication harder to access in Canada than a death by lethal injection (76). Thus, while women are overrepresented among those with chronic pain, women’s pain is more likely to be undertreated, thereby also making it more likely that their suffering becomes intolerable.

Women Perceiving Themselves as a Burden

Women are socialized to be the caregivers in society. Thus, it is not a big leap to assume that when women are the ones needing care, they are more likely to perceive themselves to be a burden (77,78). As mentioned above, 49% of those who accessed Track 2 MAiD in 2023 expressed being a burden on their families as one of the reasons for their suffering (18). We do not have a gender breakdown for this form of suffering. I am not suggesting that men never perceive themselves to be a burden, but rather that the particular pressures on women to play a caregiving role, and their perceptions of themselves in that role, are evident throughout their lives.

Older women with disabilities also tend to be socially isolated. Men are more likely to abandon their female partners with disabilities than women are to abandon disabled men (78-80). In a 2009 study of over 500 patients, Glantz et al. (78) found that women with cancer were much more likely to be left by their partners than were men with the same diagnosis — 90% of the separations involved women as the unwell spouse being left by their male spouse. Female sex of the ill partner was the strongest predictor of divorce or separation in each of the three patient populations under study (78). In addition, women who were left by their male partners did less well medically on a number of variables — they were less likely to be able to die at home, less likely to be enrolled in clinical studies and more likely to take antidepressants than those who had a supportive spouse. It is notable that, in 2023, recipients of Track 2 MAiD were most likely to live alone whereas recipients of Track 1 MAiD were most likely to live with family members (18).

And finally, as Sheehy has pointed out, perceived burdensomeness and male violence often intersect. Being constructed as a burden may well be an integral part of a pattern of a coercively controlling relationship (43,81). Women in these relationships are made to feel of no value, a burden to society and to their families. It is notable that a recent UK study on so-called “mercy

killing” revealed that overwhelmingly the killings of elderly persons with disabilities involved men killing disabled women (82). The potential that MAiD can be weaponized in such a relationship is a real concern (83), which will only be exacerbated in 2027 when MAiD on the sole basis of mental illness comes into force.

In response to my argument that women are disproportionately harmed by Track 2 MAiD, it might be argued that women have also, to a great extent, been the face of MAiD in Canada. Pullman has highlighted the prominent role of women in MAiD, both in terms of the plaintiffs in landmark cases and vocal MAiD activists and providers (84)¹¹. He explores the thin version of autonomy that is used by these activists to promote MAiD, which focuses on the individual as an autonomous actor, unencumbered by social context, and demonstrates that this view fails to incorporate an ethic of care which “trades on a richer and more nuanced sense of human flourishing.” (84, p.18)

Seen through a lens of equality under section 15 of the *Charter*, the view of autonomy espoused by scholars like Downie and Llewellyn (85), is more consistent with a formal approach to equality where everyone is assumed to have the same starting point and where equality simply requires that we treat everyone the same. Aside from the fact that our MAiD law does not treat everyone the same, this view fails to reckon with the Supreme Court’s mandate that equality be looked at substantively and that the social context in which choices play out is important to understanding substantive inequality (38).

CONCLUSION

I have argued here that Track 2 MAiD is discriminatory against all people with disabilities, but that it also has a disproportionate impact on women with disabilities. I make the sex discrimination claim to highlight what has been largely ignored in the literature. Track 2 MAiD does not have an equal impact on the privileged and the less privileged. A law that purports to offer death as a form of medical treatment to address the suffering of people living with disabilities is discriminatory and a particular danger to those within the broader umbrella of disability who are the most marginalized.

As Peters has noted, by framing MAiD as being exclusively about choice, we have obscured the role of the state in the lives of people with disabilities (48). The state plays an important role in perpetuating the disadvantage experienced by people with disabilities. This law posits death as an affordable and convenient response to the suffering of people with disabilities, whereas supports like housing and home care are neither convenient nor affordable. One of the plaintiffs in the Ontario litigation notes that they had contemplated MAiD because they could not get adequate pain medication since the opioid crisis, even though they had no history of drug abuse (36). Pain relief is increasingly hard to access while lethal injections are increasingly accessible. How does that make sense?

Track 2 MAiD exceptionalizes the suffering associated with disability as different and inherently worse than other human suffering. But many of the factors motivating MAiD Track 2 deaths are social factors that are not unique to disability but may be exacerbated by it. While disability may contribute to that suffering, the failure to meet the needs of people with disabilities also contributes to the intolerable suffering experienced disproportionately by disabled women. We would never tolerate this for any other protected group under our *Charter*, other than people with disabilities. In fact, it would be unthinkable to suggest a MAiD regime that only ends the lives of Black, Indigenous or transgender people. We would understand why such a law would be discriminatory — why we cannot isolate one marginalized group who may disproportionately experience suffering and dress up death as a desirable solution to that suffering. Yet, when that targeted group is people with disabilities, we do not recognize the discrimination. We see disability as unique and as sometimes justifying death. In fact, for people with disabilities, death is equated with compassion. Track 2 MAiD is only compassionate if we believe that some people with disabilities are in fact better off dead. While I have focused on the inequality of women and the disproportionate numbers of dead women, I could have discussed the suicide crisis in Indigenous communities, the dangers of MAiD in Canadian penitentiaries, especially for Indigenous people with disabilities, or the lack of access to adequate medical care for transgender Canadians with disabilities. Track 2 MAiD preys on our most marginalized citizens.

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¹¹ Pullman notes that “the dominant voice that has emerged in this ongoing discourse is increasingly the familiar voice that champions a narrow view of personal autonomy and individual rights. We must question whether this voice speaks to the needs of the most vulnerable members in our midst, namely those contemplating the end of their existence.”

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

MAiD, Mental Disorders, and Vulnerability: How Common Responses to Vulnerability Concerns are Inadequate

Loughran Butcher^a

Résumé

Le concept de vulnérabilité est fréquemment évoqué dans les débats actuels sur l'aide médicale à mourir (AMM) et sur les personnes qui devraient y avoir droit, mais il est souvent utilisé comme une expression fourre-tout pour désigner une sorte de risque ou de préoccupation que les gens ont. Cette utilisation imprécise obscurcit les préoccupations des opposants à l'AMM concernant son extension aux personnes souffrant de troubles mentaux comme seule condition sous-jacente. Comme la signification du terme « vulnérable » n'est pas toujours claire, les tentatives visant à répondre à cette vulnérabilité ou à l'atténuer peuvent manquer leur cible. Les arguments fondés sur la vulnérabilité qui s'opposent à l'élargissement de l'accès à l'AMM soulignent les facteurs sociaux ou systémiques qui peuvent influencer le choix des personnes atteintes de troubles mentaux de recourir à l'AMM, tels que le manque d'accès à des soins adéquats, la stigmatisation et la discrimination, les tendances suicidaires et la corrélation entre les troubles mentaux et le faible statut socio-économique. Cependant, la réponse courante aux préoccupations relatives à la vulnérabilité, apportée par ceux qui plaident en faveur de l'élargissement, consiste à mettre en avant les garanties actuellement en place pour s'assurer que seules les personnes éligibles à l'AMM y aient accès. Selon ce point de vue, la vulnérabilité est déterminée en évaluant l'éligibilité des individus. Ceux qui ne remplissent pas les critères d'éligibilité ne seraient pas autorisés à y avoir accès. Pourtant, cela passe complètement à côté des préoccupations soulevées qui mettent en évidence les sources de risque systémiques ou sociales. S'assurer que les personnes qui ont recours à l'AMM répondent aux critères revient à ignorer les raisons qui les poussent à y avoir recours.

Mots-clés

aide médicale à mourir, AMM, vulnérabilité, troubles mentaux, critères, expansion, sources sociales de risque

Abstract

The concept of vulnerability is bandied about frequently in ongoing debates about medical assistance in dying (MAiD) and who should be eligible, but is often used as a broad catch-all phrase to capture some sort of risk or concern that people have. This imprecise usage obfuscates the concerns that opponents to MAiD have about expansion to include those suffering from mental disorders as the sole underlying condition. Since what is intended to be captured by the term 'vulnerable' is at times unclear, attempts to respond to or mitigate this vulnerability can miss the mark. Arguments from vulnerability against expanding access to MAiD point out social and/or systemic factors that may influence the choices of people living with mental disorders to access MAiD, such as lack of access to adequate care, stigma and discrimination, suicidality, and the correlation between mental disorders and low socio-economic status. However, the common response to concerns about vulnerability, made by those who argue for expansion, focus on highlighting current safeguards that are in place to ensure only those who are eligible for MAiD gain access. Under this view, vulnerability is determined by assessing individuals for eligibility. Those who cannot meet the eligibility criteria would not be permitted access. Yet, this entirely misses the concerns being raised that point to systemic or social sources of risk. Ensuring that the individuals who access MAiD meet the criteria is to ignore the reasons for accessing it in the first place.

Keywords

medical assistance in dying, MAiD, vulnerability, mental disorders, criteria, expansion, social sources of risk

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INTRODUCTION

Expanding Medical Assistance in Dying (MAiD) to include those suffering from a mental disorder as the sole underlying medical condition (MD-SUMC) has been hotly contested in Canada for the past several years. In the ongoing ethical debate, a common concern that is raised to caution against expansion is that those suffering from mental disorders are particularly vulnerable, and that to protect these individuals they should be excluded from accessing MAiD (1-4). Common responses to this vulnerability concern point to existing safeguards for MAiD for physical conditions where death is not reasonably foreseeable, or they argue that more stringent safeguards could be implemented to mitigate risks (5). However, while arguments based on vulnerability are common, what is meant by 'vulnerability', or to be vulnerable, is often ill-defined and under determined (6). This has resulted in debates where interlocutors are effectively talking past each other, each missing important aspects of the other's argument, and often resulting in unproductive discourse. This paper aims to address this conceptual ambiguity with a goal of bringing clarity to and progress in the debate concerning MAiD for MD-SUMC.

Borrowing from and building upon the work of Lazin and Chandler, the first part of this paper highlights the integral role that the concept of vulnerability has played historically in the development of MAiD in Canada, by examining how it was employed in legal arguments (6). Next, using the work of Mackenzie, Rogers, and Dodds, a clearer definition of vulnerability is provided and defended. This clarified notion will then be applied in the context of individuals living with mental disorders who are seeking

access to MAiD (7,8). Finally, after explaining the risks that arguments from vulnerability are intended to capture, it will be argued that the current common responses of pointing to current safeguards, or simply increasing safeguards to protect the vulnerable, are insufficient. These arguments focus on issues of individual capacity and conviction in pursuit of MAiD but miss the social context that is often the driving motivation for seeking MAiD in the first place.

MAiD, VULNERABILITY AND THE COURTS

MAiD in Canada has developed through a series of court challenges, the first of which was unsuccessful. In 1993 Sue Rodriguez, who suffered from amyotrophic lateral sclerosis (ALS), challenged the criminal prohibition of assisting suicide (9). A neurodegenerative disease, people suffering from ALS start with a loss of voluntary muscle control which then progresses to being unable to breathe or eat without mechanical assistance, and eventually death. In 1993, assisting another person in suicide in any capacity could result in criminal charges. Rodriguez wished to live as long as she was capable of enjoying her life; however, when she deemed her suffering to be intolerable and her life no longer worth living, she feared that she would not be able to commit suicide on her own. Hence her request to have the Criminal Code amended so that she could receive physician assisted suicide. Rodriguez challenged the criminal prohibition of assisting suicide on the grounds that it: 1) infringed upon her rights to life, liberty, and security of person (section 7 of the Charter); 2) violated her right to be free from cruel and unusual punishment (section 12); and 3) amounted to discrimination based on disability (section 15). In a 5-4 split decision, the majority of the court ruled that the outright criminal prohibition of assisting another to commit suicide was not unconstitutional, and so the law remained unchanged (9). Part of the reasoning employed to support this judgment was that section 241(b) of the Criminal Code, the outright criminal prohibition of assisting suicide, was necessary in order to achieve the legislative objective of protecting human life and dignity:

Section 241(b) has as its purpose the protection of the vulnerable who might be induced in moments of weakness to commit suicide. This purpose is grounded in the state interest in protecting life and reflects the policy of the state that human life should not be depreciated by allowing life to be taken (9).

While the majority of the Supreme Court justices recognized that Rodriguez's rights to security of person and equality were being limited by the outright criminal prohibition of assisting suicide, the court maintained that these rights infringements were justified under section 1 of the Charter (9). The court recognized two competing values, the protection of which justified the prohibition of assisting suicide: the sanctity of life and the protection of vulnerable persons (6). So, while the court recognized that section 241(b) of the Criminal Code infringed on Rodriguez's section 7 rights, this infringement was justified due to the government's objectives to uphold the sanctity of life and to protect the vulnerable. Their reasoning was that the cost of Rodriguez's right to liberty and security of person being upheld via assisted suicide would be the degradation of the sanctity of life and risk to vulnerable persons. The court specified that the criminal prohibition of assisting suicide was necessary to protect people who might be induced to commit suicide in moments of weakness, and stated that those who are terminally ill are particularly vulnerable (9). However, what it meant to be 'vulnerable' was not specified nor elaborated upon. Although the court recognized that it might have been acceptable for Sue Rodriguez herself to have access to assisted suicide, it was concerned about what a federal regime of allowing assisted suicide for persons like her might cause. However, the specific cause for concern is vague, beyond individuals receiving assisted suicide in moments of weakness, as seen in the identified objective of the criminal prohibition by Justice Sopinka above. As such, what it means to be vulnerable, and what these people are vulnerable to, is not entirely clear. While these facets of vulnerability are not clear, it is important to highlight how the label of 'vulnerability' or being 'vulnerable' is applied. In this case, a group of persons, the terminally ill, are being labelled as "particularly vulnerable" in the context of assisted suicide. The court then argued that the only method of sufficiently protecting those that are vulnerable due to being terminally ill was to continue the criminal prohibition of assisted suicide. In other words, the Supreme Court took the risk of physician assisted suicide to vulnerable people to be too great and argued that protection through paternalism was necessary.

In 2015, the criminal prohibition of assisting suicide again came before the Supreme Court in the case of *Carter v. Canada* (10). The criminal prohibition of assisting suicide was challenged on the grounds that it infringed upon section 7 and section 15 Charter rights. The court reiterated the objective of the Criminal Code identified in the Rodriguez case as being to protect those who are vulnerable from committing suicide in moments of weakness, although Canada argued the objective was more broadly the preservation of life, which was rejected by the court:

The trial judge, relying on Rodriguez, concluded that the object of the prohibition was to protect vulnerable persons from being induced to commit suicide at a time of weakness (para. 1190). All the parties except Canada accept this formulation of the object (10).

Canada agrees that the prohibition is intended to protect the vulnerable, but argues that the object of the prohibition should also be defined more broadly as simply "the preservation of life" (R.F., at paras 66, 108, and 109). We cannot accept this submission (10).

Vulnerability and the specific risk, beyond inappropriate access to assisted dying, was not specified (6). The respondent, Canada, argued that the law needed to remain unchanged in order to fulfil this objective (10). However, the Court concluded that the outright prohibition of assisting suicide was too broad, as it unjustifiably restricted the autonomy of those who were not vulnerable and forced them to either live a life of suffering or to end their lives on their own (6,10). While what is meant by

vulnerable is not specified, it is frequently contrasted with autonomy in the Carter ruling, leaving the impression that those who are vulnerable are those who are unable to autonomously consent to assisted suicide. This can be seen in how the term vulnerable is used:

Applying this approach, we conclude that the prohibition on assisted dying is overbroad. The object of the law, as discussed, is to protect vulnerable persons from being induced to commit suicide at a moment of weakness. Canada conceded at trial that the law catches people outside this class: “It is recognised that not every person who wishes to commit suicide is vulnerable, and that there may be people with disabilities who have a considered, rational and persistent wish to end their own lives” (trial reasons, at para. 1136). The trial judge accepted that Ms. Taylor was such a person — competent, fully informed, and free from coercion or duress (para. 16). It follows that the limitation on their rights is in at least some cases not connected to the objective of protecting vulnerable persons. The blanket prohibition sweeps conduct into its ambit that is unrelated to the law’s objective (10).

Instead, the court stated that vulnerability can be assessed on an individual basis through the standard informed consent and capacity assessment process that physicians apply for all treatments (6,10). The final ruling was that the criminal prohibition of assisting suicide unjustly infringed upon the rights to life, liberty and security of person in cases where an individual suffers from a grievous and irremediable medical condition that causes intolerable suffering, and who freely consents to their own death. The result of the Carter case led to the first iteration of MAiD legislation, Bill C-14.

The debates on the proposed bill, and the resulting preamble, again highlighted the importance of protecting the vulnerable, and contrasted it with promoting the autonomy of others (6). Unsurprisingly, vulnerability and the precise risk that was of concern remained unspecified (6). In order to balance the perceived competing values of protecting the vulnerable, on one hand, and respecting autonomy on the other, Bill C-14 restricted access to MAiD to those whose deaths are “reasonably foreseeable” (11). As such, despite it not being mentioned in the Carter decision, MAiD under Bill C-14 was permissible only for those who had an illness that could foreseeably cause their death.

The requirement that one’s death be reasonably foreseeable in order to access MAiD was challenged in the Quebec Superior Court. The applicants in *Truchon and Gladu v. Canada (Attorney General) and Quebec (Attorney General)* argued that the MAiD legislation was not consistent with the Carter ruling as it included the requirement of reasonably foreseeable death, and that this requirement infringed on their section 7 and section 15 rights (12). The analysis of section 7 infringements went similarly to the Carter case. The rights to life, liberty, and security of person were all taken to be engaged for the reasons provided in the Carter case. The prohibition of assisting the suicide of those whose death is not reasonably foreseeable limited the right to life by potentially forcing individuals to end their lives earlier than they would like while still capable of doing so themselves, and the rights to liberty and security of person because it deprived individuals with non-terminal severe disability of their bodily autonomy by preventing them from accessing a medical treatment and forcing them to continue to live a life of suffering that they do not value (12). An analysis of the provision was also conducted on section 15 right to equality. In this analysis, it was found that the requirement of reasonably foreseeable death creates a distinction based upon disability, preventing individuals who are suffering from a grievous and irremediable but non-terminal physical condition from accessing MAiD, and perpetuates prejudice and disadvantage based on physical disability. Since section 7 and 15 rights were taken to be engaged, the question then became whether these infringements were justified by the principles of fundamental justice or section 1 of the Charter.

To determine whether the infringements are justified, the objective of the provisions needs to be clearly defined. The attorney generals provided three objectives of the requirement of reasonably foreseeable death:

1. That it is important to affirm the inherent and equal value of every person’s life and to avoid encouraging negative perceptions of the quality of life of persons who are elderly, ill or disabled;
2. That suicide is a significant public health issue that can have lasting and harmful effects on individuals, families and communities;
3. That vulnerable persons must be protected from being induced, in moments of weakness, to end their lives (12).

However, only the third objective of protecting vulnerable persons from being induced to end their lives was accepted. Justice Badouin recognized that while the concept of vulnerability and vulnerable persons was integral to this case, it was not defined in the legislation (6,12). As such, expert testimony was heard on the meaning of vulnerability with regard to MAiD (6). Importantly, the attorney generals argued for a conception of vulnerability that applied at a group level, with the elderly, the ill, and the disabled, as well as those who are suicidal and cannot make a free and informed choice all being labelled as vulnerable groups. In other words, if one fell into one of these groups, such as being elderly, the implication was that one would be vulnerable to being induced to accessing MAiD in a moment of weakness. As such, restricting MAiD to only those who have a reasonably foreseeable death was necessary to protect members of these groups. However, the applicants argued that vulnerability should be understood and assessed on an individual level, as any individual member of one of these groups could be capable of making personal decisions in their best interests. According to this individual application of vulnerability, an individual is vulnerable in the context of MAiD only if they do not have the capacity to consent to MAiD.

In the court’s opinion, a collective understanding of vulnerability was too broad. Instead, vulnerability should be determined at an individual level with only those who were incapable of consenting being considered vulnerable. As such, the requirement

of reasonably foreseeable death was deemed to unjustly infringe upon section 7 and 15 rights, as the objective of protecting the vulnerable could be achieved through less restrictive means, such as capacity assessments conducted by physicians (12).

As a result of the Truchon and Gladu case, Bill C-7 was introduced, which changed MAiD to a two-track system depending on whether the applicant's death is deemed reasonably foreseeable. If death was reasonably foreseeable, safeguards are lesser, including the ability to waive final consent if there is a concern that capacity will be lost between assessment and provision (13). If death is not reasonably foreseeable, the person would be subject to further safeguards, such as a minimum 90 day assessment period (13). However, Bill C-7 explicitly excluded those who sought MAiD for MD-SUMC. This limitation was "sunsetting" to be lifted after 3 years (13). Yet, despite the original date for MAiD to expand to include MD-SUMC being March of 2023, this exclusion has been continued until at least March of 2027, due to concerns that Canada was not ready for the expansion. One of the main concerns cited was the need to protect the vulnerable (14).

As can be seen, the concept of vulnerability has played an integral role in the debates surrounding MAiD, up to and including MAiD for MD-SUMC. Yet what it means to be vulnerable, and what people of concern are vulnerable to, is often not clearly defined. Furthermore, the concept of vulnerability has been applied in two different ways: at a group level by those who sought to restrict access to MAiD, and at an individual level by those who argued for expansion. In the next section, a clearer definition of vulnerability will be provided, including the precise risk that is of concern. It will be argued that the vulnerability debate continues to be so contentious due, at least in part, to the dual application of the term — whether it be to groups or individuals. Finally, I argue that the current strategy of responding to vulnerability concerns, which primarily focuses on pointing to existing safeguards, relies on the individual application of the concept of vulnerability. As such, the response often misses the ethically relevant concerns being highlighted by those who continue to argue for restricting access to MAiD. In particular, the focus on individual capacity assessments to remove those who are incapable of consenting to MAiD can miss the reasons that motivate the decision to seek access to MAiD in the first place.

CLARIFYING THE NOTION OF VULNERABILITY

What does it mean to be vulnerable? For clarity, I will be using the definition of vulnerability provided by Mackenzie, Rogers, and Dodds and apply it to MAiD (7). In a very real sense, everyone is vulnerable due to being physically embodied (7). We all require food and shelter, are susceptible to illness and injury, and need care at the beginning and ends of our lives. These physical necessities mean that all people are vulnerable to harm. However, this is not what people mean when they use the term 'vulnerable' because people vary in their exposure to risk and resources available to mitigate risk (7). To be vulnerable then, according to Mackenzie, Rogers, and Dodds, is to be at an increased risk of harm and/or decreased capacity to protect oneself from harm (8). It is important to note that this increased risk of harm, or decreased ability to protect oneself, is context dependent. A person could be vulnerable to harm in a particular context without being globally vulnerable. For example, consider an argument against the legality of selling blood: people that are impoverished will be compelled to sell their blood due to financial necessity (15). The concern here is that people living in poverty are uniquely vulnerable to exploitation and to donate blood when it could pose a risk to themselves in order to receive a cash payment. That is not to say, however, that people living in poverty are vulnerable (in other words at increased risk) when donating blood without financial compensation, as it comes without financial pressures. It is unlikely that a person would donate blood for free if it could potentially pose a risk to their own health. As such, one could argue that those living in poverty are uniquely vulnerable in the context of paid blood donation, but not in the case of uncompensated blood donation.

When the concept of vulnerability is applied, it is rarely just an observation, but often rather carries with it a demand for an ethical response (8). So, to be vulnerable is to be at an increased risk of harm in a particular context, and this increased risk of harm comes with an ethical responsibility of others to mitigate that risk. What then is the risk facing vulnerable people in the context of MAiD for MD-SUMC, and what does this risk require of policy makers?

In the Truchon and Gladu case, the court took the time to specify what it understood vulnerability to mean, and how it applies. It was determined that vulnerability should be applied at an individual level, and that those who are vulnerable are those individuals who lack the capacity to consent to MAiD (12). From this, the court determined that the standard informed consent process was sufficient to prevent vulnerable persons from accessing MAiD. This individual approach to vulnerability has continued to be adopted by proponents of expanding MAiD, with the addition of further safeguards and processes that were developed in the MAiD Model Practice Standard (16). This standard guides MAiD assessors and providers through the assessment process, with the aim of ensuring that only those people who meet the criteria have access. This is undoubtedly a good thing, as it promotes consistency amongst assessors and should help reduce the likelihood of individuals who do not meet eligibility criteria from gaining access. Yet, despite the new practice standard, arguments from vulnerability continue to be levied in attempts to push back against expansion. I argue that this is because the way in which the term vulnerability is applied is different, as too is the risk that they are trying to identify.

If one understands vulnerability on an individual level, and the risk to which people are vulnerable — to assent to MAiD while lacking capacity to do so — then the current process works very well. It applies the eligibility criteria: capacity, grievous and irremediable medical condition, and enduring physical or psychological suffering, and anyone who does not meet the criteria will not be permitted access to MAiD. However, the risk that is identified with current arguments from vulnerability against expansion is different and is being applied differently.

Rather than focusing on whether an individual meets the eligibility criteria for MAiD, the concern is that those living with mental disorders as a population may be subject to disproportionate pressures to access MAiD. In other words, rather than focusing on whether any one individual can meet the MAiD eligibility criteria, the focus is on the motivation for accessing MAiD in the first place. The risk then is one of individuals accessing MAiD not because they want it due to irremediable intolerable suffering, but because their needs as a group are not being met. This concern, and the argument that MAiD should not be expanded due to those suffering from mental disorders being vulnerable as a group, was made apparent by disability rights activists and disability scholars during the consultation period for Bill C-7. Briefs and testimony were presented to the House of Commons and the Senate highlighting the risks of expanding MAiD to include those with non-life-threatening disability, pointing out how those with physical disabilities are systemically vulnerable. The sources of systemic vulnerability included Canada's long history of social disadvantage for those who live with disability, inadequate social supports such as housing and insufficient income support, and healthcare discrimination and barriers to care (17-19). The focus on systemic vulnerability that apply to an entire group is leveraged to argue that individuals living with disability should not have access to MAiD. Again, the use of the term 'vulnerability' here, and how it is applied, is different from the use of the concept in the relevant court cases. It is also different from the way the concept is used by those who argue for expansion and focus on individual eligibility assessments. This line of reasoning can similarly be applied to those living with MD-SUMC.

The entire population of individuals living with mental disorders are similarly considered particularly vulnerable because their mental health needs are inadequately met, and they are subject to social stigma and discrimination. Since these two sources of vulnerability are systemic, the argument is that that all members of the affected population are uniquely vulnerable.

The argument that people living with mental disorders are uniquely vulnerable due to lack of adequate access to mental healthcare and social supports, in my opinion, is the stronger of the two arguments. That there are issues with access to adequate mental health care is a broadly accepted fact and includes lack of access to mental health care in rural settings, long wait times to visit psychotherapists, and the unaffordability of some aspects of mental healthcare (20). Depending on the province's health insurance plan, effective treatment interventions, such as cognitive behavioural therapy, may only be covered in particular settings, such as in a hospital, with therapy outside of these settings being prohibitively expensive for many. On top of this, if there are treatment centres outside of the hospital that are covered by provincial health insurance, wait times to gain access can be long. This problem applies to some prescription medications as well. If one does not have private insurance through an employer or otherwise, prescription drugs to treat one's mental disorder may be unaffordable. Lack of access to mental healthcare is considered problematic in the context of permitting access to MAiD because of the requirement that one suffers from a grievous and irremediable medical condition (19). This naturally raises the question: if one has not received adequate treatment, then how can their condition be considered irremediable?

Jocelyn Downie, echoing a common response in a recent Senate Committee Report, argued that individuals without a demonstrable history of failed treatment attempts would not be eligible for MAiD (14). As such, if someone did not receive adequate mental health care, while this may be tragic, they would not be eligible for MAiD. However, this does not necessarily appear to be the case according to the MAiD Model Practice Standard. The MAiD practice standard provides guidance on determining irremediability. However, in an effort to not make the error of being too restrictive, the current MAiD standard allows for a fair amount of space for judgement on behalf of the assessor. The following definitions of incurable and irreversible are provided:

9.5.2 'Incurable' means there are no reasonable treatments remaining where reasonable is determined by the clinician and person together exploring the recognized, available, and potentially effective treatments in light of the person's overall state of health, beliefs, values, and goals of care (16).

9.6.4 'Irreversible' means there are no reasonable interventions remaining where reasonable is determined by the clinician and person together exploring the recognized, available, and potentially effective interventions in light of the person's overall state of health, beliefs, values, and goals of care (16).

Note that there are no specifics in terms of number of treatment attempts, whether specific standard treatment interventions have been undertaken, or the length of time one has had the condition (21). As such, while some may claim that individuals who have not received adequate care will not be eligible, this may not be true (21,22). Rather, the assessment relies on a determination of what is reasonable, made between assessor(s) and individuals. If one cannot afford potentially efficacious treatment interventions, and so does not undergo them, is that reasonable? If one lives in a rural area and has neither the money nor the time to commute to an urban area for mental health care, is that reasonable? What is being highlighted here is that if systemic barriers to accessing care exist, then not accessing care due to these barriers could presumably be considered reasonable, and therefore an individual who has not accessed standard mental healthcare could potentially access MAiD. This argument may seem convoluted, but what it is intended to highlight is a systemic vulnerability faced by people living with mental disorders. If it is more difficult to access mental healthcare, then it is more likely for people living with mental disorders to have what appears to be an irremediable condition that causes intolerable suffering as it is more difficult to access the means of alleviating it. As such, the argument is that individuals living with mental disorders are at a greater risk of accessing MAiD. This greater risk is due to unmet needs and is greater than the general population. According to this line of reasoning, those living with mental disorders are uniquely vulnerable in the context of MAiD and so should be prohibited from accessing MAiD for their own safety.

The other main argument as to why those living with mental disorders are uniquely vulnerable in the context of MAiD is due to pervasive and historic stigma and discrimination. This argument is more difficult to pin down as it is more speculative due to being difficult to prove the link between social stigma towards those living with mental disorders and a potentially increased chance of accessing MAiD. Stigma and discrimination towards people living with mental disorders is well documented and researched (20,22-24). The concern is that this pervasive stigma will disproportionately influence individuals living with mental disorders to access MAiD when other treatment interventions or social supports would alleviate suffering, and as such, people living with mental disorders are uniquely vulnerable (24). Discrimination and stigma can affect people living with mental disorders in a variety of ways, yet arguably the most relevant in the context of MAiD is how stigma can affect the person's willingness to pursue and continue care, the value they place on themselves, and the perceived efficacy of treatment interventions (22). Socially embedded stigma and stereotypes send conflicting and problematic messages to people living with mental disorders. On the one hand, there can be a denial of the seriousness of mental disorders, with there being a perception that some instances of mental disorders are fabricated for attention, not particularly harmful or debilitating, and as such do not require treatment (22). On the other hand, people suffering from mental disorders can be seen as 'insane', suffering from so severe a mental disorder that they are unable to capably make their own decisions. These stereotypes constitute what is known as 'public stigma', which is the negative perception of a group by the general public. When pervasive stigma exists, it can become internalized by individuals within a stigmatized group, which is known as self-stigma (20,22). This self-stigma in the case of individuals suffering from mental disorders has been shown to negatively affect the rate at which care is sought, adhered to, and believed to be effective. Internalized negative beliefs can erode self-trust and self-worth, which in turn affects mental healthcare. If one does not believe that their life has value, or that their condition is treatable, they are less likely to seek out or continue care (23).

Since there is fairly strong evidence showing the impact of stigma on perceived self-worth and self-trust of individuals living with mental disorders, and how this in turn affects propensity to access mental healthcare, the concern in the context of MAiD for MD-SUMC is two-fold: first, permitting MAiD for MD-SUMC reinforces negative stereotypes, and second, self-stigma could lead to disproportionate seeking of MAiD by those suffering from mental disorders. In regard to the first concern, the argument is that by permitting access to MAiD for MD-SUMC, perceptions of hopelessness are reinforced and the value of the lives of individuals living with mental disorders are undermined (25,26). If one accepts that MAiD should be available for those suffering from MD-SUMC, this must come with the belief that mental disorders are, at least in some instances, irremediable. This recognition could reinforce beliefs in the futility of mental healthcare. Permitting MAiD for MD-SUMC may also, even if it is not intentional, send the message that the lives of people who are mentally ill are not worth living, or not worth protecting (25,26). As such, permitting MAiD for MD-SUMC in the first place may perpetuate stigma that already exists.

Even if one does not believe that expanding MAiD would reinforce harmful stigma, it is clear that stigma towards those who live with mental disorders exists (21-23). This stigma, as demonstrated above, can have a measurable impact on the mental healthcare pursued, and received, by those living with mental disorders (22). The second concern is that the effect of stigma on self-worth and propensity to seek care may cause individuals suffering from mental disorders to disproportionately request MAiD due to not adequately accessing care or internalizing disvalue of their own lives, thus rendering them vulnerable in the context of MAiD. There is evidence that higher self-stigma is correlated to increased suicide rate (21). Therefore, stigmatized persons living with mental disorders may also be more likely to seek access to MAiD. On top of this, self-imposed barriers to care due to self-stigma may function similarly to systemic barriers, where individuals who have not received adequate mental healthcare may nonetheless seek out and potentially access MAiD.

CONCLUSION

Two broad arguments as to why people living with mental disorders are particularly vulnerable in the context of MAiD have been outlined. Notably, these arguments rely on a notion of vulnerability that is different from the vulnerability identified in the Truchon decision. The risk identified, rather than being that a person may access MAiD who cannot meet informed consent requirements, is that there may be greater pressures on those living with mental disorders to access MAiD due to impaired access to treatment and stigma affecting self-worth. This vulnerability is applied to the group as a whole: since the source of these pressures are systemic and social, all people who are mentally disordered can be affected. As such, everyone who lives with a mental disorder is vulnerable in the context of MAiD and should be protected by exclusion. Proponents of expansion, however, argue that rather than excluding those living with MD-SUMC from accessing MAiD, implementing safeguards and careful individual assessments are sufficient for ameliorating risk. However, to focus on whether an individual meets eligibility criteria misses the critique being raised by those making arguments from social or group vulnerability. The concern is not that some individuals will access MAiD who are ineligible, but rather that people living with mental disorders will choose to access MAiD due to unmet needs, with the implicit assumption that if these needs were met, these individuals would not access MAiD.

This difference in understanding and application of the concept of vulnerability invariably leads to difference in opinion as to how we ought to respond ethically. If the risk of concern is believed to be ineligible individuals accessing MAiD, then standardizing and enforcing assessments is an adequate response. Yet if the risk of concern is systemic and focused on the underlying reasons for seeking out MAiD in the first place, ensuring that individuals seeking MAiD meet eligibility criteria entirely misses the concern. As such, the vulnerability debate continues to rage on, with opposing groups applying and using vulnerability in different ways, leading to different strategies of addressing said vulnerability.

Vulnerability is a concept oft used in the debates surrounding MAiD in its various forms. However, it is often ill-defined and under determined and used in myriad ways. Vulnerability is to be at an increased risk of harm or decreased ability to protect oneself from harm (8). Vulnerability in the context of MAiD for MD-SUMC is used in different ways depending on if one is arguing for expansion or exclusion, leading to interlocutors effectively talking past each other. The court stated that vulnerability should be understood on an individual level, with the solution to vulnerability being careful application of assessment criteria. This does little to address the broader concern that individuals living with mental disorders may experience systemic pressures to access MAiD in the first place. Unless or until arguments for expanding MAiD seriously contend with the social and systemic sources of risk for individuals with MD-SUMC accessing MAiD, vulnerability arguments will continue to be raised.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

MAiD, Mental Disorder, and Capacity: Recognizing the Complexity of Moral Agency in Capacity Assessment

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Résumé

L'aide médicale à mourir (AMM) est devenue une forme importante de soins de fin de vie au sein du système de santé canadien, mais elle ne fait pas l'unanimité. La possibilité que le Canada élargisse l'admissibilité à l'AMM aux personnes souffrant d'un trouble mental comme seule affection médicale sous-jacente (AMM TM-SPMI) suscite encore plus de critiques. Contrairement aux conditions physiques qui causent de la douleur et de la souffrance, les troubles mentaux ont le potentiel intrinsèque d'affecter la capacité d'une personne à comprendre et à évaluer de manière appropriée les conséquences de ses actions et de ses décisions. Il existe donc un risque important qu'un patient qui a demandé l'AMM TM-SPMI ne soit pas en mesure de donner son consentement valide en raison d'une capacité réduite à : 1) comprendre adéquatement les conséquences du recours à l'AMM ou 2) replacer ces conséquences dans un ensemble cohérent de valeurs. Compte tenu de l'importance de l'influence des troubles mentaux sur les valeurs et les désirs d'une personne, le présent document soutient que nous devons évaluer la capacité décisionnelle de manière plus holistique, en tenant compte à la fois des facteurs cognitifs et évaluatifs. Mon argument repose sur une présentation des facteurs évaluatifs impliqués dans la prise de décision, une démonstration que ces facteurs peuvent être considérablement affectés par la maladie mentale, et une suggestion selon laquelle nous avons besoin de critères plus holistiques pour l'évaluation de la capacité que les critères excessivement cognitifs préconisés par les outils d'évaluation les plus couramment utilisés. En raison de l'interaction entre ces aspects de mon argumentation et les enjeux extrêmement importants liés aux évaluations de l'AMM, je suggère que les évaluations de la capacité (en général et en particulier pour les demandes d'AMM) intègrent un aspect d'évaluation narrative permettant de mieux évaluer les valeurs et la compréhension de soi du patient.

Mots-clés

AMM, TM-SPMI, agence morale, capacité décisionnelle, consentement, trouble mental, valeurs

Abstract

Medical assistance in dying (MAiD) has become a prominent form of end-of-life care within the Canadian health system, yet it is not without its critics. Drawing even more critical attention is the possibility of Canada expanding MAiD eligibility to persons who suffer from mental disorder as their sole underlying medical condition (MAiD MD-SUMC). Unlike physical conditions that cause pain and suffering, mental disorder has the intrinsic potential to affect one's ability to understand and appropriately value the consequences of one's actions and decisions. There is thus a significant risk that a patient who has requested MAiD MD-SUMC may be unable to provide valid consent due to an impaired ability to either: 1) adequately understand the consequences of receiving MAiD or 2) place that consequence within a consistent set of values. Due to the important ways in which mental disorder can affect one's values and desires, this paper argues that we must evaluate decision-making capacity in a more holistic way that includes both cognitive and evaluative factors. My argument is based upon a presentation of the evaluative factors involved in decision-making, a demonstration that these factors may be significantly affected by mental illness, and a suggestion that we require more holistic criteria for capacity evaluation than the excessively cognitive criteria espoused by most commonly used assessment tools. Because of the interplay between these aspects of my argument and the extremely high stakes involved in MAiD assessments, I suggest that capacity evaluations (both in general and *especially* for MAiD requests) ought to incorporate an aspect of narrative assessment by which the patient's values and self-understanding can be better assessed.

Keywords

MAiD, MD-SUMC, moral agency, decision-making capacity, consent, mental disorder, values

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INTRODUCTION

On March 17, 2027, the eligibility criteria for medical assistance in dying (MAiD) is set to be expanded to including those patients whose sole underlying medical condition is a mental disorder (MAiD MD-SUMC) (1). The proposed legislative changes are contentious, and ethicists disagree on whether providing MAiD for relief from suffering caused by mental disorder is morally justifiable (2). Given that MAiD is a legitimate and legal medical procedure within Canada, all patients who meet the diagnostic criteria must be permitted to receive it; anything else verges upon discrimination or other forms of injustice. As such, if a person meets the eligibility criteria for MAiD and holds decision-making capacity, they cannot be denied the procedure. Due to the expanded criteria, MAiD is set to become a more frequent cause of death among Canadians and the expansion to include mental illness as a potentially valid reason for pursuing MAiD presents a specific cause for worry.

Bracketing any concerns about the wider acceptability of MAiD as a practice, the issue that I raise is solely to do with MAiD MD-SUMC. Unlike physical conditions that cause pain and suffering, mental illness has the intrinsic potential to affect one's ability to understand and appropriately value the consequences of one's actions and decisions. There is thus a significant risk

that a patient who has requested MAiD MD-SUMC may be unable to provide valid consent due to an impaired ability to either: 1) adequately understand the consequences of receiving MAiD or 2) place that consequence within a consistent set of values. The impairment of consent that I am concerned about in this essay is not due primarily to the patient's cognitive functioning but instead concerns the risk of MAiD MD-SUMC administrations prioritizing the cognitive criterion over the coherence of the MAiD request with the authentic values of the person themselves. This, I will argue, constitutes an important oversight insofar as the consent that is received is not one that is made in full capacity as it overlooks the fact that personal values are a fundamental component of personhood and, therefore, moral agency.

Unlike other issues, taking mental disorder as the sole underlying condition for MAiD requests has the added problem that, "with serious mental illness, the focus of treatment decisions and the source of potential incapacity are one and the same." (3) This is morally problematic as the severity of the disorder that would justify one of the criteria for MAiD would cause another criterion (consent) to be problematic, if not impossible to obtain. For this reason, the very disorder that would cause the patient to seek MAiD puts them at a high risk of being unable to consent to the procedure. For example, it has been suggested that a number of mental disorders can manifest as a desire for death (4). This complicates the evaluation over whether the desire for death can be truly considered the patient's own desire or if it should be better understood as the disorder's interference in the patient's cognition, which manifests as a transient and misplaced desire that does not reflect the patient's considered, rational desire (5-7). In line with this concern, depression has been found to be both common within palliative care and "strongly associated" with a desire for death among patients in palliative care (8). Given that we recognize mental disorder as something that ought to be cured, we cannot recognize decisions based in the mental disorder to be true reflections of the person themselves — such decisions ought to be recognized as inauthentic until they are able to be proven authentic.

Due to the complicated interactions between mental disorder and decision-making capacity, MAiD assessors require a more subtle means of evaluating patient decision-making capacity than that which is currently commonly relied upon. Specifically, I am concerned that some capacity assessment evaluations, such as the MacCAT-T, obscure certain components of decision-making in favour of an overly cognitive understanding of capacity. My argument in this paper is based upon a presentation of the factors involved in decision-making, a demonstration that these may be obstructed by mental illness, and a suggestion that more holistic criteria for capacity evaluation be used instead of the excessively cognitive criteria espoused by most commonly used assessment tools. Because of the interplay between these aspects of my argument and the extremely high stakes involved in MAiD assessments, I argue that capacity evaluations (both in general and especially for MAiD requests) ought to incorporate an aspect of narrative assessment by which the patient's values and self-understanding can be better assessed.

CONSENT & THE PATIENT'S MORAL AGENCY

When we consider the justification for any medical procedure, the primary limitation on whether a physician may perform a medically advised treatment is the patient's consent or lack thereof; without the patient's informed consent to waive certain of their rights, the physician's act of treatment may, regardless of their intent to help, infringe upon the patient's right to bodily and personal integrity (9). As I will show in this section, obtaining valid consent depends upon the ability for the person providing the consent to be responsible for their decisions or, in other words, to have moral agency. To quote Doorn at length:

To meaningfully pursue the right of self-determination, an abstract view on human being does not suffice. If we lack a clear view on human being, every criterion to assess mental competence becomes arbitrary. We need a richer interpretation of the person in which the question of mental competence can be linked to the person's ability to respond to a given situation in coherence with what he values in life. The human will is closely connected to this life coherence. A proper account of mental competence should therefore be based on a clear view of how one's conduct or choices reflect one's deepest values and commitments. In the literature on mental competence, this view is often absent. (10)

Doorn's perspective is closely allied to my own in that it adopts a richer understanding of human willing than the purely cognitive approach to capacity evaluations would suggest is possible.

Given that consent is a requirement for justified euthanasia, we are led to ask about whether a person suffering from a mental disorder severe enough to request MAiD is able to provide true consent. The answer to this question turns on the capacity of the person to make the specific medical decision at hand; namely, do they have the capacity to consent to MAiD? Such a concern requires not merely 1) the non-coerced and informed consent of the patient but also that 2) the request being made is consistent with the patient's authentic values and self-understanding. These values, however, are rarely taken to have important bearings upon a patient's capacity. To rectify this oversight, I begin my argument by providing a brief analysis of moral agency and personhood. My reason for doing so is that if we are to determine what it truly means for a person to have capacity, we require a clear understanding of what moral agency itself entails.

Within bioethics, moral agency is often considered to be interchangeable with autonomy (11). However, the sense of autonomy that is often taken to be definitive within bioethics is not autonomy in a robust sense but rather a stripped down "sheer choice" understanding of autonomy that is based in the absence of external coercion (i.e., negative freedom) and is not ethically fundamental (8,12). Indeed, one of the founding figures of bioethics, Albert R. Jonsen, lamented that in our efforts to protect the importance of autonomy within ethical discourse, the principle of respecting autonomy has been reduced to the imperative that, "one merely respects the wishes and choices of every person without passing judgment on further moral grounds" simply

because this “shallowest meaning of respect for autonomy is the most readily grasped.” (13) While politically important, this voluntaristic understanding of autonomy is not ethically fundamental because it is not clear why an act of sheer choice should hold any moral value whatsoever unless it is grounded within and expresses the person themselves and is, therefore, no longer sheer choice (12).

Against such reductive accounts of autonomy, it seems that we value autonomy because it is directly connected to the person *qua* person, rather than because it implies an absence of coercion: an autonomous act is an expression of the person themselves (14-16). Moral agency thus depends upon the ability to ground an act or decision in the specific characteristics of a person. If a decision is not grounded in a person's character and the values to which they are authentically committed, then we have no reason to morally attribute the decision to them even if they were implicated in the causal chain of actions that brought about the event. If a person is to be self-governing (or autonomous) then they must be able to recognize a set of beliefs, and values as their own and to use these mental contents to pursue the life plan (or narrative) that they have set out for themselves (17). This means that moral agency is concerned with more than the merely intellectual or rational part of the person but must consider the person as a whole. Thus, when we protect a person's autonomy, what we are trying to protect is a person's ability to express themselves in their outward actions and decisions.

Granting that moral agency requires a consideration of the person taken as a whole rather than a reductive understanding of autonomy, we must be clear on what aspects of personhood are relevant. Typically, personhood is defined as the ability for a human being to be self-conscious or to possess “a capacity for a first-person perspective.” (18) The first-person perspective of self-consciousness implies the ability to make oneself an object of one's own understanding, to evaluate one's self and actions from this third-person perspective, and to alter one's behaviour according to the person one wants to become (18). Analyzing and adjusting oneself according to one's moral ideals is the threshold of rational, moral agency (18,19). Because self-consciousness implies that the person can both understand and change themselves according to their self-understanding and their conception of the good, we must recognize that self-consciousness must always be accompanied by a set of values (however basic) by which these acts of evaluation might occur. Indeed, the possession of a stable, minimally consistent and self-affirmed set of values or conceptions of the good are required for decision-making capacity (19). Without having some act, action, characteristic, or state of affairs that one takes as “good,” there is no way to orient one's practical action and no way to evaluate whether one is acting in a way that one would choose or, ultimately, whether something is (im)moral. It is therefore the evaluative aspect of self-consciousness that enables a person to understand the repercussions of their actions and to judge themselves in line with a moral ideal. This makes self-consciousness (including both self-reflection and self-revision) the necessary and sufficient condition for someone to be considered a moral agent (18,20).

While the assessment of a person's rationality is pivotal in determining whether they hold decision-making capacity, there is more to truly autonomous decision-making than pure rationality (21). Capacity is bound up with a patient's ability to form and act upon both cognitive commitments (including understanding, knowledge, and appreciation) and practical/evaluative commitments (including personal values), yet a patient's evaluative commitments are often omitted from procedural accounts of capacity (12,21-23). Agential decision-making therefore requires that we are able to connect our cognitive commitments with our practical commitments, thereby forming an inferential system of interconnected values, beliefs, and desires that allow us to act meaningfully (12,21). Purely cognitive accounts of capacity are thus defective insofar as they rely upon an inadequate phenomenology of action that takes knowledge and reason to be sufficient to motivate action.

Of course, this concern with the authenticity of medical decisions is implicit in the bioethical emphasis on autonomy. Biomedical ethics typically asserts that it should be the person potentially receiving medical care who makes decisions concerning their care. This conviction is spelled out quite explicitly by Beauchamp and Childress in their definition of autonomy as “a form of personal liberty of action where the individual determines his or her own course of action in accordance with a plan chosen by himself or herself.” (24)

From this brief examination of the relationship between personhood, moral agency, and autonomy, it follows that valid consent requires a person to be self-conscious and to make decisions in light of their authentically held values. Without basing their decisions in their authentic values, it is unclear how a person would be able to judge whether an act is to their benefit or aligns with their desires, even if their intellect is still functioning as it should. The conceptualization of autonomy as merely a lack of coercion that is endorsed by purely cognitive accounts of capacity is therefore insufficient to guarantee the patient's moral agency, autonomy, or valid consent. If valid consent is to be acquired, moral agency cannot be reduced to intellect but must also include the person's evaluative commitments. Consent relies not on the abstraction of autonomy understood as absence of coercion but upon autonomy as expressive of the person as a moral agent.

HOW MIGHT MENTAL DISORDER AFFECT DECISION-MAKING?

When discussing capacity, it is necessary to recall both that capacity is assumed unless there is reason to doubt it and that mental disorders do not necessarily affect decision-making capacity (25). That said, some scholarship on mental disorder has problematized the ability for those suffering from such disorders to provide informed consent insofar as mental illness may affect their values, desires, and reasoning and thereby impact decision making capacity (9,25-27). Importantly, the impact of mental disorders on decision-making is not limited to the more “obvious” mental disorders such as dementia, schizophrenia, or other psychotic disorders that have been shown to be positively correlated with incapacity. A wide range of “non-psychotic” disorders — such as depression, anxiety disorders, eating disorders, and Parkinson's Disease, to name a few — may also

impair decision-making in a way that is relevant to judgments about medical treatment (28-30). As a person's evaluative functioning and the consistency of values cannot be extracted from their decision-making capacity, it is possible for their capacity to be affected by severe mental disorder in a way that may not be detectable through purely cognitive evaluation approaches (31). For example, in a study of patients with either schizophrenia or anorexia nervosa, patients were shown to be capable of succeeding at tasks based solely on their rational abilities yet struggle to incorporate certain important information into their decision making; and those suffering from anorexia were capable of coherent decision-making but frequently suffered from distorted values (21). Both patient groups showed that cognitive considerations alone are insufficient to determine capacity because it is not necessarily the cognitive functioning that is impaired by the disorder. Instead, it may be that the evaluative functioning or values themselves that are affected. This then poses a serious problem for decision-making capacity insofar as "if a patient's values or value system can be traced back to a mental disorder [...] these cannot be considered authentic to the patient himself" (10).

This ability for mental disorders to affect the decision-making capacity of patients means that patients may be authorized to make treatment decisions that require decision-making capacity while not truly possessing that capacity at the time of evaluation (32). This potential for the symptoms of mental disorder to appear as the reasoned autonomy of the person makes it difficult to discern between an autonomous request for euthanasia and suicidality as a symptom of a patient's disorder (2,33). While decision-making capacity will, of course, still have to be evaluated on a case-by-case basis, the empirically attested possibility for severe mental disorder to affect a person's evaluative structure presents a high-risk of impaired capacity and the heightened need for improved capacity evaluations. Actively providing a life-ending treatment to a patient who had no valid ability to consent to such a treatment has the potential to be a grievous failure of the duty to do no harm. Mental disorder thus poses a threat to obtaining morally legitimate consent for any medical procedure and especially one with the finality and ultimacy of euthanasia. When we judge a patient's capacity, we do so with a two-fold goal of respecting their autonomous decision-making ability and protecting them from harmful decisions made at a time when they do not have the ability to completely judge the options available to them (34). While we ought to respect patients suffering from mental disorder as persons who are typically responsible for and free to make their own decisions regarding their healthcare, attributing capacity to a patient who does not have it is equally or even more harmful than claiming incapacity as we would not protect the patient in a time of vulnerability (33). What is more, in the context of MAiD, our lack of protection for such patients would amount to an active ending of their life; there are few acts of greater moral gravity than this. This is not to say that those suffering from mental disorder should be disqualified from MAiD, but rather that due to the complications that attend upon the mentally ill, we must treat such cases with extreme caution and determine a more holistic way of evaluating the capacity of every patient, and especially those who seek MAiD for mental illness.

THE LIMITATIONS OF COGNITIVE-BASED CAPACITY EVALUATIONS

The traditional four criteria for assessing capacity (understanding of one's situation, appreciation of potential consequences, reasoning about options, communication of a choice) has come under scrutiny for overlooking the evaluative basis for patients' decision-making (35,36). There is a growing sense that the excessive rationalism of some models of decision-making capacity (such as the MacCAT-T) are unable to account for the changes in emotions and values that can be found in some cases of psychiatric disorders wherein the patient's cognitive ability is not impaired (23,32). The problem is not so much that standard lists of criteria are wrong, but that they omit the importance of evaluative considerations that undergird the patient's appreciation and reasoning in favour of an overwhelming emphasis on cognitive ability. According to this choice-based form of moral agency, all that is required for a person to be morally responsible for an action is the ability to rationally deliberate between alternative options. Such reasoning may be conceived of as solely "instrumental", considering neither the authenticity nor content of a person's actions and decisions provided that the person expresses a general rationality (20). This formal testing relies upon there being an objective "fact of the matter" that is accessible to both patient and analyst and by which the analyst can judge the patient's correspondence through "observation and measurement via the construction of behaviour indices." (31) The patient's cognitive capacity is thus evaluated on the simple empirical ground of their fidelity to the shared experience of the facts of their condition and life. This formal cognitive testing is easily scorable, replicable across different persons and demographics, and due to these criteria, has high reliability across analysts.

The reason for taking such a "procedural" approach to capacity is clear — it provides a strong safeguard against unjustified paternalism on the part of healthcare providers by ensuring that patients can rationally grasp the details of their situation and determine whether they accept to receive a suggested treatment. This, in turn, protects the patient's ability to make decisions that others may not agree with while simultaneously attempting to protect the patient from making decisions during states of irrationality (21). However useful such formal tests of capacity may be, they are still incapable of testing for other criteria that may be required for an act to be truly attributable to a person and, hence, for which they may be truly responsible. Per Banner, we must recall that "intrinsic to assessing whether a patient is using or weighing information is a normative judgment about the role his value system plays in his decision making." (31) This is an important consideration. If capacity tests do not test for this more robust conception of capacity, then they are flawed from the start due to their methodological adoption of a sense of the moral person as a disembodied rationality who is not influenced by their own set of values and motivations (20). Such an account of the patient as a purely rational moral agent is not a realistic portrayal of the way that people actually make decisions. Instead of such a depersonalized, machinic decision-maker, real persons act based on reason, emotion, values, goals, beliefs, and an assortment of other characteristics and personality traits that come together to inform their decision-making. Given how important capacity judgments are for the practice of MAiD, the medical profession requires a stronger evaluative model for capacity.

What is missing from such assessments of patient capacity is consideration of the patient's current treatment decision in light of their evaluative functions and underlying values, both of which are central to decision-making (34-37). Yet formal capacity tests are methodologically incapable of testing the authenticity of patient beliefs due to the constitutional difference between the empirically verifiable facts that cognitive tests rely upon and the way in which a person's values and beliefs are subjectively held and determined, and which are without an empirical correspondent. When it comes to determining the ability of a patient suffering from severe mental disorder to make end-of-life decisions (especially an active request to die), we ought not consult only with other healthcare providers but also with family members and potentially documents made by the patient that might explain their values. This would then enable a more reliable determination of the coherence of the patient's current decision (which may be caused by the mental disorder) with their person as a whole (34). Considering the person as a whole would require that we include not just their current ability to cognitively assent to a specific treatment but also a more holistic account of the person's life (2). Such an integration is important insofar as mental disorders have the potential to preclude a person's assimilation of their life's history and their long-held values into their current decision-making, thereby impairing their moral agency (14,37). Taking a more holistic, person-centred approach to analyzing capacity may actually make a patient's decision more intelligible by making breakdowns in their reasoning process more apparent (21).

Despite the importance of understanding a patient's capacity to make medical decisions, the reliability of capacity assessments has been called into question such that verdicts reached through formal capacity assessments might be considered inconclusive or inconsistent (19,38). Some studies dealing specifically with patients with depression have suggested that these patients suffered no impaired capacity whereas other studies showed that up to 30% of patients did suffer an impairment (28). Again, when relying solely upon the MacArthur assessment, clinicians often come to different conclusions about a patient's capacity than when the same clinician evaluates the patient without the tool, thereby highlighting a discrepancy between the clinician's expert opinion and the results of the test (31). In one reported case, a psychiatrist experienced moral distress over the evaluation of a patient (39). The patient, Jim, passed the MacArthur criteria while being unfit to be declared competent to refuse treatment according to the psychiatrist's own judgment. Goldberg explains that "Jim, despite his adamant refusal of dialysis, had the brief insight to identify his suicidal desire as uncharacteristic, acknowledging that he might well view things differently outside the fog of his depression." (39) Yet, Jim still expressed his desire to forego treatment. This suggests that the MacCAT-T criteria are missing a means of testing the patient's ability to govern themselves according to their own self-understanding, criteria that must accordingly be updated (39). As there is this potential for important differences in capacity evaluations that can have very real effects on the legitimacy of patient decisions, the accurate evaluation of capacity is paramount. When it comes to life and death decisions and especially those wherein a medical professional will be ending a patient's life (i.e., MAiD, PAS, and similar procedures in other jurisdictions), we must have more thorough means of understanding a patient's capacity to make their own treatment decisions from a position of rationality and authenticity.

THE POTENTIAL ROLE OF NARRATIVE IN CAPACITY ASSESSMENTS

As I've suggested above, personhood and moral agency are inextricably connected to a person's values, and these are a necessary component of decision-making. The development of one's values is thus fundamental to understanding and evaluating decision-making capacity. According to Doorn, "it is more important to see to what extent the patient is able to shape his own life in accordance with the things he values. Not so much rational considerations, but rather the incorporation of moral, social, and ideological values becomes important in this view." (10) To understand the way in which the patient is able to shape their life or decisions in accordance with their values, we must recognize that personal identity and sense of self are developed through the act of interpreting one's history over time, culminating in a rich personal narrative (17,40). It then follows that a person's values, as a component of their personal identity, are a product of this process of self-interpretation; recognizing that they are derived from this narrative process is fundamental to understanding whether a person has decision-making capacity. Following Goldberg, I suggest that a patient's decision-making capacity is best gauged through analyzing how they construct an autobiographical narrative and whether that narrative is coherent (39). Drawing on Goldberg's definition, I take "narrative" to be an "imposition of both temporal and conceptual organization onto fragmented, disparate life experiences." (39) In this account, we are not concerned with tracking the correspondence of the narrative with reality (i.e., its "truth-value") but with its internal rationality/coherence and the meaning that the patient attributes to different aspects of the narrative. By seeking a narrative explanation for the origin of the values that are underlying the MAiD request, the clinician elicits a greater expression of the patient's self-understanding than is possible through more typical capacity evaluations. Narrative assessment elicits not only the rational/logical demonstration of whether the patient's values and decisions align, but also whether the patient understands how their values came to be, the nature of large shifts in their values, and why they hold the values that they currently do.

Of course, changes in patient values alone are insufficient to justify a judgment of incapacity (22). It is a normal part of human life for our values to change over time and the simple alteration of values cannot be taken to indicate that the new values are inauthentic. What we ought to be concerned with when dealing with MAiD requests based upon mental illness is whether the values displayed in the request are actually attributable to the person; in other words, whether the desire for MAiD is authentic. The innovation of the narrative approach to capacity evaluations is that the physician can question the origins of the patient's current values by asking "Why?" questions and see if the patient can provide a coherent narrative for how these values and decisions originated. In the event of a seeming shift in patient values, a clinician can then determine whether the new values can be ascribed to the patient's person by testing whether the patient can provide a coherent narrative of how the shift in values came about. If the patient can provide such a coherent narrative, then, providing that the patient satisfies the typical

MacArthur criteria, the clinician can confirm the patient's decision-making capacity regarding the decision at hand. If the patient cannot provide a coherent narrative regarding their altered values and reasoning about the decision at hand, then the clinician cannot confirm the patient's decision-making capacity. It should thus be clear that evaluations of "narrative coherence" are tracking something different than the canonical MacArthur criteria. Whereas the MacArthur criteria are concerned with ensuring that the patient is cognitively capable of making the decision in question, the narrative approach to capacity evaluation is concerned with ensuring that the decisions are made authentically.

The important thing about the narrative approach is that it is able to assess alterations within a patient's values and beliefs and draw attention to incongruities that may indicate a lack of self-understanding or self-awareness in an important area. This does not in any way indicate that alterations in values and beliefs are themselves to be discounted or indicative of incapacity but simply that the patient ought to be able to provide a coherent narrative of how these changes came about. If no narrative explanation is forthcoming, the clinician may continue to work with the patient through various forms of psychological counselling to help elicit a greater degree of self-understanding or expression, thereby eliding any a priori disqualification of the patient's decision-making capacity on the basis of a clinical diagnosis. Instead, the narrative approach that I've suggested seeks to foster relational autonomy while also safeguarding those patients whose decision-making capacity is affected by their mental disorder. Using the narrative approach to capacity evaluation provides a means of actualizing Doorn's suggestion that capacity evaluation be used to "foster the patient's capacity to respond to his own situation and to form his will" through inquiry into the patient's own reasoning, values, and self-understanding (10). This method of ongoing narrative evaluation means that a patient who, at one point in time, is unable to provide a coherent self-narrative may at a later time be capable of providing such a narrative. That is, a patient suffering from a mental disorder may request MAiD MD-SUMC, be denied it on the basis of incapacity, and then, at a later time, be found to have full decision-making capacity and be approved for the treatment on the same basis that they initially applied for MAiD. The key difference would be that the patient would be able to place their decision to seek MAiD within a coherent account of their life, experiences, values, beliefs, and relationships; in short, within a coherent narrative.

It should be noted that this narrative approach aims to be non-stigmatizing towards persons with mental illnesses; there is thus the possibility for a narrative approach to capacity evaluation that justifies rational suicide (39). Through assessing the patient's ability to narrate the development of or change in their values, a narrative approach to capacity evaluation would allow patients suffering from long-term mental illnesses to be eligible for MAiD MD-SUMC. The patient would explain why their values had shifted and thereby show that their MAiD request was not based in the symptoms of their illness but in their considered, authentic values and self-understanding. The goal of the narrative approach to capacity evaluations is simply to assess the patient's ability to provide a coherent narrative, not to provide a normative judgment of the narrative. The objective is an assessment of the process by which a decision is made rather than an assessment of the content of that decision; in this way, the evaluation remains neutral in its judgment of patient decisions. What the narrative is assessing is the patient's ability to 1) grasp the cause-and-effect relationships between agents and events within their life, 2) reflect upon their own values and beliefs and how they may have changed or remained the same. Narrative allows one to place objects, people, and events in a causal sequence through explaining their relevance to the narrative conclusions. This is not an abnormal method of elucidating causal relationships but is the central method involved in any historical inquiry; and it allows us to grasp causal relationships that are less certain because more complex than what simple "if X, then Y" statements can express. Such "mechanistic" causal statements are rarely sufficient when it comes to moral agency and, in such cases, describing the causal relationship in terms of teleological orientation is the only plausible option. While standard evaluations of rationality, such as the MacArthur criteria, are useful in assessing whether patients can understand basic cause/effect relations, they cannot test for whether the patient's own evaluation of these relations is true to themselves.

Banner has criticized approaches that rely upon the internal rationality of a person's reasoning process as a test for capacity (such as the narrative approach) on the grounds that we do require a normative evaluation of the content of the person's decision, not just its form (31). She suggests that there is an "appropriate response" that a patient ought to have to information concerning their situation, and if they do not have the appropriate response, then this is evidence of a lack of decision-making ability (31). Per Banner, analyzing whether a person is making a decision in full capacity requires a normative evaluation of their decision which evaluates whether they are appropriating and using the information given to them in a way that they ought to (31). Yet this need not imply any judgment about the conclusion, only that the patient is using the information in a way that does justice to its major normative implications and includes these implications in their deliberations. The narrative assessment allows us to understand whether the patient is placing sufficient normative weight on the information prior to a decision being actualized. While Banner may be correct that information ought to be weighted appropriately, this is not an indication that the end-result ought to be uniform among all persons or that a decision made against the wider consensus is irrational. Indeed, many normative systems, such as virtue ethics or natural law theory, reject there necessarily being only a single "right answer" to any morally charged situation. This means that Banner's suggestion would have to assume a normative framework (and its concomitant axiology and understanding of a good human life) within which the patient's weighting of information would be situated and judged. According to Rawls, "a modern democratic society is not characterized simply by a pluralism of comprehensive religious, philosophical, and moral doctrines but by a pluralism of incompatible yet reasonable comprehensive doctrines. No one of these doctrines is affirmed by citizens universally." (41) Given that no such "comprehensive doctrine" is ubiquitously held by the pluralistic citizens of Canada, Banner's demand to judge the outcome of the patient's deliberative process according to a determinate moral standard is untenable. Instead, the narrative approach to capacity assessment can test the internal rationality of the patient's deliberative process and then aid in determining whether the patient is acting consistently with their own authentically held values and beliefs.

CONCLUSION

Most will agree that there must be restrictions or guidelines on who qualifies for MAiD and under what conditions they qualify. While decision-making capacity is paramount to any refusal of or request for treatment, it is widely agreed that when the stakes of a medical decision are significant, higher thresholds of capacity are required to make that decision (8). Because MAiD entails the willed death of a person, opting for MAiD may require a higher threshold for capacity (25). My contention is that current means of evaluating who qualifies for MAiD are inadequate to deal with requests for MAiD MD-SUMC. Given that the mental disorder is sufficiently severe to cause suffering serious enough to bring a person to pursue MAiD, there is good reason to question whether the mental disorder may have negatively affected the patient's capacity to consent to such a serious procedure. The problem is that consent requires not only that one possess adequate decision-making capacity but, as I've argued, is fundamentally about the authenticity of the values guiding the patient's decision-making. My concern is that in trying to uphold the autonomous decision-making of patients suffering from mental disorders, we may actually betray their true convictions, beliefs, and values; in short, betraying their true moral agency. Due to this possibility, I've argued that we need a more subtle form of capacity assessment that enables greater understanding of whether the values guiding the patient's request for MAiD are authentically their own and are not a symptom of their disorder. I believe that the narrative approach to capacity evaluation that I've sketched here can promote the more holistic type of assessment that is required for determining the patient's decision-making capacity. While it will have to be fleshed out in greater detail, I hope to have contributed to the discussion surrounding the complexity of decision-making capacity, mental disorder, and end-of-life care.

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COMMENTAIRE CRITIQUE / CRITICAL COMMENTARY (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

First They Came for the Physical Crips: The Eugenic Logic Driving MAiD

Heidi Janz^a

Résumé

Dans cet article, j'examine de manière critique l'expansion de l'aide médicale à mourir (AMM) au Canada sous l'angle de l'éthique du handicap. Je soutiens que le discours dominant qui présente l'AMM comme une politique compatissante et favorisant l'autonomie occulte le capacitisme systémique inhérent à sa mise en œuvre. En m'appuyant sur des expériences vécues, des décisions juridiques et des débats bioéthiques, je démontre comment les personnes handicapées sont de plus en plus poussées à recourir à l'AMM, non pas en raison de leur état de santé, mais à cause de la négligence structurelle, de la pauvreté et du manque de soutien. Je critique la justification de l'AMM par la « réduction des méfaits », en montrant qu'elle perpétue une logique eugénique qui dévalorise la vie des personnes handicapées. En mettant l'accent sur l'éthique du handicap, je propose une redéfinition de l'autonomie qui reconnaît l'interdépendance et remet en question la primauté biomédicale de l'individualisme. Cette approche met en évidence les failles éthiques de la politique actuelle en matière d'AMM et appelle à une évolution vers des pratiques anti-capacitistes et valorisant le handicap dans les domaines des soins de santé et de la bioéthique. En fin de compte, je soutiens que sans un tel changement, l'aide médicale à mourir risque de devenir la voie de la moindre résistance pour les personnes handicapées structurellement vulnérables, plutôt qu'un choix véritablement autonome.

Mots-clés

aide à mourir, capacitisme, principes bioéthiques, éthique du handicap

Abstract

In this paper, I critically examine the expansion of Medical Assistance in Dying (MAiD) in Canada through a disability ethics lens. I argue that the dominant narrative framing MAiD as a compassionate, autonomy-enhancing policy obscures the systemic ableism embedded in its implementation. Drawing on lived experiences, legal decisions, and bioethical debates, I demonstrate how disabled individuals are increasingly driven to seek MAiD not due to their medical conditions, but because of structural neglect, poverty, and lack of support. I critique the “harm reduction” justification for MAiD, showing that it perpetuates a eugenic logic that devalues disabled lives. By foregrounding disability ethics, I propose a redefinition of autonomy that recognises interdependence and challenges the biomedical privileging of individualism. This approach exposes the ethical flaws in current MAiD policy and calls for a shift toward anti-ableist, disability-affirming practices in healthcare and bioethics. Ultimately, I argue that without such a shift, MAiD risks becoming a path of least resistance for structurally vulnerable disabled people, rather than a truly autonomous choice.

Keywords

assisted dying, ableism, bioethical principles, disability ethics

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INTRODUCTION

In his famous 1946 poem, “First They Came for the Communists,” German Lutheran pastor, Martin Niemöller, laments the silence of German intellectuals and clergy — including, by his own admission, Niemöller himself — following the Nazis’ rise to power and subsequent incremental purging of their chosen targets, group after group. In this paper, I will demonstrate that, contrary to the dominant public narrative which asserts that the legalization and ongoing expansion of Medical Assistance in Dying (MAiD) in Canada is all about giving suffering people autonomy over when and how they die, the reality is altogether different. The introduction of MAiD into a healthcare system plagued by ableism is resulting in increasing numbers of people with physical illnesses and disabilities who are not at end-of-life being driven to end their lives because they cannot access sufficient financial, housing, and/or personal care supports to live with dignity in the community. More specifically, I will engage with the bioethical argument that MAiD should be considered a form of “harm reduction” for people living in “unjust circumstances” who are unable to get the supports they need to live, and who are experiencing “intolerable” suffering as a result. Using a disability ethics framework to critique this argument, I will show that it is rooted in a fatalistic acceptance of systemic ableism as an immutable fact of life, rather than as a fundamental injustice that a free and just society has a responsibility to dismantle. I will conclude this paper by considering how an increased acceptance and application of a disability ethics framework in medical and bioethical discussions of MAiD could help to better diagnose the ableism that is endemic within Canada’s MAiD regime.

ABLEISM AND EUGENIC LOGIC IN THE MEDICAL SYSTEM

Both the initial 2016 legalization of MAiD in Canada for people with “grievous and irremediable” medical conditions whose natural death is “reasonably foreseeable,” (1) and the 2021 expansion of eligibility to include people with disabilities whose natural death is *not* reasonably foreseeable (2) marked seismic shifts in the already-often-troubled relationship between people

with disabilities and healthcare providers. It created a situation in which clinicians embedded in a healthcare system saturated by ableism were given the responsibility of deciding which disabled lives should be ended via MAiD, and which should not. As Anita Ho asserts, “Even as dependency is a natural and unavoidable part of the human condition, dominant social structure continues to espouse individual self-sufficiency as a norm and an ideal, such that technological and human assistance to daily living is often interpreted by health care providers and others to indicate an unacceptably low quality of life.” (3)

The manifestations of ableism in healthcare and health ethics are legion. They range from genetic screening to detect potential disabling conditions in fetuses, which will then become candidates for selective abortion (4), to doctor’s offices with examination tables that are inaccessible to wheelchair users (5), to pandemic triage protocols that list preexisting disability as an exclusion criterion for receiving critical care in the event that critical care resources need to be rationed (6,7). All of these manifestations of ableism in healthcare and bioethics are rooted in what Rosemarie Garland-Thomson calls “eugenic logic,” that is, an ableist belief that “our world would be a better place if disability could be eliminated.” (8) MAiD is the most recent, lethal, expression of this eugenic logic.

“WAIT! NO ONE’S ‘COMING FOR’ ANYONE HERE! MAiD IS ALL ABOUT AUTONOMY, NOT EUGENICS!!!”

Despite the ubiquity of medical ableism rooted in eugenic logic, whenever anyone — including and especially disability rights advocates — suggest that Canada’s MAiD regime is fundamentally ableist, and, indeed, eugenic, proponents of MAiD promptly dismiss such concerns as being, not only unfounded, but paternalistic, insofar as they undermine the autonomy of disabled people who choose to die by MAiD. Perhaps the most notable example of this is a paper entitled, “Choosing death in unjust conditions: hope, autonomy and harm reduction,” published in the *Journal of Medical Ethics*. In this paper, Kayla Wiebe and Amy Mullin “consider and reject arguments that the autonomy of people choosing death in the context of injustice is necessarily reduced, either by restricting their options for self-determination, through their internalisation of oppressive attitudes or by undermining their hope to the point that they despair” (9). Using what they term a “harm reduction” approach, they argue that “even though such decisions are tragic, MAiD should be available” to people with disabilities who cannot get the supports they need to live with dignity. This is because:

Rather than betraying an ‘ableist bias,’ their decisions can be more charitably and respectfully interpreted as an accurate assessment of their situation. It is one thing to identify an ableist bias in a person or a policy where there is no lived experience with a disability, and quite another to attribute ableism to a person who has intimate experience living with their disability, and to on this basis question the legitimacy of their decisions regarding their own care (9).

Rephrased in plain language, what Wiebe and Mullin are essentially saying is, “Yeah, ableism exists, and it sucks. And we should work to reduce it. But the reality is that we will never eradicate it. So, if a person with disabilities wants to get MAiD to escape the crappy life they have because they live in an ableist society, we should believe them regarding how crappy their life is and let them die by MAiD.” In my view, such an argument is nothing other than eugenic logic cloaked in the language of autonomy.

I am far from the first person to find Wiebe and Mullin’s notion of MAiD as a form of “harm reduction” deeply problematic from an ethical standpoint. For example, in their response to Wiebe and Mullin’s original paper, Christie and Li point out that:

Although the authors concede that providing MAiD in unjust circumstances causes harm, they do not interpret the principle of non-maleficence. Instead, they appeal to what they call ‘harm reduction,’ which is basically a restatement of the well-known ‘maximin’ rule. This approach ranks options according to outcomes and recommends the option with the least harmful consequences. They conclude that making MAiD available to these patients is less harmful than making them continue to live with intolerable suffering. This approach, however, uncritically accepts the assumption that living in unjust circumstances is the type of intolerable suffering for which MAiD is the appropriate ‘medical treatment.’

The definition of ‘intolerable suffering,’ adopted by the authors and found in the Criminal Code is based on circular reasoning, [albeit intuitively appealing.] The patient is obviously the expert in their suffering, suggesting that they be the one to determine whether their suffering is intolerable. However, this reasoning is circular because any suffering the patient says is intolerable, is in fact intolerable. (10)

I would argue that the central safeguard of “intolerable suffering” is further compromised by the ubiquity of medical ableism and what disability ethicist Joel Reynolds has termed the “ableist conflation” of disability, suffering and death: “wherever operative, the ableist conflation flattens communication about disability to communication about pain, suffering, hardship, disadvantage, morbidity, and mortality” (11).

This ableist conflation of the mere presence of disabling conditions with “intolerable suffering” that is caused by a lack of community-based disability-related supports that is embedded in Canada’s MAiD regime is actually rooted in the *Truchon* decision itself. In this decision, Justice Beaudoin repeatedly states that the Plaintiffs’ mental suffering is caused by their “complete dependence and total loss of autonomy.” (12) But then, two paragraphs later, she argues that “the decision to

request medical aid in dying is not motivated by their disability.” (12) This strikes me as, at best, flawed reasoning, or, at worst, disingenuous. Indeed, it seems self-evident that the Plaintiffs would not be facing a state of “complete dependence and total loss of autonomy” if they did not have disabilities. However, the assertion of a distinction between the Plaintiffs’ disabilities and their “total loss of autonomy” does point to a tangible connection between the Plaintiffs’ wish to hasten their deaths and the lack of social supports that many disability scholars and activists cite as major factors in making the lives of people with disabilities who lack the means of maintaining control of their personal care and daily choices untenable. Justice Beaudoin’s ruling thus clearly conflates the Plaintiffs’ suffering due to a loss of control with the fact that they have disabilities. Disability-rights advocate, Gabrielle Peters, calls out this ableist conflation as promulgating “a demonstrably false version of autonomy,” (13) one that is “consistent with an ableist worldview that dominates in law and culture.” (14) Yet, thanks to the Canadian federal government’s refusal to challenge this flawed decision by appealing it, we now have a MAiD law that has both this ableist conflation and this false version of autonomy as its basis.

COLLATERAL DAMAGE? MAiD AS THE PATH OF LEAST RESISTANCE

There is an ever-growing body of evidence indicating that increasing numbers of disabled people are, in fact, “choosing” to end their lives via MAiD, not because of “intolerable” suffering caused by their physical condition, but because they are unable to access sufficient medical, disability, and social supports to be able to live self-determined, dignified lives in the community (15-17). The following two cases are notable examples.

“Sophia” (a pseudonym), was a 51-year-old Ontario woman who had multiple chemical sensitivities, a chronic condition. She underwent a medically-assisted death after her desperate two-year search for affordable housing free of cigarette smoke and chemical cleaners failed. “The government sees me as expendable trash, a complainer, useless and a pain in the ass”, Sophia said in a video filmed on Feb. 14, 2022, eight days before her death. She died after a frantic effort by friends, supporters and even her doctors to get her safe and affordable housing in Toronto. Four Toronto doctors were aware of Sophia’s case, and they also wrote to federal housing and disability government officials on her behalf. In that letter the doctors confirmed that her symptoms improved in cleaner air environments and asked for help to find or build a chemical-free residence. “We physicians find it UNCONSCIONABLE that no other solution is proposed to this situation other than medical assistance in dying,” they wrote (18).

Equally troubling and tragic is the story of Sathya Dhara Kovak, a Winnipeg woman who died by MAiD on October 3, 2022. Kovac lived with amyotrophic lateral sclerosis (ALS). Her condition was worsening, but she felt she had more life to live — just not enough home care support to do so. “Ultimately it was not a genetic disease that took me out, it was a system.” Kovac wrote in an obituary to loved ones. Her obituary continues, “There is desperate need for change. That is the sickness that causes so much suffering. Vulnerable people need help to survive. I could have had more time if I had more help.” (19)

There is indeed a desperate need for change. In the words of Canadian disability scholar, Jerome Bickenbach, when an individual chooses death as the only viable way to escape an intolerable situation partly brought on by the social environment, it seems “perverse and unfair to say that this is an expression of self-determination or autonomy.” (20) There are thus two critical ethical flaws in the argument that MAiD should be considered a purely autonomous act and a form of harm reduction for structurally vulnerable disabled people who are experiencing *intolerable* suffering due to a lack of support. First, this so-called “harm reduction” approach overemphasizes an impoverished notion of autonomy at the expense of other fundamental ethical principles, such as non-maleficence and justice. Within this MAiD-as-harm-reduction approach, the only ethical consideration that matters is *who* decided on MAiD as the chosen course of action. Questions around *how* and *why* a structurally vulnerable person made the decision to die via MAiD are rendered irrelevant. Related to this is the second critical ethical flaw in the argument that MAiD should be considered as a form of so-called “harm reduction,” namely that this argument ignores the broader ethical and societal implications of viewing the lives of structurally vulnerable disabled people as harms which can be (and, ultimately, ought to be) reduced via MAiD.

Indeed, once eligibility for MAiD was expanded to include people with illnesses and disabilities whose natural death is not reasonably foreseeable, Canada became a country in which it is accepted that certain sorts of lives with certain limitations can be terminated with medical assistance. This means that ill and disabled Canadians, along with their families, are now routinely encountering messages telling them that, if they are experiencing X, Y, and Z because of their condition, ending their lives through MAiD is a valid solution to their suffering. Thus, it is the lives of any and all disabled people who suffer hardship and deprivation as a result of living in an ableist society, rather than the ableism at the root of their suffering, that become “harms” to be eliminated. Canadians with disabilities are consequently rendered a dispensable class of people within Canadian society. This ultimately creates a high risk of suicide contagion among disabled people who are likewise experiencing X, Y, and Z, not simply because of their condition, but because they live in an ableist society that does not prioritize the needs of disabled people.

Given the lethal threats to disabled people that have arisen from the introduction of MAiD for disabled people who are not at end-of-life into a society and a healthcare system that are saturated in ableism and fixated on a narrow, individualistic notion of autonomy, I will spend the remainder of this paper considering the potential for disability ethics to function as a disruptor of this biomedical and bioethical privileging of a notion of autonomy that is grounded in ableism.

FOREGROUNDING DISABILITY ETHICS TO DISRUPT ABLEISM IN CANADA'S MAID REGIME

Disability ethics is an interdisciplinary approach to ethical dilemmas regarding life with disability. It addresses many of the same issues that bioethics addresses, and expands the focus beyond medical issues. It includes legal, policy and social justice issues that affect daily living for people with disabilities. Disability ethics shares the central theme of the disability-rights movement, "Nothing about us without us." The primary aim of disability ethics is thus to ensure that the perspectives of people with lived experience of disability are central to discussions and debates about ethical issues involving disability and people with disabilities. In the words of Jackie Leach Scully:

Disability ethics, like feminist ethics, is a form of ethical analysis consciously and conscientiously attentive to the experience of being/having a 'different' embodiment. ... And doing this means working from people's experience of disability to see if and how it colors their perceptions, interpretations, and judgments of what is going on in moral issues, especially in moral issues that have direct relevance to disability and where differences in the experience of disability might be expected to have weight (21).

Viewed through a disability ethics lens, autonomy looks and functions very differently than it does in traditional bioethics. This is because, as Katherine Moore points out, "People with disabilities may experience autonomy and choice — and therefore their sense of self — differently than non-disabled people. It is of unique concern to people whose autonomy is often taken away." (22) For many disabled people, exercising autonomy necessitates some form of dependence on others to help create and/or maintain the conditions that make it possible for them to enact a chosen course of action. Reindal argues that:

Professionals tend to define independence in terms of self-care activities. So, independence is measured against skills in relation to performance of these activities. Disabled people, however, define independence as an ability to be in control of and make decisions about one's life. Independence is then not linked to doing things alone or without help, but by obtaining assistance when and how one requires it (23).

Disability ethics thus problematizes and disrupts traditional biomedical and bioethical conceptions of autonomy in some interesting and important ways, particularly in relation to MAiD. Within a disability ethics framework, autonomy is re-defined from an independent action carried out in isolation, to the facilitated ability, through the assistance of others, to choose a course of action and carry it out. Such a redefinition of autonomy calls into question the ableist assumption that it is a person's disability, and not the fact that they live in an ableist society, that so limits their ability to make life choices that their only tenable choice is to die by MAiD. Furthermore, this redefinition of autonomy necessitates a shift in focus away from a narrow definition of autonomy as necessarily carried out completely independently by a self-governing individual, towards a broader definition of autonomy as, in some sense, a co-operative project that works towards a common good. Disability ethics thus functions in a manner similar to feminist ethics in that it broadens the concept of autonomy from being a purely individualistic phenomenon and places it into a relational context. When applied to the practice of MAiD, this exposes the ableist underpinnings of the MAiD-as-harm-reduction argument in two ways. First, it exposes the strident utilitarianism inherent in declaring disabled lives as harms to be eliminated through MAiD. And second, it reclaims space in which to consider the broader social consequences of uncritically accepting the conceptualization of the lives of disabled people as "harms" which can and should be reduced.

It is important to recognize that such a decoupling of autonomy from individualism constitutes a major heresy against what Charles Foster calls "the orthodoxy of autonomy." (24) According to Foster, autonomy:

... means that we all have a life-plan, we all have a right to have it respected, and if we're to talk about such disreputable, autonomy-truncating things as duties at all, we merely have duties not to interfere with others' life-plans. Anyone so contemptibly sub-rational or unreflective as not to have a life-plan is hardly human at all. If one can spare a little time in one's own life-plan to help the unreflective limp towards higher self-realisation, that is a Good Thing, and the god will be pleased. (24)

Foster goes on to argue that "[t]his is the orthodoxy, and it is policed with terrifying vigour. To depart from it is dangerous ... And so the medical ethics journals are full of detailed descriptions of and reflections on the brocade on the Emperor's entirely absent clothes." (24) Most troubling though, is that this strictly prescribed adherence to the "orthodoxy" of autonomy is not just limited to the field of bioethics, rather, it has become the cardinal ruling principle of many Western democracies. Consequently, during the debate around Bill C-7, which would expand eligibility for MAiD to people with disabilities whose death is not reasonably foreseeable, both disability-rights advocates who raised concerns about introducing MAiD into a medical system and a society that is steeped in ableism, and, physicians who raised concerns about being compelled to end life rather than preserve it, were promptly dismissed as fear-mongering enemies of autonomy.

Importantly however, like Justice Beaudoin and Wiebe and Mullin, what the policymakers who thus dismissed disability-rights advocates' concerns about introducing MAiD into a medical system and a society that are steeped in ableism failed to recognize is that their arguments for the further expansion of MAiD are rooted in inherently false and ableist notions of autonomy. The application of a disability ethics analysis to notions of autonomy that are commonly used to promote the practice and further expansion of MAiD reveals this fact. It further reveals that these arguments are centred around the erroneous and ableist isolation of a person's disability as necessarily the cause of their intolerable suffering, without any consideration of how consequences of systemic ableism, such as poverty, lack of supports, or social isolation often combine to make their suffering

intolerable. More often than not, proponents of MAiD will respond to such critiques, as do Wiebe and Mullin, by claiming that they are paternalistic in that they undermine the autonomy of disabled people who have chosen to die by MAiD rather than to continue to endure the deprivations and consequent suffering that too often come with living in an ableist society. However, this claim is deeply problematic from an ethical standpoint in that it entirely ignores and nullifies the core ethical principles of justice and nonmaleficence by uncritically accepting systemic ableism and the harsh and multifaceted deprivations that it often leads to as immutable facts of life, rather than as affronts to these core ethical principles. Furthermore, viewing this claim through a disability ethics lens necessarily challenges its narrow, individualistic conceptualization of autonomy by revealing the ways in which this individualistic view of autonomy undermines and devalues the lived experience of a multitude of disabled people for whom exercising autonomy necessitates some form of dependence on others to help create and/or maintain the conditions that make it possible for them to enact a chosen course of action.

Finally, foregrounding a disability ethics approach in the context of MAiD would foster among clinicians what Eva Kittay calls “epistemic modesty”, that is, “knowing what one does not know” (25). However, true epistemic modesty among clinicians necessitates not only knowing what one does not know but also owning (acknowledging) what one does not know in terms of unrecognized personal ableist biases.

CONCLUSION

As I have endeavored to demonstrate throughout this paper, both healthcare and bioethics suffer from metastatic ableism, which is often driven by underlying eugenic logic. The introduction of MAiD into a healthcare system thus plagued by ableism has further increased the precarity of the lives of disabled people who are compelled to enter the realms of healthcare and bioethics. This is because clinicians embedded in a healthcare system saturated by ableism were given the responsibility of deciding which disabled lives should be ended via MAiD, and which should not. Consequently, in this era in which MAiD for disabled people who are not at end-of-life is becoming increasingly legalized and normalized in Western societies, it is now more than ever incumbent upon clinicians who are treating disabled patients to practice epistemic modesty. They must know and own what they do not know about their patients' experiences of disability, and consciously and conscientiously foster anti-ableist, and disability-affirming clinical practices. Short of a successful constitutional challenge and repeal of Bill C-7, this is the only way that the realms of healthcare and bioethics can be rehabilitated into safer spaces for disabled people.

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TÉMOIGNAGE / PERSPECTIVE

The Unique Role and Contribution of Peer Supporters to MAiD in Canada: Lessons Learned from a National Discussion Series

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Résumé

Cet article décrit les enseignements tirés d'une série de discussions nationales organisées en 2024-2025. Des pairs aidants de tout le pays se sont réunis virtuellement pour discuter du rôle particulier et important qu'ils jouent dans les conversations, les soins et les politiques liés à l'aide médicale à mourir (AMM), en s'appuyant sur des valeurs, des points de vue, des expériences vécues et des modes de relation qui leur sont propres et qui se distinguent de ceux des professionnels de la santé réglementés et des réseaux de soutien informels. Nous recommandons que les personnes qui envisagent l'AMM se voient offrir — et aient accès à — un soutien par les pairs, si elles le souhaitent, et que les programmes de soutien par les pairs disposent des ressources nécessaires pour fournir un soutien émotionnel et affectif authentique qui honore la vision du soutien par les pairs en faveur de l'autodétermination.

Mots-clés

aide médicale à mourir, AMM, soutien par les pairs, mouvement des consommateurs/survivants/anciens patients, autodétermination, suicide

Abstract

This paper describes lessons learned from a 2024-2025 national discussion series. Peer supporters from across the country came together virtually to discuss the special and important role they play in conversations, care, and policy related to medical assistance in dying (MAiD), building on unique values, standpoints, lived experiences, and ways of being in relationship that are distinct from those of regulated health professionals and informal support networks. We recommend that people exploring MAiD should be offered — and have access to — peer support, if desired, and that peer support programs be properly resourced to provide authentic emotional and love labour that honours a peer support vision for self-determination.

Keywords

medical assistance in dying, MAiD, peer support, consumer/survivor/ex-patient movement, self-determination, suicide

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INTRODUCTION

Peer support (PS) is, in its most expansive sense, “a naturally occurring, mutually beneficial support process, where people who share a common experience meet as equals, sharing skills, strengths and hope; learning from each other how to cope, thrive and flourish” (1). Self-help and mutual aid was a common way of life until the 1850s when, particularly in white, Western jurisdictions, a culture of professionalism developed; important roles were extracted from communities and transformed into elite areas of expertise (2). In the Canadian context, one effort to reclaim and re-practice peer support is a tradition that traces its roots to the 1960s-1970s psychiatric consumer/survivor/ex-patient (C/S/X) movement, where participants engaged in political action to expose the dehumanization of psychiatric practices and to advocate for legal and social rights. They also developed their own independent alternative supports (3).

This C/S/X movement-inspired PS was initially available informally through naturally occurring interpersonal relationships and grassroots groups like Vancouver's Mental Patients Association, formed in 1971, and the Ontario Mental Patients Association founded in 1977 (4,5). Increasing in the 1980s and 1990s, PS was intentionally fostered through government funding of community initiatives run by and for people with lived experience (PWLE) of mental health and/or substance use concerns as an alternative to conventional, hierarchical service models. Over the last 15 years, we have seen a growing recognition of the value of lived experience, an increase in paid PS roles, and the movement of these roles from grassroots initiatives into formal mental health services (6,7).

Although PS has been growing, it remains poorly resourced in Canada (8). In the national expansion of medical assistance in dying (MAiD) over the past decade, larger, well-established and funded health professions have been acknowledged as having a significant role and have had the resources to develop and disseminate discipline-specific position statements, policies, and educational materials on MAiD. PS has had scant resources to develop its own materials. Yet a study by one of our co-authors on patient and family perspectives on MAiD for persons with mental illness suggested the importance of ensuring access to

peer supporters for those considering MAiD and providing peer supporters with relevant training on MAiD (9). In this paper, we share what we have learned from coming together to respond to this need.

Our colleagues in Mad Studies, the academic discipline that has developed from the C/S/X movement, have been weighing in on MAiD conversations (10-12). PWLE of mental health conditions have been providing testimonials (13-16). There has also been some discussion within C/S/X movement news sources, though these have largely not been noticed by academic scholarship (17-19). To date, lessons from the C/S/X movement's historical and contemporary national PS practice have not been explicitly part of scholarly discussions about MAiD. We seek to address this gap. In doing so, we see this work as one of "Mad Ethics," the elaboration of how PWLE of mental health and/or substance use concerns put values into action in the context of PS. To reflect this contribution, we draw on several common terms to refer to our communities, including peer (peer support participant), peer supporter, and people with lived experience (PWLE).

After briefly outlining our collaborative initiative over 2024 to develop tailored educational resources for peer supporters on MAiD, we share learnings from this initiative that have much to contribute to national conversations. We demonstrate how peer supporters play a unique and important role in peers' explorations of MAiD, building on the PS discipline's long experience supporting peers' explorations of desires to die, possibilities for living, and options other than dying. This role is distinct in notable ways from those of regulated health professions or a peer's informal support network of friends and family, offers a special contribution to MAiD discourse, policy, and care in Canada, and requires greater recognition and resources.

BACKGROUND: PROJECT DESIGN AND APPROACH

Our work to facilitate opportunities for learning and dialogue for peer supporters on MAiD proceeded in seven steps.

Exploring the Focus

Our initial work began over November 2023-January 2024, when there was uncertainty over whether MAiD for Mental Illness as a Sole Underlying Medical Condition (MI-SUMC) would be decriminalized on March 17, 2024, following a one-year extension of ineligibility announced the year before. We proceeded with the knowledge that regardless of whether the government extended the ineligibility date (as became the case), peer supporters had much to contribute to holistic support for people considering and pursuing MAiD. For example, through supporting peers already participating in PS who were receiving terminal diagnoses and planning for end-of-life, potentially through Track 1 MAiD for individuals whose natural death is reasonably foreseeable, as well as people experiencing unbearable suffering from chronic pain, illness, or disability who were considering Track 2 MAiD for those without a reasonably foreseeable death. Regardless of their identity or experience with respect to the mental health system, peers expressing desires to die sooner or differently than they might otherwise may seek or benefit from PS. We wanted peer supporters across the country to feel prepared for these conversations.

Gathering the Team

Our team included an ethicist, PS learners, lived experience scholars, MAiD researchers, one of us with lived experience of a family member's death with MAiD, and the Executive Directors of our national and provincial peer support associations. The mission of Peer Support Canada, formed in 2010 as the national voice for PS, is to "increase the recognition, growth, and accessibility of peer support within the mental health and substance use health spaces." (20) PeerWorks, established in 1991, pursues a mission to "strengthen, amplify and deepen diverse peer voices in Ontario through community building, information-sharing, collaboration, advocacy and education." (21) Both organizations play an active role in advancing PS in Canada, including through professional development for peer supporters.

Searching for Information

Peer Support Canada and PeerWorks circulated a call for information to their national and provincial membership lists to inquire into existing — or desired — resources for peer supporters on MAiD. We also conducted an environmental scan of roughly 300 academic and community resources, aided by the reference lists provided by colleagues. We learned that peer supporters are eager for educational materials but did not identify any specifically tailored to their role.

Curating and Developing Educational Content

A team of nine PWLE related to PS and the mental health system assessed resources for relevance and accessibility to arrive at a final list of 34 sources considered most helpful to our audience of peer supporters. To meet different learning needs, we ensured multiple formats (e.g., recorded webinars, government reports, podcasts) and summarized key points. The final 14-page list was graphically designed to reduce information overload (22).

Team members also felt that we should facilitate a tailored interactive learning opportunity. We therefore invited peer supporters with a basic knowledge of MAiD to attend a discussion series focused on the PS role. We designed the series as a 3-part discussion (90 minutes weekly over three weeks) so that participants had time to build rapport before the most challenging conversations in week 3. The series was based on five PS scenarios and associated prompts, which covered topics of death, dying, end-of-life, grief, suicide, and MAiD, seeking to situate MAiD within a broader, familiar context for peer supporters, encouraging them to bring forward a range of experiences to inform the discussion. Honouring the PS value of

mutuality, facilitators positioned themselves as learners, highlighting that because there are no existing guidelines informing peer support's relationship to MAiD, we would develop this knowledge together.

Taking a Provisional Stance

In anticipation of mixed reactions to the resources, we included a preamble acknowledging diverse views in PS communities with respect to MAiD (13), and how peer supporters deserve equitable access to education and support:

Peer supporters need to be prepared to have conversations about death, dying, and end-of-life, whether they are supportive or not supportive of MAiD. As people who have often personally navigated challenges associated with death and dying, peer support workers are naturally equipped to be able to navigate these conversations.

[Peer supporters] should not be expected to participate in providing support that they feel unprepared and/or unable to provide due to a lack of training, guidance, support, and/or on the grounds of personal convictions and beliefs. Peer supporters are also entitled to the resources and support they need to be able to have these conversations. (22)

This focus is consistent with Peer Support Canada and PeerWorks' mission statements and work to increase tailored education for peer supporters.

Facilitating the Discussion Series

We advertised the series to peer supporters across the country through the membership lists of Peer Support Canada and PeerWorks. In keeping with our goal to involve a group diverse by geography and other identities, and to ensure that the series would meet participants' needs, we developed a brief application form. We had over 250 people apply. To date, we have facilitated the series six times with a total of 67 peer supporters representing 8 provinces and 1 territory. 59.7% of participants identified as belonging to one equity-deserving community (beyond mental health/substance use), and 25.4% as belonging to two or more. Each series has included two co-facilitators, a person available to offer confidential PS in a breakout room, and a note-taker/technology support person.

WHAT CAN PEER SUPPORTERS CONTRIBUTE TO MAID CONVERSATIONS IN CANADA?

In 1981, the Editors of *Phoenix Rising*, Canada's national C/S/X movement magazine, explained that there are "five good reasons" why people became active in the movement: "support; information-sharing; power; developing alternatives to psychiatry; and changing unjust 'mental health' laws." (23, p.2) Nearly 45 years later, we focus below on how contemporary PS practice rooted in C/S/X traditions and unique PS values and standpoints continues to offer support, information-sharing, power, and alternatives to the health system in ways that make a distinct and important contribution to conversations on MAiD. We specifically focus on how PS offers: 1) a vision in which self-determination and active support — often understood to be in tension — are deliberately combined; and 2) alternative ways of being in relationship that offer flexible, resonant, and authentic forms of accompaniment.

A vision in which self-determination and active support, often understood to be in tension, are deliberately combined

In 2013, Peer Support Canada released national guidelines regarding the core values, principles, and standards of practice of PS (24). These values are: hope and recovery; empathetic and equal relationships; self-determination; dignity, respect, and social inclusion; integrity, authenticity, and trust; health and wellness; and lifelong learning and personal growth (25). Similar values have been identified for PS traditions internationally (26-28).

Discussions about MAiD in Canada often emphasize a tension between dominant ethical principles of bioethics — on the one hand, autonomy (capacity to make a free choice) and on the other, beneficence (promoting a person's welfare, acting in their best interests). PS follows a different intellectual tradition where self-determination and active support are deliberately combined rather than incompatible, which we unpack below.

The peer support value of self-determination is different from the medical ethics principle of autonomy

The conception of autonomy that has become dominant in Western bioethics and medicine is focused on an individual's capacity to reason and express a voluntary choice. This principle has been primarily operationalized in healthcare and research with human subjects through the practices of informed consent and confidentiality (29)¹. However, this informed consent view of autonomy does not serve PWLE well in part because of its focus on 'reason' and 'capacity' (32). PWLE continue to be routinely treated as incapable of making their own treatment decisions and therefore not given the opportunity to consent to or refuse treatment (33).

¹ Development of this conception of autonomy is often attributed to the 1979 American publications of the *Belmont Report* (30) on the ethical oversight of research involving humans and the first edition of Beauchamp and Childress' *Principles of Biomedical Ethics* (31), which draw on earlier philosophical work of Immanuel Kant and John Stuart Mill (29).

In contrast, the C/S/X movement traces its practice of self-determination to the 1960s-1970s civil rights, Indigenous sovereignty, feminist, gay, and other liberation and consciousness-raising movements of the era, the 1966 *International Bill on Human Rights*, the counterculture writing of Thomas Szasz (USA), Michel Foucault (France), Erving Goffman (USA), R. D. Laing (UK), and others critical of psychiatry, and the experiential knowledge exchange and generation among ex-patients (33-38)².

Empowerment is the fundamental philosophical basis for this tradition, wherein self-determination is one component. Both are core and pervasive concepts in C/S/X history and practice that have not been precisely and comprehensively defined (36). But we know that thinkers like Foucault and Szasz were concerned about the power of the psychiatric establishment over the liberty of psychiatric patients. To them, empowerment meant: 1) oppositional efforts to address perceptions that patients are incapable of exercising free will and associated restrictions on freedom, and 2) liberation from professional control and its negative consequences (36).

This focus on regaining power and control is ubiquitous in C/S/X literature: “By participating in the Movement, people experience a real sense of power. They...are listened to and taken seriously for a change. ...The Movement will help us gain power to control our own lives and live the truth as we know it.” (23, p.3) In contrast with a narrow conception of autonomy as the personal autonomy of an individual, the C/S/X movement advocated for the self-determination of PWLE as a population group. And rather than rely on the state, health system, or health professionals to produce meaningful options, the C/S/X movement created its own peer-led and controlled alternatives (discussed below). Aspects of this vision of empowerment and self-determination echo in current disability advocacy around MAiD³. This is a much more expansive view of liberty and freedom than the definition of autonomy that has become dominant in Western healthcare.

Peer support is wary of beneficence, and acts to protect against paternalism

The C/S/X movement emerged as a critique of psychiatric practices justified by a bioethics principle of beneficence, such as involuntary hospitalization and treatment defended in the name of promoting a person's welfare. (3,34) Alongside the primacy of the value of self-determination, contemporary PS values remain wary of paternalism and protect against it in several ways.

The value of equal relationships requires peer supporters to minimize power differences by affirming a peer's self-knowledge and focusing on “what people have in common and can teach each other, rather than on how one person may diagnose and treat another.” (41, p.247)

The philosophy of peer support is that each individual has within themselves the knowledge of what is best for them and a strong desire to find a path towards improved health [or quality of life]. The peer supporter supports that person as they search for that inner knowledge. (24, p.3)

Peer supporters in our discussion series explained how in intervening to ‘protect’ a peer, they would be adopting a clinical approach inconsistent with PS values and outside of the scope of their role⁴.

Peer supporters also differentiate their professional role from that of a friend, who may experience a felt duty to promote a loved one's welfare, a conflict between their personal interests and the loved one's interests, or entitlement to greater influence over a loved one's decision (42). Peer supporters are instead in a special relationship with a peer bound by PS values and practice standards to nonjudgmentally support peers to explore and make decisions that are right for them.

In our discussion series, it was evident that through daily use of their lived experience, peer supporters have developed strong practices of self-awareness and personal reflection. They notice their own biases, personal values, and discomfort, actively resist value-laden connotations that specific choices are good or bad, and skillfully ensure their own needs and interests do not exert influence or control over a peer's choices.

In peer support, self-determination is a positive right, requiring extensive action and supportive conditions to be realized

In healthcare, autonomy and informed consent are often treated as a negative right to non-interference. To honour this right requires “inaction” and not providing healthcare without valid consent. In PS, self-determination is a positive right; it requires extensive action and supportive conditions to be realized. Accordingly, core features of PS are to “facilitate the self-

² While many foundational C/S/X movement texts refer in passing to academic intellectual ancestors, the works themselves are much more focused on describing the experiences and perspectives of movement champions and participants in their own words (3,34). As the UK-based Survivors History Group explains, there are “two features tending to make survivor histories different from other people's histories. One that stands out is that our histories are usually descriptive rather than theoretical. Less obvious, but important, is that survivor research has focused on the continuity of survivor action instead of considering it a by-product of intellectual trends, such as Laingian anti-psychiatry. We argue that this corresponds more closely to the reality of what happened. As Louise Pembroke, founder of the National Self-Harm Network has said, we were not ‘sitting around talking about Laing’ — ‘our role models were each other.’” (39, p.7)

³ For example, analyses that focus on the population-level implications of MAiD for disability communities rather than as only an individual decision, demands for affordable and accessible housing and alternatives to living in long term care, and testimonies that a choice between living in dehumanizing social conditions or death is no choice at all (40).

⁴ For example, any action to ‘assess’ a peer for symptomatology of mental illness affecting their choices, to give advice based on presuming the peer supporter knows more or better, or to influence or control the actions, beliefs, decisions, or movements of a peer, reflect a deviation from the PS role and equal relationship into a hierarchical relationship (8).

determination and the empowerment of peers,” (24, p.8) to “demonstrate knowledge of local resource options and how to access these resources,” (24, p.11) and to “support peers to identify their needs and rights to make informed choices.” (24, p.10)

Through their lived experiences, peer supporters are attuned to how powerlessness, hopelessness, and isolation can influence decision-making. The mental health system and other experiences of oppression “often are experienced as a stripping away of choices, personal control, and decision-making.” (43, p.115) Peers may therefore “need assistance in recognizing that they do have choices and are capable of making choices. ...[They] benefit from knowing about what choices are available and when their choices are being limited.” (43, p.116) Peer supporters can assist peers in developing their choice-making competencies and to “recognize that their lives have value, dignity, and worth,” (44, p.6) thereby enhancing the voluntariness of a peer’s choices.

Peer supporters have a deep, experiential knowledge of what it takes to navigate resources and services, the energy and persistence required to do so, challenges with access, and the importance of creating their own unique survival strategies. In contrast, clinical professionals are often unfamiliar with (or misinformed about) peer, community, and grassroots support (45). For example, a MAiD assessor in a study led by one of our co-authors spoke of knowing a lot about medical services but much less about social and community services. Some, but not all, assessors have access to system navigators or social workers to help address these gaps (46). As the PS role is to “support an individual’s expressed wishes,” (1) but not to determine or carry out the wish, peer supporters in our discussion series described the practical ways they might support a peer raising the topic of MAiD, such as offering to look with the peer for resources and information or accompanying them to a MAiD-related medical appointment to take notes and debrief afterwards.

Peer supporters shared with us how, regardless of their personal views on MAiD, the PS value of self-determination would keep them focused on honouring and not judging a peer’s choice. As peer support movement leader Theresa Claxton put it, “It is a principle of peer support to encourage self-determination and respect the fact that people will make their own choices, whether or not I, as their peer support worker, agree or would choose the same for myself.” (47, p.20) PS affirms how “people make good decisions when they are free of shame and blame. A fundamental aspect of peer support is that it provides a relationship and ongoing exchange that purposely avoids shame and blame.” (48, p.32)

Alternative ways of being in relationship that offer flexible, resonant, and authentic forms of accompaniment

Peer supporters’ unique positionality enables them to engage in conversations and support less constrained by conventional norms, assumptions, and practices. We unpack these alternative ways of being in relationship in four sections below.

Sharing power in peer support relationships and initiatives sets peer supporters outside of and less constrained by the mainstream healthcare system

Peer supporters endeavour to share power. In contrast to the considerable authority granted to registered health professionals by health legislation⁵, the day-to-day work of peer supporters is not as heavily influenced by this legislation, legal authority, standards of care, fee-for-service compensation schemes or fear of litigation, complaint, or losing a license. Peer supporters are thus in a position to accompany people expressing desires to die in a greater range of ways.

In the context of MAiD, this means that peer supporters are not focused on playing an evaluative, clinical, or legal function within the formalized MAiD process. In the discussions we facilitated, peer supporters were not riveted by a peer’s mention of MAiD and did not zero in to further investigate a peer’s eligibility, legal capacity, or motivation for MAiD, or referral pathways. Nor did peer supporters rush to try to create an offramp from the path to MAiD. Peer supporters instead sought to follow the peer’s lead on where they wanted to take the conversation, with no agenda, no power, no judgment⁶.

Peer supporters described how their approach to supporting someone raising the topic of MAiD would be no different from their everyday experience discussing desires to die with peers, or other important decisions a peer might be considering (49). Peer supporters provide a space for peers to explore aspects of their choices that they may not be able to in other relationships due to particular clinical consequences. For example, opening a space for ambivalence, where peers have the opportunity to talk confidentially about the dynamic nature of desires to die without this fluctuation being used to deem them ineligible for MAiD as evidence of a kind of “lack of persistence” in their desire.

This sharing of power in PS extends to the operations of small, grassroots, peer-led initiatives and creative crisis supports, such as Alternatives to Suicide groups, Emotional CPR (eCPR) conversation methods, ‘warm’ PS phone lines, and peer respites (4,50-53), which are less common in hierarchical, bureaucratic, risk-averse clinical organizations. Several peer supporters in our discussion series shared how working in a peer-led initiative gave them more control and flexibility with their

⁵ Such as the power to label experiences with a diagnosis, prescribe mind-altering drugs, provide psychotherapy, and suspend a person’s freedom through involuntary detention in a hospital or finding a person incapable of making their own medical decisions (8).

⁶ A co-author brought to our attention that this centrality of the peer supporter-peer relationship in the design of our discussion series scenarios is in contrast to her observations of how ‘cases’ are commonly used in MAiD education sessions for registered health professions. Our scenarios begin from an existing relationship rather than a cluster of diagnoses and symptoms. Peer supporters in our discussion series consistently related to the person in the scenario as a peer, and someone they cared about, using their name and pronouns and noting connections between their experiences in ways that felt particularly respectful and holistic.

schedule so they have time to listen to a peer's whole story and build a relationship without an arbitrary time or session-limit. Peer supporters are able to use flexible modalities like meeting people in the community, connecting by phone or virtually, and accompanying peers to appointments.

PS that involves a drop-in, groups, or other community-building aspect is especially well suited to easing loneliness and isolation (54), such as the loneliness that nearly 50% of people report as an aspect of the unbearable suffering underlying a request for Track 2 MAiD (55). Our Voice / Notre Voix, a peer-led initiative that has been publishing a national newsletter for 38 years, has advocated that these grassroots alternatives for relieving suffering need more attention by the Government's MAiD policy (17).

Shared frustration and harm from the health system creates a point of connection between peer supporters and peers exploring MAiD

PS communities hold deep, lived experiences of frustration and harm from health and social service systems. For example, they share experiences related to coercion and not being believed or taken seriously; abandonment from being passed from one professional to another, not being able to tell their full story, and having conversations shut down; and the limits of biomedicine, such as unsuccessful or inaccessible treatments and medical errors (3,34,56). While these forms of suffering do not appear in Government reports of why people choose MAiD, peer supporters understand how such experiences can contribute to broken trust in the health system and a sense of having no other options to help relieve one's suffering.

Because frustrations with the health system are among the causes of persistent, long-lasting suffering that has led to poor quality of life (56), conversations between people requesting Track 2 MAiD and health professionals can be tense: As one MAiD assessor explained (in a study one co-author is undertaking with colleagues), efforts to understand whether suffering is 'intolerable' can be experienced as raising doubt about the legitimacy of (for example) chronic pain, and questions designed to assess whether a condition is 'irremediable' can suggest disbelief about the person's efforts to seek help or participate in their recovery.

Because peer supporters are intentionally an alternative to mainstream health services, their relationships are not conditioned by these difficult histories. Peer supporters' own experiences of disappointment and distrust in healthcare is a source of connection, uniquely positioning them to build trust with people seeking MAiD, especially those on long waitlists, found ineligible, or living with government policy delays and uncertainty. For example, in our discussions about responding to a peer's despair over the postponement of the legalization of MAiD for MI-SUMC, peer supporters in our series expressed how they would validate the peer's feelings and experiences, reflecting on their own challenges accessing desired resources, their experiences of hopelessness, and strategies to cope.

Peer support's experiential, critical perspectives on mainstream interventions into desires to die enable them to create safe spaces to talk about these desires

Peer supporters have distinct standpoints on suicide that differentiate them from other disciplines in conversations about MAiD and may mean they face fewer barriers in supporting people considering MAiD.

Informed by their unique positionality⁷, PS communities de-medicalize suicide and de-professionalize strategies for addressing suicide. In PS, desires to die are not assumed to result (primarily or solely) from untreated mental illness and perceived impairment in reasoning. Instead, PS actively recognizes suicidal people as legitimate knowers who have deep insight into their living conditions, suffering, and options (49,61,64). Furthermore, PS does not stigmatize the decision to end one's own life. Stigmatizing suicide blames the peer for the unjust social conditions that contributed to their death, hides the peer's resistance, obscures broader society's responsibility in the death and its role as the perpetrator of harm (59), and disenfranchises the grief and bereavement of peers and peer supporters who disproportionately lose community members to suicide.

Additionally, in PS, suicide is not viewed as a failure of care or a peer supporter's 'fault.' (49,55) In contrast to psychiatry, psychology, and mental health counselling, PS is not grounded in an established tradition, expectation, and professional self-image around preventing people from dying (66). Peers act from a place of mutuality, not clinical expertise, recognizing the importance of validating a person's suffering and desires to die, not exerting force to talk them out of this (67). Peer supporters admit that they are powerless to save anyone or radically alter another person's circumstances or feelings; and let go of the idea that they are responsible for a peer or that it is their job to keep someone else alive. Instead, peer supporters feel honoured when a peer trusts them with their story around desires to die; are realistic about what they can do, with no expectation of fixing or finding a solution; and do their best to work with peers to "figure out how to go on living," (50, p.198) while accepting that peers may still choose to end their life (49,51,65). Living this philosophy can take serious unlearning and self-exploration:

⁷ This standpoint is significantly informed by peer supporters' experiences of the intolerability of surviving in an oppressive society with unmet needs for food, shelter, security, and belonging, and appreciation, among many, of how choosing to end one's life lived in such conditions can be an understandable option. Many peer supporters have been affected by the loss of peers through suicide and drug toxicity, who are dying from abuse, abandonment, neglect, hate, and isolation, not biological illness (57-60). Peer supporters may also have complex and varied lived experiences related to considering and attempting to end their life; notably, the harms of forceful intervention to prevent suicide. They understand how interventions to prevent people from dying can contribute to their deaths, such as through shame and a breakdown in trust (37,51,61-63).

to de-escalate a conditioned panic or fear response, live with uncertainty, and not shut down conversation, and to remain present and authentic, listen, witness, and stay emotionally close (49,51,65,67).

Over decades of experience in the C/S/X movement, and increasingly demonstrated in peer reviewed research, this approach is known by peer supporters to be profoundly meaningful for those experiencing desires to die (62,68-70). Peer supporters in our discussion series talked about how peers entrust them with stories that the peer has not felt safe sharing with anyone else, and has been struggling with in silence (50). Peer supporters understand firsthand how being able to talk about wanting to die or thinking about killing themselves, being listened to and respected, can help peers go on living, at least for a time (11).

Likewise, for some people exploring MAiD, particularly where their death is not reasonably foreseeable, having their request for MAiD taken seriously, and a place to talk about death, has helped people better cope with suffering, regain control over their lives, realize they do not want to die, and/or delay MAiD (56,71). Peers exploring options to die — whether they frame this in terms of suicide or MAiD — can benefit from peer support. Drawing on PS knowledge to offer this support, such as in the form of PS groups for people exploring MAiD, is likely to produce more dividends than focusing on distinguishing MAiD from suicide⁸.

The peer support value of authenticity encourages honest human discussion of love and the impact of loss in a context of MAiD and suicide

In their unique role, peer supporters are empowered to speak honestly and sincerely about how a peer matters to them, that they do not want the peer to die, that they hope the peer won't end their life, and how the peer will be missed if they do. Love and care for their peer, and the PS value of authenticity, encourages this kind of earnest expression of desire for the peer to continue to live, all the while nonjudgmentally affirming the peer's power to choose (49,53,60,64,65).

These relationships, conversations, and losses can have a profound impact on peer supporters. Participants in our discussion series talked about the importance of personal boundaries, limits, and consent — how they need to be a willing participant in accompanying someone on their journey, and to regularly reflect on whether they are in a place where they can carry the peer's story (49). They spoke about the importance of affirming their humanity, their background experiences (e.g., of loss, death, grief, mental health recovery), what it will be like for them to bring their lived experiences in these areas to work every day, and the support they need. To remain loving, genuine, and sincere in a relationship with a peer, they are mindful of only committing to what is possible and manageable for them (49).

In contrast with the formal MAiD policy that emphasizes legal language of eligibility, safeguards, rights, and conscientious objection, PS approaches MAiD in a way that emphasizes our common humanity, the meaning of our relationships with each other, and how people matter to us. PS suggests pathways for grounding MAiD policy and practice in this common humanity.

CONCLUSION: VALUING THE PEER SUPPORT ROLE IN MAiD CONVERSATIONS

Peer supporters have an important role to play in conversation and care related to people exploring MAiD, building on long experience and values-based approaches to supporting people who express wishes to die. PS values and standpoints offer a different way of being in relationship, caring for and not abandoning each other, and supporting decision-making.

Yet, peer supporters cannot have the positive impacts described above when they are restricted from contributing (62,74), or when they feel they must work outside the lines of organizational policy in order to maintain integrity with PS values, as several worried about in our discussion series. We have not yet seen an organizational MAiD policy that references the role of peer supporters in the process — and we imagine very few, if any, peer supporters have been involved and consulted in such policy development at organizational, provincial, or national levels. Organizational policies that block (or fail to encourage) peer supporters from having meaningful conversations with peers about desires to die should be revised through consideration of PS knowledge (74).

Peer supporters also require support that is rarely available, due to a lack of dedicated funding towards peer support within community mental health care in Canada and severe underfunding of independent PS initiatives (8). Talking about desires to die is emotionally challenging. Peer supporters in our discussion series made difficult decisions about how they might be able to support a peer's journey based on whether their employer would provide the support needed to replenish. Most peer supporters face significant employment precarity, such as low pay, part-time roles, lack of paid sick days, bereavement, or holidays, or health benefits. They are often working in isolation on interdisciplinary teams without PS from colleagues with lived experience (8). There is much work to do to ensure PS programs across the country are properly resourced and supported, with tailored educational opportunities, particularly on the topic of MAiD. Peer supporters are owed this social solidarity and reciprocity in recognition of their love labour to honour the painful stories entrusted to them.

⁸ While to some, MAiD and suicide may be legally and medically distinct (73), in a study by Fruhstorfer et al. (57), none of the people pursuing Track 2 MAiD they interviewed discussed any moral or philosophical difference between the two. The suffering from social conditions that underlies both MAiD and suicide have similar sources and solutions, the overmedicalization of both can limit or shut down conversations, and the knowledge and expertise peer supporters bring to both are undervalued and deserve greater recognition. Instead of focusing on the similarities or differences between MAiD and suicide, "opening a dialogue about the wish to die might provide more dividends." (74, p.322)

All people experiencing social and existential suffering, loneliness, and the emotional and spiritual impacts of societal prejudice deserve access to the support, information-sharing, power, and alternatives offered by social movement-inspired PS initiatives. MAiD policies and programs should require the offer of PS to people exploring MAiD, and access to it, if desired. Registered health professionals who have benefited from increasing professionalization and associated disintegration of informal supports have a duty to ensure every patient they treat also finds opportunity for belonging and connection in their community.

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Conflicts of Interest

None to declare

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TÉMOIGNAGE / PERSPECTIVE

What Ontario MAID Death Review Committee Reports Tell Us About Canada's MAID Policy and Practice — And About the Overhaul It Needs

Trudo Lemmens^a

Résumé

Cet article examine de manière critique les preuves relatives à la pratique de l'aide médicale à mourir (AMM) en Ontario, telles qu'elles sont documentées dans les rapports du Comité d'examen des décès liés à l'AMM (MDRC) du coroner en chef de l'Ontario, dont l'auteur est membre. S'appuyant sur des récits de cas et des discussions anonymisées résumés dans un récent rapport du MDRC sur la démence et dans des rapports antérieurs du MDRC, l'auteur met en évidence les aspects préoccupants de la pratique actuelle de l'AMM, en se concentrant particulièrement sur l'AMM pour les personnes atteintes de démence. L'article documente des évaluations de capacité parfois minimalistes, des procédures de consentement éclairé discutables et des interprétations flexibles de critères juridiques tels que « mort naturelle raisonnablement prévisible » et « état avancé de déclin irréversible ». L'analyse révèle comment les pratiques actuelles peuvent contourner les garanties législatives fondées sur le droit pénal, notamment par le recours à des dérogations au consentement final qui s'apparentent à des demandes anticipées d'aide médicale à mourir, lesquelles sont interdites par le Code criminel. L'article soutient que les documents d'orientation de l'Association canadienne des évaluateurs et prestataires d'AMM contribuent à des pratiques qui semblent en contradiction avec la loi. En conclusion, le document préconise une refonte du système, notamment par le biais de critères législatifs plus stricts, de mécanismes d'examen indépendants et d'une surveillance professionnelle renforcée, qui devraient refléter le résultat irréversible et le plus grave de la procédure.

Mots-clés

aide médicale à mourir, AMM, euthanasie, suicide assisté, Ontario, politique, droit, démence

Abstract

This paper critically examines the evidence of Medical Assistance in Dying (MAID) practice in Ontario, as documented in reports from the Ontario Chief Coroner's MAID Death Review Committee (MDRC), of which the author is a member. Drawing on case narratives and anonymized discussions summarized in a recent MDRC report on dementia, and in earlier MDRC reports, the author highlights troubling components of current MAID practice, particularly focusing on MAID of persons with dementia. The paper documents at times minimalistic capacity evaluations, questionable informed consent procedures, and flexible interpretations of legal criteria such as "reasonably foreseeable natural death" and "advanced state of irreversible decline." The analysis reveals how current practices may circumvent criminal law-based legislative safeguards, including through the use of Waivers of Final Consent that resemble advance requests for MAID, which are prohibited under the Criminal Code. The paper argues that guidance documents of the Canadian Association of MAID Assessors and Providers contribute to practices that appear in tension with the law. In conclusion, the paper calls for an overhaul of the system, including through stricter legislative criteria, independent review mechanisms, and enhanced professional oversight, which should reflect the irreversible and most serious outcome of the procedure.

Keywords

medical assistance in dying, MAID, euthanasia, assisted suicide, Ontario, policy, law, dementia

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INTRODUCTION

A recent New York Times interview with Canadian children's author Robert Munsch revealed that he struggles with dementia and Parkinson's disease, and that several years ago he was approved for Medical Assistance in Dying (MAID) (1). The article received much attention in Canadian media and public debate, fueling ongoing discussion about advance requests for MAID. Advance requests for MAID have already been introduced by provincial law in Quebec, even though it remains prohibited under the Criminal Code. Advocacy organization Dying with Dignity jumped on the occasion to renew its call to legalize the practice (2). Yet, advance requests raise profound ethical, legal and policy challenges (3,4), which I will touch upon here mostly indirectly.

For me, three components of the Canadian reporting on Munsch's choice for MAID stood out. Most seemed to accept MAID as an obvious, or even the only reasonable choice for people who, like Munsch, are facing physical or cognitive decline and fragility. All except one commentator (5) reported uncritically Munsch's in-jest, but rather ableist comments about why he preferred death over decline with dementia: to avoid that his wife would be "stuck with me being a lump." (6) Most did not critically question why he could be approved for MAID several years earlier, even though he and his family declared that even now, he still has a reasonable quality of life.

The media report about Munsch coincided with the publication of a new Ontario Chief Coroner's MAID Death Review Committee (MDRC) report on dementia and MAID (7). The MDRC, of which I am a member, is an interdisciplinary committee

set up by the Chief Coroner's office. It reviews the files of a selection of MAID cases. A team of trained professionals review all of Ontario's reported MAID cases. A sub-set of these cases are then shared with the MDRC to explore the common issues they raise. The MDRC's review and discussion informs Coroner's recommendations for various stakeholders. The Coroner's office has so far prepared seven reports that contain narrative summaries of cases, anonymized discussions of these cases, and recommendations for policy and guidance on various topics. My comments here reflect my personal views.

The MDRC dementia report, and earlier reports, document numerous examples of questionable MAID practices that should be taken seriously by policy makers, health professional organizations, and anyone concerned about patient safety. They confirm in my opinion, concerns that have been raised in the past about Canada's MAID practice, including in media reports and expert commentary and analysis (8): 1) that people are at times approved for MAID based on remarkably flexible interpretations of legal access criteria and following minimalistic capacity and informed consent procedures; 2) that unaddressed mental health or substance use issues and lack of social supports are not seen as a hindrance for providing MAID; and 3) that overall, Canada's MAID policy and practice focus on facilitating broad access to death as a form of therapy, not on protection against premature death. This latter concern is evidenced in various guidance documents issued by the Canadian Association of MAID Assessors and Providers (CAMAP), a semi-professional organization that has received significant funding from the federal government to develop guidance and education.

In what follows, I illustrate these issues using examples of the various MDRC reports, with a particular focus on the last dementia report. Worth noting is that earlier MDRC reports also contain some narrative cases of persons with dementia opting for MAID, in circumstances seemingly comparable to those of Mr. Munsch.

HOW PERSONS WITH DEMENTIA ARE APPROVED FOR MAID UNDER CURRENT MAID PRACTICE

The MDRC report confirms that MAID for reasons of dementia occurs frequently in Ontario, even if it has until now, at 1% of cases, not been a dominant ground for MAID. In Ontario, 103 people received MAID for reasons of dementia in the 2023-2024 period, with nearly 2/3rds of the cases in 2024 (7). All but one obtained access under 'Track 1' and were thus considered to be approaching their natural death. All likely involved euthanasia, i.e., a lethal injection, since there are nearly no assisted suicide cases (self-administration of prescribed drugs) in Canada.

In the context of a disease that inherently involves a progressive loss of cognitive function, which becomes particularly pronounced closer to the person's natural death, these MAID approvals evoke several questions: 1) Since about all were assessed as Track 1 cases, with situations of "reasonably foreseeable natural death" (RFND), were there no problems with capacity for decision-making? How thorough were the capacity assessments? How did people provide informed consent? 2) In the cases where capacity for decision-making was abundantly clear, and thus their death not likely to occur in the near future, why were these applications not considered under Track 2? 3) How do persons with an early diagnosis of dementia satisfy the MAID access criteria, which require under both Track 1 and 2 an advanced state of irreversible decline of capability and intolerable suffering?

CONCERNS WITH CAPACITY AND INFORMED CONSENT ASSESSMENTS

The answer to the first question is straightforward: case narratives and discussions in the MDRC dementia report reveal that there are concerns about capacity for decision-making in at least some of the cases. The MDRC dementia report, but also earlier MDRC reports, document how some MAID assessors followed questionable capacity assessment procedures; and how information about the capacity assessment process is often too limited to determine how it was done.

It is important to emphasize again that the federal criminal law does not yet allow MAID on the basis of advance requests, and that MAID applicants must be capable of consenting at the time of the MAID approval. Moreover, unless they signed a Waiver of Final Consent (WofFC), permitted only under Track 1 (I briefly discuss this further, below), they must confirm consent just prior to receiving a lethal injection.

Obviously, cognitive decline or mental illness do not, in and of themselves, deprive people of capacity (9). Canadian law emphasizes that every person is presumed to have capacity. Yet, severe cognitive decline is among the most common reasons for findings of incapacity. When it comes to informed consent, not only does cognitive decline evoke concerns in the context of dementia, but also the impact of increasing vulnerability, dependence on family members and others, existential fears, isolation, anxiety, and intersecting issues of physical decline and mental health challenges, such as depression and severe anxiety. As Ramona Coelho writes in a commentary on the MDRC dementia report, "perceived loss of dignity, feeling like a burden, emotional distress, and the fear of decline" often characterise the experience of living with dementia (5). This is often particularly pronounced shortly following diagnosis.

It would seem in a dementia context particularly appropriate to take time to evaluate what is going on, whether problems of adjusting to the challenges associated with dementia, family pressure or burn-out, or other factors, are inappropriately influencing MAID requests, and whether people's suffering could be addressed in other ways. Yet, the reports document cases of people getting MAID while they struggle with adjustment to a long-term care home placement, or to loss of ability to engage

in activities; and a case of a woman whose spouse was struggling with caregiver burnout — she had previously explicitly indicated she wanted palliative care rather than MAID, for personal and religious reasons (10).

Some cases combine several troubling components. Take the case of 6F, a woman in her 80s with advanced dementia (7). She was initially hospitalized following multiple falls. During the hospital stay, a family member initiated a first MAID request, allegedly after she expressed a “desire to die”. A MAID ‘navigator’ felt uncomfortable “facilitating a written request,” due to the woman’s severe cognitive limitations. The woman then opted for continued care in a long-term care home. Four months after her admission, a family member initiated a new MAID request. This time, an assessor approved her for MAID during a single interaction. The assessor mentioned “marked existential suffering” and that it was “clear that she did not want to continue to live as she [was]” (7, p.34). They further acknowledged “communication challenges” and that the assessment was “managed in a way that worked for her [i.e. the patient].” The assessment report contained further general statements about capacity, but no details of any in-depth assessment. The second assessment also failed to mention how capacity was determined.

The MDRC report documents additional capacity concerns just prior to the MAID procedure itself, which took place one week after approval. Mrs. 6F appeared “overwhelmed by the presence of additional visitors” (7, p.34), who were therefore asked to leave the room. “Final express consent” was deemed capable and informed based on her “ability to repeat the consent question and via squeezing the provider’s hand.” (7, p.35)

Hand squeezing as expression of informed consent is matched by at least one other case of remarkably minimalistic consent in an earlier MDRC report. A report on “Complex Same Day/Next Day Provisions of MAID” describes the case of Mr. 4C, a man in his seventies diagnosed with metastatic cancer who requested a MAID assessment five days after palliative care admission (10). He was at risk of losing capacity due to brain metastases and opioid analgesics. Before a formal assessment could be conducted, he experienced cognitive decline and could no longer communicate. Even though the palliative care team informed the MAID provider that he no longer had decision-making capacity, the provider “vigorously roused” the patient, who “mouthed yes” when asked if he wanted MAID (10). After withholding pain medication, he appeared more alert, and the MAID provider organized a second assessment, transmitting questions and answers to a second assessor virtually. The patient’s nodding or “mouthing yes” in response to questions was again accepted as expression of capable and informed consent.

While these cases are clearly at the extreme end of remarkable capacity assessment and informed consent procedures, several other cases in the MDRC reports, some of which I discussed elsewhere (11), raise related capacity concerns. Some also raise concerns about potential pressure or influence by family members, at times with remarkably fast approval and provision of MAID, with one report discussing various cases of same-day or next-day provision of MAID (10). Take the earlier mentioned case of a woman who preferred palliative care, whose husband struggled with caregiver burn-out. In that case, it was the husband who contacted the MAID coordinator service, after a request for placement in hospice care was rejected. She received MAID the same day as the rejection of the request.

DEMENTIA AND FLEXIBLE INTERPRETATIONS OF A REASONABLY FORESEEABLE NATURAL DEATH

Even though some other cases of the MDRC dementia report involve people with severe cognitive decline and questionable capacity for decision-making, with only limited documentation of how capacity was assessed, other cases involve people in earlier stages of dementia with less cognitive decline. But those cases raise the question how they were deemed to fulfill the legal access criteria related to intolerable suffering and an advanced state of irreversible decline of capability, and how nearly all were approved under Track 1.

It is important to emphasize here that to be approved for MAID, a person must have a grievous and irremediable medical condition, which is defined as: a serious illness, disease or disability, with an *advanced* state of irreversible decline of capability, either of which cause intolerable physical or psychological suffering that cannot be relieved in circumstances that they find acceptable. In addition, to qualify under Track 1, a person’s death must be reasonably foreseeable (12).

When it comes to the qualification under Track 1, some of the dementia cases as well as cases in earlier MDRC reports confirm how a remarkably broad interpretation of the concept of a “reasonably foreseeable natural death” (RFND) has been embraced by some of Canada’s MAID providers. These interpretations are likely influenced by CAMAP guidance documents, which in turn were inspired by some academic scholars who have been putting forward interpretations that facilitate a very broad application of MAID.

According to the CAMAP guidance on RFND, for example, a person whose condition would make them normally only qualify under Track 2, can still fit the RFND criterion to qualify under Track 1,

...if they have demonstrated a clear and serious intent to take steps to make their natural death happen soon or to cause their death to be predictable. Examples might include stated declarations to refuse antibiotic treatment of current or future serious infection, to stop use of oxygen therapy, to refuse turning if they have quadriplegia, or to voluntarily cease eating and drinking (13, p.1).

So far, no federal or provincial health authority and none of the health professions' regulatory colleges have pushed back against this remarkable interpretation, which facilitates a circumvention of the longer and more 'complex' (albeit in my view insufficient) review procedures the legislature deemed necessary for Track 2.

MDRC reports reveal that CAMAP's interpretation, allowing a transfer of Track 2 into Track 1 cases, has found its way into MAID practice. Take the case of Mr. 5B, a man in his 60s with cerebral palsy (14). He was noted to struggle with "profound psychosocial suffering and loneliness due to limited social relationships and isolation from community," and "anticipatory fear of further dependence" (14, p.22). The MAID assessor emphasized that "they did not counsel Mr. B on Track 1 vs Track 2 determinations to avoid influencing or coaching his personal care decisions," with respect to "voluntary stop eating and drinking." (14, p.22) The report does not reveal if anyone else counselled the patient. What we know is that Mr. 5B stopped eating and drinking and was then deemed to qualify under Track 1 because of a RFND.

A CAMAP Guidance on Dementia further explicitly claims that a mere diagnosis of Alzheimer's satisfies the RFND criterion, even though it acknowledges that such persons have a median survival of 4 to 7 years (15). It embraces an interpretation put forward by Jocelyn Downie and Jennifer Chandler, who suggest that a RFND is fulfilled either if the person's death is "not too remote" or "the cause of the person's death is predictable" (16). But it is questionable whether this is really what the legislature had in mind. A Canadian government website on MAID states, for example, that RFND requires "the person to be approaching the end of their life in the near term." (17)

Those who interpret the RFND very broadly tend to invoke an interpretation of the access criteria and RFND in a 2017 Ontario Superior Court decision by Justice Perell (18). However, a careful reading of that judgment reveals that it is doubtful that an early onset of dementia would align with this interpretation. Justice Perell recognized that there may be doubt in some cases whether a person has a RFND. But the case "of an almost 80-year-old woman in an advanced state of incurable, irreversible, worsening illness with excruciating pain and no quality of life" (18, para 87) clearly satisfied for him the criteria. He suggested that the "proximity or remoteness of death and the duration of suffering must be considered." (18, para 85) An early dementia diagnosis with years of life left is clearly fundamentally different from the facts in this case.

DEMENTIA AND ADVANCED STATE OF IRREVERSIBLE DECLINE OF CAPABILITY

CAMAP further puts forward that the future loss of capacity associated with dementia results *prima facie* in the satisfaction of the criterion of an advanced state of irreversible decline (19). In a recent article, Christopher Lyon, Scott Kim, and I suggest that this shows that for CAMAP "the potential *future* impossibility to satisfy a legal requirement for access to MAiD (resulting from possible loss of capacity ...) turns a person's *present* health situation into an advanced state of irreversible decline" and "[a] potential ineligibility condition [into] positive evidence of eligibility" (20, p.15). It is puzzling how such intellectual gymnastics have not yet been challenged by our medical professional organizations, which appear to grant CAMAP remarkable freedom in constructing peculiar interpretations of the law.

The MRDC dementia report reveals that committee members had starkly differing opinions on this interpretation. Some opined that to respect the legislative intent, the term should be reserved for situations where a "loss of function is profound and enduring, and significantly compromises [people's] quality of life." (7, p.38) They suggested that a subjective interpretation would permit ableist biases to influence assessors' judgment about the value of life for people who struggle to perform complex tasks. Others, seemingly following CAMAP guidance, argued that the term should be understood within a "person-centred and psychosocial framework", which recognizes the "subjective meaning persons assign to their cognitive and functional decline." (7, p.38) In other words, the fear of losing higher-order cognitive functions would be an "advanced state of irreversible decline" for some people with strong cognitive capacities in the first place, but not necessarily for others (7) A retired mathematics professor's fear of losing the ability to play chess might, according to this approach, thus be evidence of an "advanced state of irreversible decline", whereas for another person it would be the ability to play bingo. In some of the reported cases, assessors explicitly mention people's difficulty in practicing their usual hobbies.

In my opinion, interpreting the concept of "advanced state of irreversible decline of capability" as based on a largely subjective and individual experience further erodes an important safeguard. It also opens the door to the influence of assessors' own subjective interpretations and biases of what a life with cognitive decline would mean to *them*. The emphasis on such subjective experiences makes it difficult to create the time and space for adjustment and coping strategies in the face of slowly declining cognitive capacities. Further, in the context of dementia, it seems odd to suggest that well-recognized clinical stages of dementia, which range from very mild cognitive decline, to moderate, to severe and very severe cognitive decline,¹ would have no bearing on the determination whether a person is already in an advanced state of decline or not.

DEMENTIA AND WAIVERS OF FINAL CONSENT: HOW FLEXIBLE INTERPRETATION APPEARS TO BE USED TO ENABLE STILL PROHIBITED MAID ON THE BASIS OF ADVANCE REQUESTS

CAMAP's interpretations of RFND and advanced state of decline of capability are particularly relevant in the context of dementia because this has resulted in the construction of a form of advance requests for MAID. As mentioned before, WoFCs are only permitted in the context of a Track 1 RFND case. They were introduced in 2021 for situations where a person who is

¹ See for example the 7 stages of dementia identified by the US National Council of Certified Dementia Practitioners (20).

approved for MAID is at risk of losing capacity and would therefore not be able to confirm consent prior to the procedure. With a WofFC, a specific date in the near future must be identified for when the MAID procedure will take place. An advance request for MAID, which, as stated above, is not legal under the Criminal Code, involves a stipulation by a patient of the future conditions under which a third party can decide that the MAID procedure of the then incapable person can proceed (21).

The MDRC report on the topic of WofFC illustrates this with the case of a man diagnosed with Alzheimer's disease and Parkinsonian symptoms, who was distressed by short-term memory loss (21). The MAID assessor approved him under Track 1. The assessor documented that Mr. A experienced "suffering due to current and future anticipatory suffering of dependency," including "anticipatory fear of admission to long-term care", but that he continued to enjoy his quality of life (21, p.13-14). With the assessor's help, Mr. A signed a WofFC with a date for the MAID provision 3.5 year later. The WofFC further identified various factors that should trigger a MAID procedure in the future (e.g., difficulty eating or swallowing, bodily tremors, inability to verbally communicate), as if one would do for an advance request.

One month later, his family physician approved him under Track 2. Two months later, a third assessor, who became the MAID provider, agreed with the first assessor and approved him under Track 1. Less than a year later, Mr. A was hospitalized after a fall. He was delirious and agitated, hallucinated, and was rapidly declining. During "a period of cognitive improvement", he was deemed capable of re-consenting and, according to the MAID provider "[t]he WofFC was not invoked" before the lethal injection (20, p.15).

In addition to capacity concerns, the case reveals how an inventive use of different CAMAP guidance documents (on dementia, RFND, and waiver of final consent) opens the door to practices that appear to run counter to or at least stretch the contours of the law, in this case by allowing a WofFC that has all the characteristics of an advance request for MAID. That the MAID report states that WofFC was "not invoked" may reflect that the provider realized its validity could have been contested.

DEMENTIA AND TRACK 2 MAID

Mr. A's case is also relevant for a discussion of why approving persons with dementia for MAID under Track 2 may be in tension with the current law. It is not obvious that Mr. A satisfied the criterion of "an advanced state of irreversible decline of capability" and "intolerable suffering" that cannot be relieved at the time of his approval, since he opted for MAID several years in advance, when he appeared to have a good quality of life. These criteria need to be satisfied for a Track 2 approval. Mr. A's story reveals that MAID practitioners appear to follow the CAMAP guidance, interpreting a *future* loss of function as sufficient to conclude a *current* advanced state of irreversible decline of capability, and the fear of *future* cognitive decline as creating intolerable suffering *already now*, with future provision of MAID as the reasonable solution.

The coroner reports do not contain sufficient detail to explore in full what went on during some of these assessments shortly after a dementia diagnosis. But it is fair to also ask questions about the apparent ease by which some people obtain approval for MAID following a first diagnosis of Alzheimer's or dementia under Track 2.

As some members of the MDRC point out, it is important that people with a diagnosis of dementia receive sufficient "psychological support, existential therapies, and a focus on optimizing quality of life and function." (7, p.40) Members also emphasized "the critical role of specialized geriatric services in facilitating early and ongoing conversations about diagnosis, prognosis, and care planning." (7, p.31) In a commentary on the report, one of the MDRC members, Ramona Coelho, emphasizes that only 13.6% of dementia patients who died by MAID received palliative care (5). According to her, this raises concerns about adequate support for people when they are diagnosed with dementia; support that could assist them and family members in adjusting to the challenges of (future) cognitive decline. As some MDRC members frame it, "palliative care should be a foundational component of end-of-life planning for persons with dementia, particularly when MAID is being considered" and "supportive care options" should be available to mitigate the concerns resulting from a dementia diagnosis (7, p.42). The report refers also to the importance of dignity therapy (7), a therapeutic approach developed by Canadian psychiatrist Harvey Chochinov (23,24) aimed at alleviating the anxiety and distress of people facing terminal illness and at enhancing their psychological, existential, and spiritual well-being.

CONCLUSION

We cannot know if in individual cases — such as that of Mr. Munsch and some of the MDRC reported cases — better supports, early access to palliative and geriatric services, community-based care, and alternative interventions would make a difference in the face of what often appears to be a growing pressure to make MAID as broadly available as possible. But it is concerning, in my view, that such services are clearly not always readily available; that requesting MAID is increasingly presented, including by MAID assessors and in public discourse, as the appropriate response, as the obvious solution to the anxiety and distress of a devastating diagnosis associated with (future) cognitive decline; and that insufficient efforts are made in the context of some MAID assessments to explore different approaches. It is clear from the reports that some people die by MAID following minimalistic capacity and consent procedures, and in situations where concerns are raised about factors that may affect the voluntariness of those requesting MAID, including care-giver burn-out.

One can respond in two contrasting ways to what has been discussed here: 1) Those who support the broadest possible application for MAID and push for its normalization as a medical practice, may diminish the concerns and may suggest that

the cases and evidence analyzed in these reports show that MAID access should be made easier, and MAID options expanded. 2) In contrast, those who are concerned about MAID, or take the position that MAID should be treated as a last resort intervention aimed at facilitating the dying process in situations where there are no other reasonable forms of care, will see in these cases a confirmation of troubling aspects of our current MAID practice that require adjustment and regulatory intervention.

Some of what has been discussed here in this paper in relation to the current Canadian practice of MAID for dementia is also directly relevant for the debate about MAID on the basis of advance requests: how can we confidently conclude that people are suffering intolerably when they are no longer capable of communicating their current perception of their lived experiences? Who will decide when the time has come? On what basis will these judgments be made? How can we expect physicians or nurse practitioners to end the life of a person who has no clue as to why they are being sedated or getting a needle inserted in their arm?

Those who are concerned, as I am, about the significant expansion of the MAID practice, and the growing evidence of the at times clearly problematic practices, will find in these MDRC further confirmation that our MAID regime has serious problems. The reports provide further evidence of the use of low standards of capacity and informed consent; of MAID driven at times by structural and contextual pressures (25); of the at times remarkable drive to offer MAID to people who are suicidal and struggle with mental health issues; and of CAMAP guidance that straddles the contours of the law.

The response to these reports should not be to further expand MAID. After all, if we already have such questionable practices in the context of our current legislative regime, one can only imagine what that will mean if MAID is further expanded, in particular with MAID for sole reasons of mental illness and on the basis of advance requests. In both these contexts, the discretionary power of practitioners will be so much more substantial than what the MDRC reports reveal it already is: in the mental health context because of the vagueness of psychiatric diagnoses and the impossibility to reliably predict the irremediability of mental illness (26); in the context of advance requests because of the need to interpret patients' prior instructions, without option to communicate and obtain clarifications from them, and without being able to determine reliably, at the time of the MAID provision, whether people are suffering intolerably. The fact that much of the practice is dominated by a small number of frequent providers adds to these concerns (20). Indeed, the greater the discretionary power of MAID assessors and providers, the more likely it is that idiosyncratic practices of some will result in the broad application of MAID in contexts where many others would take a much more cautious approach. The report on same day or next day provision of MAID indicates, for example, how the practice is disproportionately present in some geographical areas of Ontario (11). Whether people will be steered towards further care and support options or rather towards MAID, would in a further expanded MAID regime even more depend on the clinician or MAID provider they encounter.

In my view, the most appropriate answer to the problems raised here is to rethink our MAID regime. There is a need to tighten the legislative access criteria, and to impose a stronger independent review of MAID requests. At a minimum, more rigorous screening and capacity procedures should be introduced to remove the overly broad discretionary power of MAID assessors and providers. In the interim, more detailed professional guidance must be developed. Stronger monitoring and scrutiny of the practice is also needed. It is troubling that documented problematic applications of MAID have not yet resulted in either criminal or professional regulatory intervention. In matters of life and death, failure to exercise utmost caution and to provide the most rigorous oversight and enforcement of criminal law-based standards are unacceptable.

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Conflicts of Interest

The author is a member of the MAID Death Review Committee of the Office of the Chief Coroner for Ontario. He was a member of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying and acted as expert witnesses for the federal Attorney General in court cases related to MAID. His research is supported by the Scholl Chair in Health Law and Policy.

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TÉMOIGNAGE / PERSPECTIVE

MAiD and the Death of Dignity

Daryl Pullman^a

Résumé

Le concept de dignité humaine occupe une place prépondérante dans les débats sur l'aide médicale à mourir. Pourtant, la notion de « dignité » est souvent ambiguë. Cet article vise à clarifier une partie de cette ambiguïté en distinguant deux conceptions différentes mais liées de la dignité, l'une étant une notion fondamentalement morale (« Dignité » — majuscule) et l'autre une conception plus esthétique (« dignité » — minuscule). La relation dynamique qui existe entre la notion morale de « Dignité » et son pendant esthétique (« dignité ») est examinée. Si une société pluraliste a besoin des deux notions, seule la notion morale objective (Dignité) est adéquate pour servir de fondement à un régime juridique fondamental. Si toute société pluraliste doit offrir des possibilités d'expression des notions esthétiques subjectives de dignité, ces dernières ne peuvent ni servir de fondement à une éthique publique globale en général, ni définir les paramètres d'une politique publique en matière d'homicide médicalisé. En effet, l'expansion sans limite d'une notion particulière de « dignité » menace d'effacer la conception plus fondamentale de la Dignité qui sert de fondement à toute société démocratique libérale.

Mots-clés

dignité, aide médicale à mourir, AMM, Canada

Abstract

The concept of human dignity figures prominently in discussions about medical assistance in dying. Yet the notion of 'dignity' is often ambiguous. This paper seeks to clear up some of this ambiguity by distinguishing two different but related conceptions of dignity, the one a fundamentally moral notion ('Dignity'—upper case) and the other a more aesthetic conception ('dignity'—lower case). The dynamic relationship that exists between the moral notion of 'Dignity' and its aesthetic counterpart ('dignity') is examined. While a pluralistic society requires both notions, only the objective moral notion (Dignity) is adequate to serve as the foundation of a fundamental legal regime. While any pluralistic society must provide opportunities for the expression of subjective aesthetic notions of dignity, the latter can neither serve as the foundation of a comprehensive public ethic in general, nor can it set the parameters of a public policy on medicalized homicide. Indeed, the unmitigated expansion of a particular notion of 'dignity' threatens to expunge the more fundamental conception of Dignity that serves as the foundation of any liberal democratic society.

Keywords

dignity, medical assistance in dying, MAiD, Canada

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INTRODUCTION¹

“Dying with Dignity Canada” (DWDC) has been a vocal and aggressive activist for Canada's expanding medical assistance in dying (MAiD) regime. On the one hand this is not particularly noteworthy in that there are many advocacy and activist groups active in Canada supporting a broad range of social and/or political causes. What is unique about DWDC, however, is that this group is closely aligned with the Canadian Association of MAiD Assessors and Providers (CAMAP), the organization that has been recognized and endorsed by the federal government to provide education and support to those providing MAiD services across the country (1). Despite the rapid expansion of MAiD services in Canada over the past decade, there are still many unsettled questions about the ethical probity of many MAiD practices. Nevertheless, DWDC and by extension, CAMAP, continue to push for further expansion and more liberal access. It is both disturbing and concerning that in promoting CAMAP the federal government is effectively endorsing the views of DWDC, a particularly aggressive advocate for liberal policies and practices regarding MAiD.

DWDC's mission, ostensibly, is the promotion of “death with dignity”; yet the notion of 'dignity' that underwrites this organization's activism is largely unexamined. Indeed, a similar unexamined notion of dignity tends to (mis)inform much of the ongoing policy debate motivating the expanding MAiD regime in Canada. In this paper, I examine the notion of human dignity as it is employed by MAiD activists in Canada. Drawing upon previous work I've done on this notion over the past three decades (2-7), I demonstrate that the narrow and somewhat skewed notion of 'dignity' employed in these public debates is ill equipped to provide a foundation for a comprehensive public policy that supports medicalized homicide.

Central to this critique is the distinction between two related but fundamentally different conceptions of human dignity, which for present purposes I will designate 'moral Dignity' (upper case) and 'aesthetic dignity' (lower case) respectively. Moral Dignity is that notion recognized in such documents as the Universal Declaration of Human Rights (8), which opens with a “recognition of the inherent [D]ignity and of the equal and inalienable rights of all members of the human family....” Such Dignity is enjoyed by every human being; nothing need be done to earn it, and nothing can ever erase it. It is an objective presupposition of international human rights legislation. But this is not the notion of dignity that underwrites the current MAiD debate and the

¹ A slightly expanded version of this paper will appear as a chapter in a forthcoming volume published by Springer titled: Medical Assistance in Dying (MAiD) in Canada: Current Trends and Consequences, edited by Jaro Kotalik and David Shannon. The title of that chapter is: “MAiD as a Harbinger of the Death of Dignity.” The version is printed here with permission.

increasingly liberalized policy in Canada. This latter conception of dignity is much more akin to an aesthetic notion. It is subjective in nature and trades on contingent variables. It is a socially constructed concept. As such, some individuals' lives may be assessed as 'dignified' while others are thought to be 'undignified'. Indeed, one of the concerns of the disability community in Canada is that the subjective aesthetic evaluations of some (the abled) are judging the lives of others (those with disabilities) to be undignified and hence not worthy of protection. Put otherwise, those consigned to such an undignified existence would be better off dead. Indeed, this last is essentially the chilling conclusion of a recent paper by two Canadian bioethicists (9).

In this paper, I discuss the dynamic relationship that exists between the moral notion of 'Dignity' and its aesthetic counterpart, 'dignity'. It will be argued that a pluralistic society requires both notions, but only the objective moral notion (Dignity) is adequate to serve as the foundation of a fundamental legal regime. While any pluralistic society must provide opportunities for the expression of subjective aesthetic notions of dignity, the latter can neither serve as the foundation of a comprehensive public ethic in general, nor can it set the parameters of a public policy on medicalized homicide. Indeed, the unmitigated expansion of a particular notion of dignity such as that promoted aggressively by DWDC/CAMAP threatens to expunge the more fundamental conception of Dignity that serves as the foundation of any liberal democratic society.

TWO CONCEPTIONS OF DIGNITY

In various publications over the past three decades, I've endeavored to articulate the distinction between the two conceptions of dignity outlined above while stressing the symbiotic relationship between the two. My argument has been that a comprehensive understanding of human dignity requires a recognition of both the moral and the aesthetic dimensions of the concept. In this respect, 'dignity' bears some resemblance to the Greek 'ta kalon' which can be translated as both 'morally good' and 'aesthetically beautiful'.

While both conceptions are necessary to a comprehensive understanding of dignity, it is useful to distinguish between the two to gain a better appreciation for the fecundity of the unified concept. Table 1 summarizes some of the basic distinctions between these two conceptions; Table 2 illustrates how various longstanding fundamental tensions in moral and social political philosophy map onto these conceptions of 'Dignity' and 'dignity' respectively.

Table 1: Dignity Value Distinctions

Moral Dignity	Aesthetic dignity
"Basic Dignity"	"Personal dignity"
Ontological	Existential/Relational
Intrinsic Worth	Socially constructed notion
Fundamental/Objective <i>moral</i> notion	Subjective <i>aesthetic</i> notion
Non-contingent: applies to all humanity categorically	Contingent: can be gained or lost
Inalienable: one does nothing to earn it, and nothing can take it away	Often closely tied to notions of individual autonomy and personal choice. As such its status is tenuous

As noted previously, Dignity emphasizes the moral dimension of the concept. As such it captures the intrinsic moral value of every human being as an ontological necessity. Elsewhere, I've argued that this notion functions as a meaning constraint on moral discourse in general (7). One does nothing to earn this Dignity, and nothing can take it away. Simply by virtue of being a member of the human species one enjoys this fundamental, inalienable moral worth.

By way of contrast, aesthetic dignity is a socially constructed notion. At times I refer to it as 'personal dignity' but this sense of dignity need not necessarily be individualistic. Inasmuch as aesthetic 'dignity' is socially constructed it could, depending on context, be tied to broader community or cultural values that extend beyond the individual. Nevertheless, in an increasingly individualistic society such as contemporary Canada, such dignity is often viewed as synonymous with individual autonomy and personal choice.

Table 2: Mapping Dignity to Common Moral and Social Political Tensions

Moral Dignity	Personal dignity
Universal	Particular
'The Right'	'The Good'
Objective	Subjective
Equality	Liberty/ <i>autonomy</i>
Species referenced	Individually referenced
Respect	Honor
We have rights because we have Dignity	An individual right to be treated with dignity

Table 2 captures how some of the fundamental tensions in moral and social-political philosophy map onto these two conceptions of dignity, respectively. Moral Dignity is a universal, objective notion while the aesthetic notion is subjective and particularist. Moral Dignity emphasizes the equal moral worth of all human beings while the aesthetic conception prioritizes liberty. While the moral conception focuses on respect for each and every human being, the aesthetic conception emphasizes

honouring particular kinds of lives that display some socially constructed perception of what it means to live a dignified life. Think here of 'dignitaries' and the honor afforded them as in some sense superior to those who lack this special status.

While the foregoing tensions have garnered much attention by moral and political philosophers in the ongoing debates between universalism versus particularism, liberalism versus communitarianism, liberty versus equality and so forth, I argue that a proper understanding of human dignity requires both the moral and aesthetic aspects. Moral Dignity is the fundamental moral concept that sets the moral foundation for a liberal society. Aesthetic dignity is the expressive dimension that allows individual citizens to choose for themselves their conception of the beautiful life. Any liberal society aims to allow for the widest expression of individual liberty/dignity. However, the latter expressive notion must always be anchored, and to some extent constrained, by the more fundamental moral conception. To paraphrase Kant, moral Dignity without aesthetic dignity is empty; aesthetic dignity without moral Dignity is blind.

THE DYNAMICS OF DIGNITY

The dynamic tension between these two complementary conceptions of dignity can be further illustrated with reference to another oft discussed tension in social/political philosophy, that between the 'Right' and the 'Good'. The question here is which notion should be prioritized when thinking about the just society. Do we settled on some shared notion of the Good that society in general aims to promote, and then use that notion to determine what is right in terms of various laws and social sanctions that promote this shared vision? Or do we determine instead some basic understanding of the Right that will set some general and common standard of appropriate social behaviour (i.e., right conduct), and then leave it to each individual citizen to determine what 'the Good' is for themselves individually?

Fundamentalist religious groups often serve as examples of communities that prioritize the Good over the Right. The religiously informed vision of what the good life should be is ostensibly shared by all members of the group; right and wrong conduct are then assessed against whether particular actions either promote or undermine this shared notion of the Good. Liberal democratic societies, by way of contrast, ostensibly prioritize the Right by setting legal standards and parameters aimed at permitting citizens the greatest liberty to pursue their individual conceptions of the Good. On this latter reading the Good in question is not a moral Good per se; it is rather an aesthetic understanding of what constitutes "the Beautiful life".

A concerning feature of the DWDC/CAMAP conception of dignity is that it tends to equate dignity with autonomy. The dignified/beautiful life on this view is one in which the individual has the greatest latitude to express their dignity as they see fit. Hence, any restrictions on the individual's liberty to choose the time and reason for dying is a matter of restricting individual choice. So far this seems to track the standard liberal democratic understanding that prioritizes the Right over the Good. At the same time, however, this notion of dignity suggests that anyone who lacks the capacity to live the beautiful life as viewed through the lens of individual autonomy thus lacks dignity and would be better off dead. In so doing, it effectively conflates its own notion of the Good with a somewhat narrow conception of what is Right. To date the Canadian political and legal systems have effectively endorsed and enforced this DWDC/CAMAP perception. Lower courts have consistently challenged restrictions on individual liberty concerning the rationale for or timing of MAiD. The federal government has in turn refused to challenge such liberal interpretations, choosing instead to amend the law to make MAiD more accessible. In so doing, however, the federal government is effectively endorsing the DWDC/CAMAP vision of the Good. That is, the good life according to DWDC/CAMAP is one that entails a particular aesthetic vision of what it means to have a dignified life and death. Canada, as a liberal democracy, should in principle endorse no particular vision of the Good. However, by succumbing continually to the DWDC/CAMAP ideology of maximum liberty tied to a narrow notion of autonomy and a particular view of what it means to live a dignified life and/or to experience a dignified death, the Canadian government has effectively prioritized this notion of the Good, using it as a guide for determining Right action. In so doing it is prioritizing a particular aesthetic notion of dignity that risks undermining the more fundamental moral notion of Dignity that underwrites the Charter of Rights and Freedoms for all Canadian citizens.

DIGNITY AND THE LIMITS OF LIBERTY

I turn now to a brief review of three hypothetical cases of "assisted dying" to illustrate why particular conceptions of liberty/autonomy that inform certain aesthetic perceptions of dignity and what it means to live or die with dignity, must always be constrained by the more fundamental notion of Dignity outlined above. Failing to do so risks undermining the moral foundations of society. Put otherwise, unbridled "dying with dignity" threatens the death of Dignity.

Three Cases of Assisted Dying

Case 1: Mrs. B is a 47-year-old mother of two young adult children. She suffers from an incurable neurodegenerative condition that will eventually result in her death. Although she does not yet want to die, she can foresee a time when her condition will deteriorate to the point that she would prefer death to life. However, she fears that by that point she might be physically unable to end her own life. Hence, she is considering MAiD.

Case 2: Mr. C is a 76-year-old gentleman who suffers from cognitive impairment. He was found wandering on the street and was taken to a medical facility. Since he lacked the ability to care for himself, he was admitted to long-term care where he has been followed by a psychiatric geriatrician for the past 6 months. From time-to-time Mr. C complains that he hates being in this

facility and says that he wants to die. His geriatrician has assessed him as globally incompetent thus lacking capacity to consent to MAiD.

Case 3: Mr. D and Mr. E are both in their mid 40's. They met in an online forum that caters to persons who like to experiment with unusual sexual fetishes. Both Mr. D and Mr. E would be considered mentally competent, and aside from what might be viewed as their somewhat extreme desires and preferences in this particular area, they would be deemed otherwise normal. Mr. D has long fantasized about killing someone and then consuming their flesh. But he would only do this if he found someone willing to consent to the act. Mr. E is so inclined and has signed an 'informed consent' to permit Mr. D to complete his fantasy.

While the three cases outlined here are all hypothetical, each is modeled on an actual situation. Case 1 closely approximates the case of Sue Rodriguez, the woman who first petitioned the Supreme Court of Canada (SCC) in 1993 to amend the law to permit her to receive medical assistance in dying. Case 2 mirrors an actual case in which I was involved as an ethics consultant. The consultation arose because the patient had been assessed by a MAiD provider as competent to receive MAiD. Case 3, while not a case of MAiD per se, nevertheless involves an instance of an assisted death. It is modeled on an actual case that took place in Germany over two decades ago involving Armand Meiwes who killed and then consumed the flesh of Bernd Brandes. Brandes had previously consented to the act (10). I do not intend to discuss these three cases in detail here, although each raises interesting discussion points regarding the notions of liberty, dignity and assisted dying. Rather, I use the three cases to illustrate the limits of liberty and why aesthetic notions of dignity must always be constrained by a moral conception of Dignity in any liberal democracy that hopes to remain healthy and functional.

Case 1, in my view, is the easiest to accommodate in a traditional liberal-democratic understanding of how to balance individual liberty against some general conception of the common good, or put otherwise, how and to what extent a notion of our shared Dignity can accommodate individual expressions of dignity in the "dying with dignity" space. Although Sue Rodriguez was unsuccessful in her petition to the SCC, essentially the same case came before the SCC again in 2015 in the person of Gloria Taylor. Although that case is widely referred to as the Carter decision after the first plaintiff named in the decision, the SCC deliberations focused on Ms. Taylor who had joined several others in petitioning the court to strike down the Canadian Criminal Code prohibition against assisted suicide. Like Sue Rodriguez before her, Gloria Taylor suffered from amyotrophic lateral sclerosis (ALS), an incurable degenerative neurological disease. When the SCC first addressed the prohibition on assisted suicide in the 1993 Rodriguez decision, both conceptions of Dignity/dignity figured in its deliberations (11). Justice Sopinka, and the majority of the SCC justices who adjudicated the Rodriguez case, worried that opening the door to assisted suicide might erode respect for the fundamental Dignity that serves as the foundation of individual rights and freedoms for all Canadians, and especially for the most vulnerable amongst us. Justice McLachlin, one of the dissenting justices, disagreed, arguing that Ms. Rodriguez's interest in promoting her own dignity over-rod such concerns. By the time the SCC revisited the issue again in 2015 in what is now known as the Carter decision (12), Justice McLachlin was the Chief justice. This time her perspective dominated, and the nine justices of the SCC voted unanimously to amend the criminal code to permit MAiD. While the notion of dignity figures again in the latter SCC discussion, it is only the aesthetic conception that receives the court's attention.

CONCERN FOR MORAL DIGNITY DOES NOT FIGURE IN THE SCC DELIBERATIONS ON CARTER

The SCC in Carter was careful to note that their deliberations focused only on the case of Gloria Taylor, a woman with a terminal illness who faced a potentially terrible death. Unlike in the Rodriguez decision in which considerations of Dignity were very much part of the deliberations, such concerns are not mentioned in the Taylor case. The implication is that Ms. Taylor's interest in protecting her aesthetic dignity did not, in the SCC's view, threaten to undermine the fundamental Dignity which serves as the guarantor of the rights of all Canadians. In my view, had the subsequent law (Bill C-14) been crafted to accommodate this somewhat narrow class of cases (i.e., those involving an imminent and potentially terrible death where resources and means to mitigate suffering are limited), "dying with dignity" in that sense would not undermine the more fundamental Dignity on which the Canadian Charter is predicated. However, once death with dignity was defined in terms of individual autonomy and the right to choose (the DWDC position), neither parliament nor the courts have been willing or able to restrain this kind of aesthetic vision. Indeed, given the reasoning of the lower courts in various decisions following Bill C-14, and parliament's subsequent acquiescence by amending the law (Bill C-7) to permit wider and easier access to MAiD, one wonders whether similar rationale might be used to justify Case 3 type scenarios as well. If not, why not?

In fact, the Case 3 cannibalism scenario is introduced as a kind of *reductio ad absurdum*. That is, regardless of one's general sense that society should promote and protect individual liberty and how that belief translates into one's position on whether and under what circumstances to permit assisted dying, generally only the most extreme type of libertarian would argue that Case 3 type scenarios should be permitted. In other words, the notion of moral Dignity that undergirds our liberal democratic society cannot sustain just any particular aesthetic vision tied to notions of individual liberty and choice. Some such aesthetic visions are simply beyond the pale. The key point here is that any liberal society requires a notion like moral Dignity to function as a background constraint on the expression of individual liberty of its citizens.

This brings us back to Case 2, the individual declared globally incompetent by one physician but deemed capable of understanding and making a formal request for MAiD by others. This case involved an extensive consultation with two physicians who are members of CAMAP, one of whom served on the board of DWDC. Both CAMAP physicians were of the opinion that even though this patient suffered from dementia, he nevertheless experienced periods of lucidity in which he was

capable of understanding what a request for MAiD entailed and was capable, in that moment, of providing consent. Even though the patient might not remember having had this conversation subsequently, these physicians were confident that the request and consent, in that moment, should be considered valid. Indeed, one of the physicians declared that he had provided MAiD to a number of similar patients in the past. The geriatrician who had been following this patient closely over an extended period of time, disagreed, arguing that the patient was simply incapable of appreciating the full extent of what a MAiD request entailed. I, as the ethics consultant, expressed my own strong reservations that a patient with dementia lacked capacity for making an autonomous choice, especially one as momentous and irrevocable as what was being contemplated. Nevertheless, the case was referred on to legal counsel for an opinion. Much to my chagrin, the legal opinion based only on a summary of the case, and which did not include direct discussion with any of the physicians involved, including the most responsible physician for this patient's care, concluded that there was no legal reason to prevent moving forward with the MAiD request.

Regardless of whether one in principle supports the availability of MAiD for Case 1 type scenarios, Case 2 should raise concerns on a number of levels. My focus here, however, is only on the DWDC position that links dignity with autonomy and personal choice. Inasmuch as this patient's capacity to make an informed and autonomous choice was dubious at best, as argued repeatedly by the geriatrician most familiar with the patient's history, the CAMAP physicians were adamant that the patient was eligible to receive MAiD. Although they did not use this terminology exactly, their position was that the patient's current life situation lacked dignity as they perceived it. Thus, even though the patient's capacity to make an autonomous decision was questionable, they concluded the patient would be better off dead. Of course, they couldn't express that position in so many words. Instead, they performed moral and legal gymnastics to shoehorn this patient's supposed expression of a desire to die into the category of a bona fide request for MAiD supported by a supposedly valid consent. It boggles the mind as to how that conversation between physician and patient might have unfolded.

EROSION OF THE MORAL CONCEPTION OF DIGNITY

When the SCC first deliberated the matter of assisted suicide in the Rodriguez case, Justice Sopinka and the majority of the SCC justices agreed that the prohibition on assisted suicide, as contained in the Criminal Code, did in fact contravene Ms. Rodriguez's equality rights as outlined in the Charter. In effect, they acknowledged that her capacity as a disabled person to express her own aesthetic dignity was compromised by the Criminal Code prohibition. Nevertheless, the majority worried that opening the door to assisted suicide might erode respect for the fundamental Dignity that serves as the foundation of individual rights and freedoms for all Canadians, and especially for the most vulnerable amongst us. This latter Dignity is the guarantor of all our rights, especially for those who may lack the physical, mental or emotional capacity or have access to the resources necessary to achieve what this now privileged perception deems to be a dignified existence. Joshua Briscoe captures succinctly what is at stake in this regard⁴. He writes:

What is our culture like? What repertoire for dying does it offer us? It is a culture that glamorizes youth and the untethered autonomy of the individual. Aging is the story of losing vitality, control, and dignity—of increasingly burdening our loved ones and our medical system to care for us until we die... Human dignity, by this reasoning, is not unconditional. Only the autonomous have it. Those who are dependent on others no longer do, and are therefore no longer deserving of our care. (13)

Inasmuch as the DWDC's conception of dignity is aesthetic in nature, it should come as no surprise that other aesthetic perceptions are also available, especially as these pertain to end-of-life care. Perhaps the most significant alternative perspective in this regard is that developed and popularized by Canadian psychiatrist Harvey Max Chochinov. Chochinov's focus is palliative care and over the past three decades he has become internationally renowned for his work on what he describes as "dignity therapy."¹⁴ The intent of Chochinov's therapeutic approach is to work with dying patients to discover what provides dignity and meaning for them as they face their final life's journey, and to support them to the end in experiencing both a dignified life and death. Of particular significance to the present discussion is Chochinov's adamant rejection of MAiD as a means of preserving dignity in the end-of-life space¹⁵. Instead, his approach entails coming along side the dying individual to journey with them through this valley of shadows. Both our terms 'compassion' and 'sympathy' connote "suffering with." The beautiful life and death from the perspective of dignity therapy entails compassionate and sympathetic care that includes an understanding of shared suffering as part and parcel of the human condition. In this respect, the aesthetic perception supported by dignity therapy remains firmly anchored to the moral Dignity that defines the kind of people we want to be.

DWDC and CAMAP have effectively conflated the moral notion of Dignity with their own narrow and somewhat impoverished aesthetic conception of dignity. But aesthetic expressions of dignity must always remain tethered to and constrained by the fundamental moral notion of basic Dignity. This latter Dignity is the guarantor of all our rights, especially for those who may lack the physical, mental or emotional capacity or have access to the resources necessary to achieve what this now privileged perception deems to be a dignified existence.

There is plenty to suggest that the concerns expressed by Justice Sopinka in the 1993 decision were warranted. The somewhat narrow perspective of what constitutes a dignified life and death championed by DWDC and CAMAP continues to shape legal precedent, legislative amendments, and public perceptions. Although disturbing cases of vulnerable individuals not near the end of their natural lives who opt for MAiD out of desperation continue to be reported, those who champion this now dominant

aesthetic perception of what constitutes a dignified life and death remain unphased. Indeed, some have openly stated that such aesthetically undignified persons would be better off dead (9).

CONCLUSION

Human Dignity is a fundamental moral notion that serves as the foundation of any liberal, democratic society. Aesthetic dignity is a complementary conception that captures the need to allow for liberty of expression in determining what constitutes a good/beautiful life and/or death for each citizen. But this latter aesthetic dignity must always be tethered to and to some extent constrained by the formal, moral conception of Dignity. Failure to do could lead eventually to Case 3 type scenarios.

Aesthetic dignity is open to wide interpretations, and as noted previously, in the context of end-of-life care a range of such perspectives are available. In the case of MAiD in Canada, however, a rather narrow conception of what constitutes a dignified life and death has been championed by DWDC, and by extension, CAMAP. That skewed perception has been effectively endorsed by the federal government. Both the courts and legislature have continually acquiesced to this narrow conception thus encouraging continuing appeals for further expansion of the law to permit even greater access to MAiD. Case 2 type scenarios are already common in Canada as we have effectively abandoned the means to constrain such narrow visions of what constitutes a dignified life and death. As such, dying with dignity in Canada as defined by DWDC/CAMAP is eroding our understanding of and appreciation for the fundamental Dignity we all share. Indeed, dying with dignity (as championed by DWDC and CAMAP) may be a harbinger of the death of Dignity.

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