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CANADIAN JOURNAL OF MAiD

MEDICAL ASSISTANCE IN DYING

Planning Committee

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Disclaimer: The planning committee was not involved in editorial review, oversight of the peer-review process, or final approval of submitted articles.

Mission Statement

The Canadian Journal of MAiD holds that ethically sound clinical practice can only be built on a foundation of robust scholarship and critical reflection. The underlying objective of the journal is to create a space where the bravery to critique current practice is met with a commitment to rigorous engagement with constructive debate that actively considers multiple points of view.

The mission of the Canadian Journal of MAiD is to foster critical and constructive scholarly debate; develop new knowledge to inform practice; and engage multiple viewpoints with the goal of supporting a high-quality and ethically sound approach to MAID in Canada.

A New Forum for Scholarship on Medical Assistance in Dying

Introduction

The practice of medical assistance in dying (MAiD) in Canada has evolved significantly in recent years, reflecting broader shifts in societal attitudes toward autonomy, suffering, and the role of medicine at the end of life. From the landmark Carter v. Canada decision in 2015 through Bill C-7 in 2021, Canadian MAiD policy has been characterized by rapid and complex developments. These changes have been accompanied by intense clinical innovation, public discourse, ethical debate, and even legal contestation. Yet despite this dynamism, and perhaps because of it, there remains a pressing need for a rigorous interdisciplinary forum to consolidate and critically examine the growing body of knowledge emerging around MAiD.

With this in mind, we are grateful to announce the launch of the Canadian Journal of MAiD, a new academic journal dedicated to the study of medical assistance in dying. As a planning committee, we see this journal as both a reflection of and a response to the complexity and growing relevance of MAiD in contemporary Canadian healthcare. Our purpose is to foster the development of high-quality, peer-reviewed scholarship that can inform clinical practice, ethical reflection, policy development, and public understanding. We aim to provide a scholarly home for the diverse perspectives that shape MAiD in Canada and to cultivate a culture of respectful and well-informed dialogue on this profoundly important topic.

CAMAP as Knowledge Broker

The Canadian Association of MAiD Assessors and Providers (CAMAP) is the unique association of professionals involved in the delivery of medical assistance in dying (MAiD) care in Canada. Founded in 2016, the mission is to support MAiD professionals in their work, educate the health care community about MAiD, and provide leadership in setting standards and guidelines for MAiD practice. CAMAP members strive to achieve the highest level of care for their patients and to model this care for a national and international audience. CAMAP works with governments in Canada at all levels, provincial medical and nursing regulatory bodies, national medical and nursing colleges, national professional groups, medical and nursing colleagues, and national organizations supporting MAiD. Delivering this kind of ongoing professional development does not come without controversy. But in the years since its creation, CAMAP has sought to ensure that providing resources, education, and community remains its north star. However, the increasing complexity of practicing medical assistance in dying also requires deep scholarly engagement.

Since 2016, CAMAP has supported health care professionals who wished to create new knowledge about MAiD using a research grant program largely funded by philanthropic donations. Grants funded by this program averaged $2,000 in value and led to multiple peer-reviewed papers. CAMAP has also acted as a knowledge broker, partnering with scholars to provide data from its initiatives, including the Canadian MAiD Curriculum, to elevate scholarship about MAiD practice.[1,2] The creation of the Canadian Journal of MAiD marks a new chapter in this evolving clinical area.

Meeting a Need

Research on MAiD fits only partially into journals focused on areas of clinical practice (nursing, palliative care, family medicine), ethics (disability studies, legal studies), or education (academic medicine and nursing). Perhaps more importantly, anecdotal reports from scholars about overcoming editorial concerns about the suitability of MAiD-related scholarship for publication in such journals suggest that important scholarly conversations about MAiD may have previously been obstructed from coming to light. We hope that this journal will create a new opportunity to overcome this barrier and provide a forum for high-quality scholarship in MAiD practice. Due to the primacy of CAMAP to its mission, the journal is rooted in the practical realities faced by clinicians who assess and provide MAiD across Canada. We recognize that MAiD is not an abstract concept, but a lived, intimate, and deeply relational practice that touches patients, families, clinicians, and communities. We hope that the journal's audience will include the clinicians involved in assisted dying, but also hope it extends to legal scholars, ethicists, policy makers, social scientists, and others whose work informs and critiques MAiD practice.

Centering Canadian Experience, Engaging International Dialogue

While the journal is rooted in the Canadian context, we recognize that assisted dying is a global phenomenon. Jurisdictions around the world—from the Netherlands and Belgium to Colombia, Australia, and parts of the United States—have adopted various approaches to assisted dying. These international experiences offer valuable comparative insights and cautionary tales. As such, we will welcome submissions that place Canadian MAiD practice in dialogue with global developments, and we hope to become a hub for cross-national scholarly exchange.

At the same time, we recognize the importance of carefully attending to the specificities of the Canadian context. Canada's approach to MAiD is shaped by its legal framework, publicly funded healthcare system, linguistic and cultural diversity, and colonial history. It is also shaped by the country's geography and demography—by rural and remote communities, by Indigenous peoples, and by the social determinants of health that influence access to care.

Commitments

A commitment to intellectual curiosity, scholarly integrity, and critical engagement guides our editorial stance. The journal will not be an advocacy agent, nor will it seek to advance a particular agenda regarding MAiD. Rather, we aim to create a platform where diverse scholarly voices—including those with critiques of the current Canadian approach—can contribute meaningfully to our collective understanding and provide scholarly context for our members. We believe that robust scholarship is essential for thoughtful practice, and that critical reflection strengthens, rather than undermines, the legitimacy of MAiD in a democratic society.

It is only through deep engagement and scholarly debate that MAiD practice in Canada will continue to progressively become more just, equitable, and compassionate. For this reason, we offer an open door to those who wish to suggest topics for discussion in the initial issues. Please write to journal@camapcanada.ca with suggestions of topics or authors who would make a strong contribution to the published knowledge in this emerging area of practice.

Origin Stories & Journal Format

CAMAP is grateful to have secured a publishing partner for the journal and for having a platform for this new scholarly venture. The initial issues of the journal will be published on an invitation basis. We hope that in time, with authentic scholarly engagement and attention to multiple perspectives, the journal will grow to offer open calls for scholarship and be indexed in scholarly search engines and directories.

As a demonstration of this commitment, the first issue of CJM will focus on a diverse set of issues related to MAiD, including the impact of socioeconomic vulnerability on MAiD requests, the relationship between palliative care and MAiD, oversight and monitoring of MAiD practice, and the role of MAiD coordinators across the country.

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Planning Committee
Canadian Journal of MAiD

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Strategizing a Qualitative Research Agenda for the Evolving Practice of Medical Assistance in Dying (MAiD) in Track 2

Sally Thorne, RN, PhD, FCAHS, FAAN, FCAN, CM
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Introduction

Since the advent of medical assistance in dying (MAiD) in Canada in June 2016, the qualitative research community has been actively engaged in asking and answering questions related to the human and system complexities associated with its practice. While a broad spectrum of research using a full range of methodological approaches has contributed to an increasingly solid evidence base for best practices and support systems, qualitative inquiry has been used to illuminate and document the nuanced experiences of MAiD seekers, their families, caregivers, communities, and the health care providers supporting these patients and/or directly participating in coordination, assessment and provision. These insights gained from qualitative inquiries have helped strengthen the MAiD community's collective recognition of patterns and trends in the complexities of this practice, offering a basis for interpretation and management as our systems evolve and adapt over time.

Qualitatively Documenting the MAiD Experience

Early qualitative inquiry on MAiD in Canada primarily focused on documenting how patients and families were experiencing this new end-of-life option, and how health care providers were encountering what amounted to a radical change in their ability to support patients experiencing intolerable suffering. Initial studies began to document a range of experiences, including those of persons pursuing MAiD,[1,2] family members supporting loved ones through the process,[3] physicians involved in its provision,[4] and nurses caring for patients who had chosen MAiD.[5] Over time, the priorities evolved to target consideration of specific complexities within the MAiD patient and family experience. This included exploring the nature of suffering experienced by patients pursuing MAiD,[6] the ethical complexities surrounding the final consent,[7] the logistical and emotional challenges for families involved in planning a MAiD death,[8] and the factors complicating bereavement following MAiD.[9,10] Researchers focusing on health care providers examined the evolving dynamics of communication associated with MAiD care[11] and the emotional and moral impact of MAiD on physicians.[12] At the institutional level, studies explored such issues as barriers to delivering high-quality MAiD care in various care contexts and workplaces,[13] experiences with institutional objection,[14] regulatory factors influencing access to MAiD,[15] and the ongoing implications of diverse attitudes to MAiD among health system leaders.[16]

Considering the Evolving Context with Track 2 MAiD

The 2021 legislation introduced Track 2 eligibility, extending MAiD access to those whose natural death is not considered 'reasonably foreseeable.' This identified a new population whose experiences warranted examination, documentation, and interpretation by the qualitative research community. Although much of Canada had openly welcomed MAiD as an option for those nearing death who were suffering, the expanded eligibility criteria cast MAiD back into the wider public domain as a highly contentious issue. This shift introduced new concerns for MAiD coordinators, assessors and providers, as well as for the broader group of health care professionals supporting MAiD-seeking patients.[17,18] While MAiD for mental disorder as a sole underlying medical condition was suspended until (at least) March of 2027, the intrinsic inseparability of body and mind within the human experience has placed many clinicians in the position of conducting complex assessments. These assessments often involve persons whose suffering arises from multiple intersecting health factors that are entwined with societal conditions and social determinants of health. As a result, the complex task of eligibility assessment has expanded beyond discerning whether unresolved suffering was occurring to untangling which of the many contributors to that suffering was most responsible, and determining whether all reasonable means for addressing suffering had been offered to the patient.[19,20] Within this context, interpreting such delicate aspects as capacity and voluntariness grew increasingly complex, not only from a clinical perspective but also in ethical and philosophical terms. At the same time, the potential risks for MAiD providers were being heightened by adversaries within the public arena and professional media. For this commentary, we have chosen on principle not to include examples of this kind of writing, although they are readily accessible through any search engine. Sensationalized fearmongering, which often drives narratives, adds a difficult layer of challenge for assessors and providers, who are already charged with highly complex determinations conducted over a much longer period of time in order to ensure the integrity of their processes and reduce their own personal risk.

While the palliative care community expressed some resistance to MAiD in the early years, this tension gradually resolved as many palliative care practitioners and services had found ways to integrate MAiD into end-of-life options, and alternative access points for MAiD-seeking patients had been established over time.[21] However, with the introduction of Track 2 MAiD, opposition persists within segments of the disability and chronic illness communities. Some individuals favoured the option for an assisted death (over alternative outcomes such as death by suicide or accidental overdose), and others voiced concern that MAiD could become a preferred strategy for Canadian society rather than addressing the well-recognized inadequate and inequitable services for those affected.[19] MAiD assessors and providers were thus confronted with the decision to engage in a practice that required extraordinary levels of effort and commitment in a context of predictable contention and professional risk. Many health care providers who had contributed effectively to Track 1 MAiD ultimately concluded that they could not accommodate the challenges posed by Track 2.[22] However, as Canadian legislation has been established with the understanding that health care systems are obliged to provide a path toward MAiD access for those meeting eligibility criteria, coordination teams were placed in a position of considerable complexity–managing requests from patients whose lives had been profoundly impacted by their conditions and were seeking an assisted death while facing a shortage of assessors and providers willing to participate. Although these systemic inequities and inadequacies are well known to health professionals, meaningful change requires sustained political will and broad societal commitment; it cannot rest solely on the MAiD community.

Orienting the Ongoing Qualitative Contribution

Unlike conventional scientific approaches, in which the ‘discovery’ of new facts drives advancements in practice possibilities, qualitative research systematically documents that which is ‘known’ by human actors within a relevant context in a manner that allows for interpretation of that synthesized knowledge into a coherent pattern of understanding that can be shared and communicated. Although each patient is the expert on their own life and illness, systematically studying that expertise embedded across a wide range of patients in comparable situations generates useful concepualizations of patient experience that can enhance our capacity to deliver optimal care.[23] Similarly, while MAiD practitioners discern patterns within their own practice domains, systematically analyzing and integrating those patterns into shared interpretations deepens our understanding of commonalities in practice, clarifies the implications of exceptional cases, and enhances the insight we can extract from cross comparisons.

While a single case might be discounted as anecdotal, credible findings based on transparent and rigorous analysis of multiple cases can yield understandings that are increasingly applicable beyond the context in which they were developed (albeit not ‘generalizable’ in the statistical sense).

As the body of qualitative findings grows, the insight produced builds a distinctive contribution to the evidence base for practice. When such findings illuminate the lived experiences of those in a particular situation, place them within a broader context, and translate them into conceptual interpretations that inform future developments in that practice, they provide an important guidance for educational strategies, practice guidelines, program development, and system-level policy directions.

In the context of Track 2 MAiD, the Canadian qualitative research community will continue to document, illuminate, interpret, and explain the experiences of all parties affected by the current and evolving legislation, regulatory guidelines, and health system supports. However, it must increasingly move beyond description toward application, by expanding study size, strengthening representativeness in sampling strategies, and diversifying angles of vision and focus. It must also ensure that those most closely in tune with the evolving complexities—such as MAiD coordinators—are actively involved in shaping research questions and the methodological approaches we take toward answering them. Qualitative researchers must also collaborate closely with the broader research community, integrating patterns emerging from national reports and aligning with emerging evidence regarding alternatives for the relief of suffering in its many forms.

Although the qualitative contribution to MAiD in Canada began with a focus on attitudes and experiences, it is also being extended to address the broader societal narratives and discourses, as these are increasingly complicating the lives of both MAiD seekers and practitioners.[24] Qualitative researchers share a collective obligation to acknowledge the contentious social world in which MAiD decisions and practices evolve and to integrate this understanding into their analyses. Qualitative research is also needed for expanding our understanding of institutional cultural change, including the influence of health leader assumptions, biases, and interests in either supporting or compromising safe and ethical MAiD-related practice.[25] Qualitative work can also help us better understand and manage workforce development, including the creation of team-based systems to support care for patients in increasingly complex health and social circumstances, and its intersections with an overburdened primary and social care system. While one function of qualitative inquiry in evolving social and health care contexts is to identify aspects requiring practice improvements, it is equally important to acknowledge and provide evidentiary support for developments in practice excellence. Ideally, MAiD practitioners, system leaders, and researchers will collaborate actively to identify issues that deserve further inquiry and where further illumination of the delicate complexities and subtle nuances will substantiate and support best practices and optimal outcomes.

It is of fundamental importance that researchers engaged in qualitative work remain aware of their own positionality. To preserve credibility, qualitative inquiry must remain distinct from political or social advocacy (in either direction) so as not to risk seriously compromising the utility of its contributions. Obvious bias renders any research meaningless or worse, and detracts from confidence in the research enterprise. Instead, we must be deliberate and strategic in selecting what to study, how to study it, and how to articulate findings in a manner that advances the practice field and optimally serves the populations for whom the legislation was intended.

Concluding Thoughts

Qualitative research has unequivocally demonstrated the exceptional care, attention, and thoughtfulness that the MAiD community has brought to this practice in Canada. It has also illuminated the multiple layers of complexity inherent in MAiD for all concerned, and it has helped establish an evidence base that defines a shared vision of rigorous adherence to safeguards alongside supportive and ethical practice within these evolving complexities.

MAiD was introduced in Canada because Canadians brought forward challenges to its prohibition. The continued expansion of requests for it[26] reflects the choices of informed citizens who, as experts in their own circumstances, health care options, and quality of life possibilities, voluntarily request this option. Since 2016, clarity around the practice has evolved because health care providers and health systems have been deeply committed to ‘getting it right’ both in terms of legal transparency in determining eligibility and safety in delivering MAiD services to eligible Canadians experiencing intolerable suffering.

The advent of MAiD in Canada did not reduce palliative care access; rather, it has clearly contributed to its expansion.[21,27] Similarly, there is strong hope that the attention it brings to societal inequities and health system inadequacies will stimulate concerted attention toward resolving those issues. Ultimately, MAiD is a story that forces us to fully embrace an understanding of that which can be learned from deep engagement with human experience and human experiential knowledge, and to integrate that knowledge into the health systems and supports we design for the future.

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Palliative Care and Medical Assistance in Dying: The State of the Relationship in Canada

Jeff Myers, MD

Introduction

Nearly a decade has passed since the Canadian government passed federal legislation that permitted eligible Canadians to request medical assistance in dying (MAiD), and it has been almost five years since the implementation of expanded eligibility criteria. Over this period, there has been a substantial increase in the number of jurisdictions around the world that have legalized assisted dying **(Figure 1)**. At a time when the global landscape of care at the end-of-life is dramatically shifting, here we examine the state of the relationship between palliative care and MAiD in Canada.

The Intersection and Access

Since the legalization of MAiD in 2016, the number of provisions has steadily increased, accounting for nearly 5% of all deaths in Canada by 2024.[2] Access to MAiD expanded significantly in 2021, with the removal of the criterion of a reasonably foreseeable natural death. Although MAiD continues to be accessed predominantly by men, individuals with cancer, and people who identify as white, these trends do not necessarily reflect issues with access among their peers.[2]

Over the same period, access to palliative care in Canada has evolved less consistently. Despite having a national palliative care framework, access remains heavily influenced by factors such as geography, care setting, and age.[3] Racialized and immigrant communities continue to face layers of barriers, and non-cancer populations (e.g., people with dementia, organ failure, neurodegenerative diseases or frailty) often experience delayed or absent involvement in palliative care.[3] A potential source of tension for the relationship between the two services is that access to MAiD has expanded and access to palliative care remains inconsistent.

In 2023, over three-quarters of Canadians who received MAiD also received palliative care, with just over half receiving it for one month or longer.[2] However, delivery of healthcare occurs at

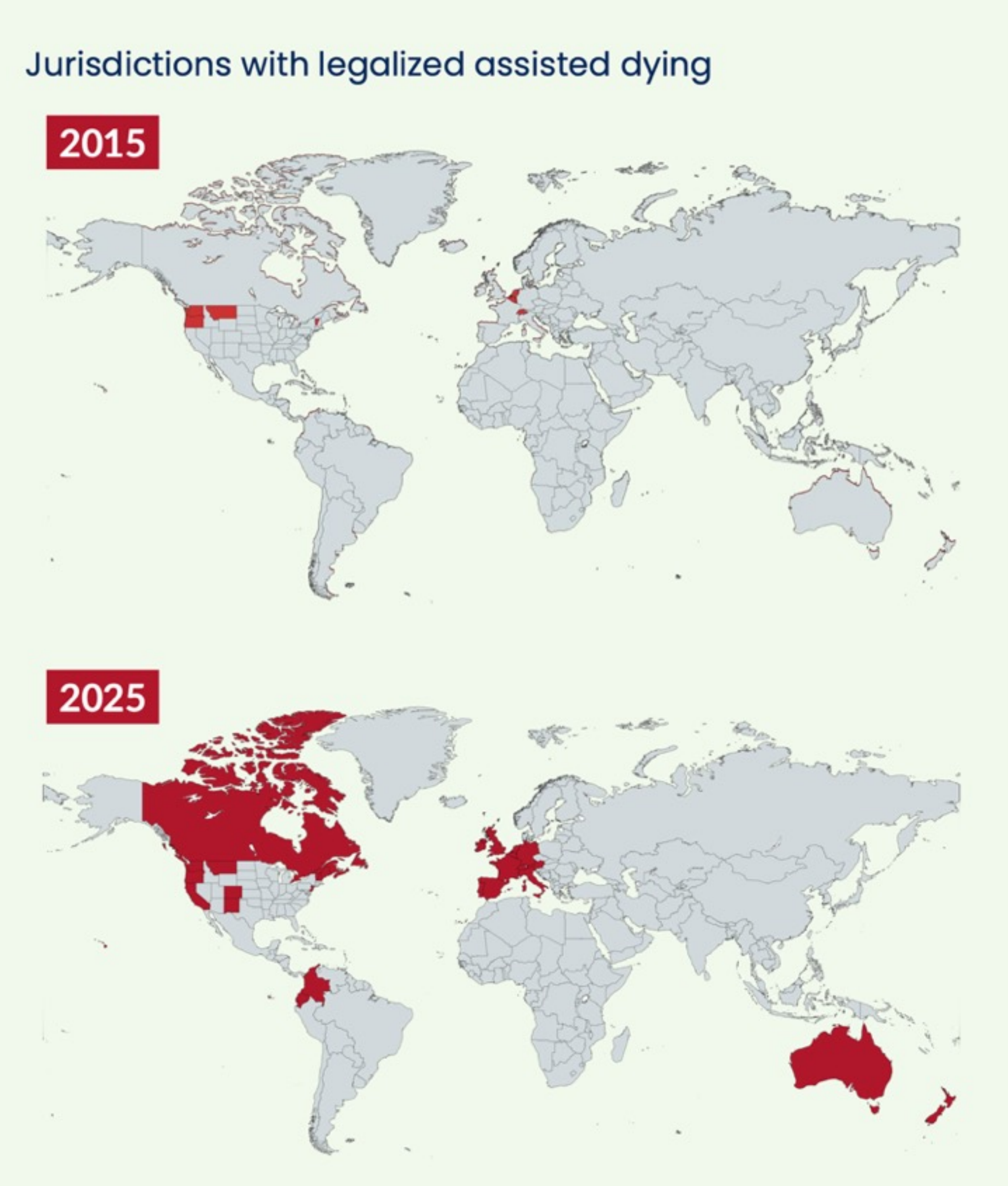

Figure 1. Jurisdictions with legalized assisted dying over time; *Source: The World Federation of Right to Die Societies*[1]

the provincial level, and closer examination reveals substantial variation in access across the country, from a low of 55.1% of MAiD recipients receiving palliative care in Nova Scotia to a high of 84.1% in Prince Edward Island.[2] Data addressing the frequency of MAiD requests and provisions among all patients cared for in palliative care settings is not readily available. This makes quantifying the overall impact of MAiD on palliative care difficult and reflects an important evidence gap.

Despite variations across provinces and gaps in the evidence, at the practice level an intersection between palliative care and MAiD exists. For patients under the care of palliative care teams who are considering MAiD, how this intersection is formed and how it functions may have substantial implications for patients, families, providers and systems of care. National or provincial standards addressing this intersection have yet to be developed, which has left the responsibility of navigating this complex task to institutions, teams, and individuals.

What is the Evidence?

Although empiric data that directly addresses the interface between palliative care and MAiD has only recently entered the literature, our understanding of their relationship has deepened. For example, Canadian health leaders report improvements in the relationship, crediting progress to better communication between services.[4] They also note the absence of a consistent framework for how palliative care and MAiD should interact, and express diverse opinions on what the optimal relationship should look like. These include models ranging from full integration, complete separation, and a model that functions in a parallel but coordinated fashion.[4] A point of agreement among leaders is the need for cooperation between palliative care and MAiD, which is viewed as essential for ensuring appropriate referrals and coordinated care.[4]

The broader body of empirical literature on the topic consistently reinforces that there is no single model for how palliative care and assisted dying relate. Within jurisdictions that have legalized assisted dying, descriptions of the relationship include integrated, synergistic, cooperative, collaborative, supportive, not mutually exclusive, neutral, coexisting, ambivalent, opposed, conflicted, and antagonistic.[5]

Among palliative care clinicians in other jurisdictions, ambiguity about their role in assisted dying is widely reported.[5] This ambiguity seems to be primarily driven by a discordance between policy and practice, largely due to a lack of clarity in what actions professional bodies consider permissible.[5] For example, in many settings nurses and social workers are unsure about what information they are permitted to share about assisted dying.[5]

Belgium is often identified as a comparator in discussions about the relationship between palliative care and assisted dying, as it has maintained a model of full integration and synergy since 2002, when assisted dying was legalized.[6] A critical element of Belgium's narrative is that, also in 2002, a statutory right of access to palliative care was legislated.[7] In contrast, Canada has not implemented a similar legal guarantee, which is an additional source of tension.

On the Frontline

The overarching view among many palliative care clinicians is that MAiD has reshaped their daily practice. They describe it as introducing a new dying experience for patients, one that is parallel to, but does not replace, a palliative approach to care.[8] Aligning with the perspective of health leaders, many frontline clinicians also characterize the relationship as having improved.[9] A notable perspective shift has occurred in several hospice settings that initially required patients who requested MAiD to be transferred elsewhere. The experiential impact of transfers has led some organizations to revisit these policies, now allowing and facilitating on-site MAiD provisions.[10] In addition, as palliative care colleagues witness well-articulated rationales for requesting MAiD from patients under their care, many MAiD providers have also experienced improvements in the relationship between the two services.[11]

For other clinicians, the relationship between palliative care and MAiD remains a challenge. A distinction is often made between moral uncertainty and moral distress, and both are pervasively present in the interprofessional discourse.[12] Dorman and colleagues characterize moral uncertainty as arising when a right action is not known, and moral distress as occurring when one is constrained from acting on what they believe to be right.[12] Palliative care clinicians report experiencing moral uncertainty around how and when to broach the topic of MAiD with patients, which is typically rooted in the fear of being misinterpreted.[12] Moral distress around professional identity is frequently described among clinicians who are either conscientious participants or conscientious objectors, as both frequently feel unsafe to identify as such.[13] Finally, moral uncertainty surfaces among clinicians who consider how the relationship between palliative care and MAiD could be reconciled.[12] Across these challenges, frontline clinicians frequently report the need for mitigation strategies that include organizational clarity, supportive policy, and explicit role delineation.[12,14]

Palliative Sedation

One source of tension in the relationship between palliative care and MAiD is how palliative sedation has become part of the broader discussion. Continuous palliative sedation therapy (CPST) involves the use of pharmacologic agents to reduce consciousness as a strategy for managing intolerable and refractory symptoms in patients with advanced progressive illness.[15] In practice, the symptoms for which CPST is most often used include pain, delirium, and breathlessness, and it is typically recommended that consultation with a palliative care clinician occur prior to CPST initiation.[16] The intent of CPST is to relieve intolerable suffering, and when used according to clinical guidelines, i.e., titrating sedation to symptom relief, data suggests that CPST neither shortens nor lengthens survival.[17]

Despite the existence of numerous national and international policies, protocols, and guidance documents, significant variability remains in how palliative care clinicians define and practice CPST, which extends to the perceived relationship between CPST and MAiD.[18,19] Some palliative care clinicians view this relationship as fluid and the two as interchangeable, i.e., if a person is unable to consent to MAiD or does not have access to a provider, CPST is considered an alternative.[20] Regardless of how this relationship is viewed, palliative care clinicians in general report that discussions about CPST have become more frequent since the legislation of MAiD, with several describing the new experience of navigating direct requests for CPST from patients and families.[21] The impetus for such requests is typically the upstream education occurring with patients about the availability of CPST and MAiD as end-of-life options.

The view of CPST and MAiD as interchangeable and positioning the two as equivalent alternative end-of-life options introduces two potentially important risks. First, when both options are presented to a person who worries that suffering will become intolerable, the typical intention is to reassure. The consequence with this however is that it can reinforce the underlying assumption that intolerable suffering is inevitable.

The second risk in blurring the distinction between CPST and MAiD lies in oversimplifying the complexity of clinical decision-making related to CPST, which can create confusion about how the two differ. This may lead to misunderstood and unmet care expectations among patients and families and ultimately impact an ability to establish trust with the clinicians who provide the care downstream.

Moving Forward

Palliative care and MAiD share important common ground: both require sensitive communication, trust, and the expertise of skilled clinicians. From here, policymakers, researchers, clinicians, and communities must engage in ongoing dialogue to ensure that the relationship between palliative care and MAiD evolves in ways that best serve Canadians. Specific actions might include:

- *Clarifying public messaging* ensuring that patients and families understand palliative care and MAiD, an essential step in maintaining trust.
- *Educating teams* about the downstream impact of imprecise or incomplete information shared with patients and families about the end-of-life, along with the risks of fragmented care.
- *Tending to clinicians* to ensure their well-being and retention in both palliative care and MAiD-related care settings.
- *Protecting equity* by monitoring for disparities across socioeconomic and geographic lines.
- *Transparent and public reporting* of national and provincial data, not only on MAiD-related care but also on palliative care access, timing, quality, socio-demographic disparities, as well as patient and family experiences.

Finally, while efforts to work toward national or provincial standards for the form and function of the relationship between palliative care and MAiD are encouraged, these efforts require stronger empirical accounts of practice models and outcomes.

Summary

The relationship between palliative care and MAiD in Canada is neither settled nor uniform. Across systems, the interface is complex and contextual and can exist in forms that range from integrated and collaborative to neutral, ambivalent, or explicitly opposed—with the potential for all views within the same jurisdictional ecosystem. This is not an impressionistic claim; it is reflected in the spectrum of relationships documented in empirical studies.[5] Given this heterogeneity and considering that the law governing assisted dying may continue to evolve toward a relationship that is cooperative and coordinated may be the most feasible path forward.

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A Snapshot of Monitoring and Oversight of Medical Assistance in Dying (MAiD) in Canada

Eliana Close, PhD
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Introduction

Medical assistance in dying (MAiD) has become a significant part of Canada's end-of-life landscape since the passage of Bill C-14 in 2016 and the law's subsequent evolution through Bill C-7 in 2021.[1,2] In 2023, 15,343 people accessed MAiD, accounting for 4.7% of deaths nationally.[3] Most of these cases (95.9%, n=14,721 deaths) involved individuals whose natural death was reasonably foreseeable (Track 1), while the remaining 4.1% (n=622) involved individuals whose death was not reasonably foreseeable (Track 2).[3]

Monitoring and oversight are central to ensuring Canada's MAiD system is transparent and accountable, and play a fundamental role in building public confidence. Monitoring provides important data on a range of factors, including who is accessing MAiD, underlying medical conditions, and clinician participation. Oversight evaluates compliance with the law. Both monitoring and oversight can support high-quality patient care and quality improvement through education and sharing information.

MAiD delivery involves a multilayered network of accountability mechanisms, including federal reporting requirements, provincial and territorial oversight (and often provincial and territorial monitoring), professional regulation by medical, nursing, and pharmacy Colleges, as well as law enforcement. A point of tension in debates about oversight is whether MAiD should be treated as exceptional—and subject to specialized scrutiny—or whether existing professional, criminal, and civil regulation provides sufficient insight and accountability.

This article provides a brief overview of the current mechanisms for monitoring and oversight of MAiD in Canada. It emphasizes the distinction Canada makes between monitoring and oversight and outlines provincial/territorial approaches. The article also summarizes existing empirical research on monitoring and oversight and identifies gaps where more research is needed. Ultimately, it argues that greater transparency is essential to properly inform public debate and shape future directions.

Mechanisms for Monitoring and Oversight of MAiD in Canada

Most jurisdictions with assisted dying laws have established monitoring and oversight mechanisms, albeit with considerable variation in form.[4,5] While some literature discusses both concepts under the broad umbrella of "oversight",[4] Canada differentiates between the two. Monitoring involves collecting data that provides critical information on the characteristics of individuals who request and receive MAiD, the contexts in which MAiD occurs, and overall trends. Oversight refers to individual case review after an assisted death to ensure compliance with legislation. These functions are distributed across different levels of government due to the constitutional separation of powers. The federal monitoring system flows from the federal *Criminal Code*,[6] while oversight is generally considered to fall under provincial/territorial jurisdiction, as it relates to healthcare and the enforcement of criminal law.

Federal Monitoring

In Canada, the *Criminal Code* establishes the framework for the legal provision of MAiD by enacting a series of requirements, which include eligibility criteria, procedural safeguards, and monitoring/reporting obligations.[6] The federal Minister of Health, through Health Canada, is responsible for monitoring MAiD.[6] In 2018, the federal Minister of Health introduced the *Regulations for Monitoring Medical Assistance in Dying* under the *Criminal Code*.[7] The Regulations were subsequently amended to align with the 2021 Bill C-7 amendments and make further refinements; these changes came into effect on January 1, 2023.[8] Under the *Regulations*, physicians, nurse practitioners, pharmacists, pharmacy technicians, and 'preliminary assessors' (i.e., individuals that triage MAiD cases) are required to report specific information about MAiD requests and provisions to Health Canada.[8] Information is reported either directly to Health Canada through an online portal, or through a designated provincial/territorial body **(Table 1)**.[7,8] This data forms the foundation of Canada's monitoring framework for MAiD. Since 2019, Health Canada has issued annual public reports of data collected under the *Regulations*.[3]

Provincial and Territorial MAiD Oversight

MAiD oversight involves individual case review to ensure compliance with the legislation. Each province/territory has developed its own approach to oversight, reflecting the broader differences in how MAiD is implemented across jurisdictions (see **Table 1** for a summary). Provincial/territorial approaches fall into five broad categories.

Independent Review

Quebec is the only province that has established an independent review body tasked with MAiD oversight. Quebec's Commission on End-of-Life Care, a multi-disciplinary group appointed by the provincial government, is empowered by the *Act Respecting End-of-Life Care* (Que) (AREOLC) to retrospectively review all MAiD deaths for compliance with the eligibility criteria and safeguards in the AREOLC.[9] Under the AREOLC, MAiD providers must report to the Commission within 10 days of administering MAiD.[9] The Commission may request additional information from practitioners as needed. If two-thirds or more of the members present determine that the MAiD provisions of the AREOLC were not met, the Commission sends a summary of its conclusions to the relevant regulatory College for further investigation.[9] The Commission publishes an annual report on its website.[10]

Existing Provincial Death Investigation Service (Coroner/Medical Examiner)

Ontario and Alberta have assigned oversight of MAiD to their existing death investigation systems. British Columbia initially followed this approach as well but later transitioned to a Ministry of Health committee, as set out below*.

In Ontario, the Office of the Chief Coroner (OCC) is charged with MAiD oversight under amendments to the *Coroner's Act*.[11] Initially, this involved a phone call with the MAiD provider after every MAiD death. In January 2023, the OCC modernized its process by implementing an online system of reporting with follow-up limited to certain more complex categories of cases. MAiD providers must submit a MAiD Death Report form to the OCC within one business day of a MAiD death.[12] While the OCC does not publish public reports on its website, it distributes regular data reports to interested parties via email. If a potential compliance issue arises, practitioners are contacted for clarification. If concerns persist, the OCC has developed a weighted response involving several possible outcomes which include issuing a notification of error, providing education, and/or referral to the appropriate regulatory authorities or law enforcement.[11]

In Alberta, all MAiD cases must be reported to the Office of the Chief Medical Examiner.[13] There is very little publicly available information about the process and extent of review. The Office of the Chief Medical Examiner does not publish reports related to MAiD.

Government Committee

In British Columbia, MAiD practitioners and pharmacists must report details of each case to the BC MAiD Oversight Unit, which operates within the provincial Ministry of Health.[14] Practitioners and pharmacists must provide additional information upon request. According to the British Columbia Government's website, the BC MAiD Oversight Unit reviews "all provisions and discontinuations ... for compliance with eligibility criteria, federal safeguards, provincial

*British Columbia initially assigned MAiD oversight to the BC Coroners Service on a temporary basis. This arrangement was largely pragmatic: the Coroners Service already maintained a province-wide system for mandatory death reporting and public data release. This assignment was never meant to be permanent, as coroner oversight is only meant for deaths requiring investigation (suspicious, accidental, violent, or unexplained). By late 2018, the province established a dedicated MAiD Oversight Unit within the Ministry of Health to manage compliance reviews, data collection and federal monitoring.

Jurisdiction	Organization of MAiD Delivery	Who Reports to Health Canada	Approach to MAiD Oversight
British Columbia	Multiple access points are available through individual practitioners and regional coordination offices, with MAiD services delivered through regional health authorities.	British Columbia Ministry of Health.	BC MAiD Oversight Unit reviews MAiD request, assessment, and provision forms for adherence to federal legislative requirements and provincial regulatory standards. Oversight Committee reviews MAiD policy and practice for continuous quality improvement.
Alberta	Central point of access and coordination through a provincial health authority.	Alberta Health Services.	All deaths are reported to the Office of the Chief Medical Examiner.
Saskatchewan	Central point of access and coordination through a provincial health authority.	Saskatchewan Health Authority (SHA) Provincial MAiD Program.	SHA MAiD Program reviews MAiD provision forms for completeness and adherence to federal requirements. Oversight Committee reviews MAiD program practices but does not review individual cases.
Manitoba	Central point of access and coordination through a provincial health authority.	Practitioners report directly to Health Canada.	Rely on existing healthcare regulation.
Ontario	Multiple access points through individual practitioners, regional institutions, or a centralized provincial coordination line.	The Office of the Chief Coroner reports all MAiD provisions. Practitioners report requests not resulting in a MAiD provision directly to Health Canada.	All MAiD deaths are reported to the Office of the Chief Coroner's MAiD Review Team (MRT). Certain categories of cases are reviewed in greater detail. A MAiD Death Review Committee (MDRC) plays an advisory role by reviewing select cases that appear to diverge from usual practice and identifying potential areas for improvement.
Quebec	Multiple access points through individual practitioners and/or regional networks or institutions.	Quebec Ministry of Health and Social Services.	The Commission on End-of-Life Care reviews reports on every MAiD provision for compliance with legislative requirements. Publishes annual reports on MAiD activity in Quebec.
New Brunswick	Combination of access points through individual practitioners and/or a regional health authority.	Practitioners report directly to Health Canada.	Rely on existing healthcare regulation.
Nova Scotia	Standardized central referral process through a provincial MAiD program office with case coordination supported by nurse navigators.	Practitioners report directly to Health Canada.	Practitioners send all MAiD forms to the provincial MAiD Program office. MAiD Program Quality Committee is involved in prospective support and retrospective quality review.

Jurisdiction	Organization of MAiD Delivery	Who Reports to Health Canada	Approach to MAiD Oversight
Prince Edward Island	Central point of access and coordination through provincial government.	Practitioners report directly to Health Canada.	Rely on existing healthcare regulation.
Newfoundland and Labrador	Multiple points of access.	Practitioners report directly to Health Canada.	Rely on existing healthcare regulation.
Yukon	Multiple access points through individual practitioners.	Practitioners report directly to Health Canada.	Rely on existing healthcare regulation.
Northwest Territories	Central point of access through the territorial government.	Northwest Territories Health and Social Services.	MAiD Review Committee reviews select cases and audits records.
Nunavut	Multiple access points through individual practitioners.	Nunavut Department of Health.	Rely on existing healthcare regulation.

Table 1. Highlights of Medical Assistance in Dying (MAiD) Delivery, Reporting, and Oversight Approaches Across Canadian Provinces and Territories; *courtesy of Eliana Close, PhD, Stefanie Green, MD, Jacquie Lemaire, MSc*

safeguards, regulatory college practice standards, and reporting requirements for MAiD.[14]" The BC MAiD Oversight Unit also adopts a model of progressively escalating responses in response to concerns about noncompliance, starting with a request for information. While the BC MAiD Oversight Unit does not publish public reports, it produces an annual internal report. The province has recently begun publishing condensed public-facing monitoring data.[15]

The Northwest Territories has a MAiD Review Committee that can review select cases, and audits records.

Regional Programs

Saskatchewan Health Authority has an "Oversight Committee", but it reviews MAiD program practices, not individual cases. While this is not oversight in the sense of individual case review for legal compliance, regional programs play a role in MAiD quality improvement. Similarly, Nova Scotia Health Authority has a MAiD Program Quality Committee supporting prospective and retrospective quality review.

Existing Regulation of Healthcare

The remaining provinces/territories (Manitoba, New Brunswick, PEI, Newfoundland and Labrador, Yukon, Nunavut) do not have MAiD-specific oversight mechanisms. Instead, they rely on provincial/territorial health regulatory mechanisms for accountability, as described below.

Provincial/Territorial Health Professional Regulation

Across all provinces/territories, existing law and other mechanisms that regulate health professionals play a role in accountability for MAiD. Provincial/territorial regulatory bodies (i.e., Colleges) for physicians, nurse practitioners, and pharmacists regulate providers' professional conduct, establish practice standards, and provide oversight by investigating complaints. Many have issued MAiD-specific practice standards and hold practitioners accountable to these standards.[16,17] Additionally, since the criminal justice system is largely administered under provincial jurisdiction, provincial police and prosecution services are also responsible for enforcing the MAiD provisions in the *Criminal Code*.

Research on MAiD Oversight and Monitoring in Canada

Research on experiences and perceptions of MAiD monitoring and oversight in Canada is still emerging. Early research exploring practitioners' experiences has found that some MAiD assessors and providers view monitoring and oversight requirements as a significant administrative burden.[18] Between 2019–2020, Wiebe et al. conducted a mixed-methods study which examined MAiD oversight practices, and obtained views of MAiD providers and the public about optimal models of oversight.[19] They found significant variation in oversight practices across provinces/territories. While MAiD providers were generally satisfied with the existing level of oversight in their provinces, members of the public showed a preference for stronger oversight by interdisciplinary committees.[19]

Between 2021–2023, Close et al. investigated perceptions of monitoring among MAiD assessors/providers, as well as organizational decision-makers involved in MAiD across a range of contexts, including government, professional organizations, regulatory bodies, and healthcare institutions.[20] Participants emphasized that monitoring was distinct from oversight, and valued the federal monitoring system's role in providing transparency. While views differed on the appropriate scope of data collection, there was consensus that practical strategies and administrative support should be used to mitigate reporting burdens on practitioners. Another article on these participants' perceptions of oversight is currently under peer review, with findings to be reported upon publication.[21]

Further empirical research is needed in several key areas. First, as provinces and territories continue to refine their organizational structures, delivery models, and associated oversight mechanisms, comparative studies are useful to understand how these systems operate, how they have evolved, and the benefits and challenges of these divergent models. Second, there is limited empirical research in Canada on the nature of case reviews, and the processes oversight bodies use to analyze cases where such bodies exist. International research has examined these issues,[22] and Canada should now do the same. Third, future research should consider the value of monitoring and oversight. Although MAiD practitioners may view monitoring and oversight as burdensome, these processes generate valuable data into what is happening in practice, what works well and what does not, all of which support evidence-based public understanding and quality improvement. Fourth, to inform best practices, further research is needed to capture diverse perspectives on MAiD monitoring and oversight: those involved in providing oversight, those who are subject to it, those responsible for developing policy, as well as the views of patients, family members, and the public. Investigating community perspectives would provide valuable insight into how oversight and monitoring of MAiD influence public trust.

Key Considerations

Monitoring and oversight are essential and complex processes, with differing views about their appropriate form and scope. We offer several key elements for consideration that may inform models of monitoring and oversight going forward.

First, an important function of both monitoring and oversight is to collect data that offers insight into clinical practice. Such data can highlight areas of concern but can also demonstrate when the system is functioning as intended. Although some clinicians resist oversight, or perceive it negatively, it does not necessarily carry adverse implications.

Second, it is important to recognize that oversight has value beyond enforcing regulatory compliance and identifying breaches. Oversight can help prevent transgressions and improve best practices by contributing to education and guidance, leading to quality improvement. In this way, oversight plays an important role in helping ensure safe, high-quality care. Oversight models should therefore reflect this broader function. One approach is to adopt a targeted system of responses. Healy's theory of "responsive regulation" in healthcare suggests that beginning with supportive, educational measures and escalating to stronger sanctions only if needed to achieve compliance, best promotes safe and high-quality care.[23] This approach encourages clinicians to come forward and enables learning from mistakes. The Canadian Association of MAiD Assessors and Providers endorses the need for MAiD oversight: "to provide continuous quality improvement.[24]" A crucial requirement for facilitating this type of model is that provinces and territories must provide adequate resources and support for MAiD programs.

Third, there is a need for greater transparency in Canada's existing MAiD oversight and accountability mechanisms. In most provinces/territories, transparency remains limited. Among those with oversight mechanisms, only Quebec regularly publishes reports with compliance data. Ontario compiles monthly statistics but does not make them publicly available. It has established a MAiD Death Review Committee (MDRC), which is "committed to increasing public transparency of the MAiD oversight and review process…[25]" However, the MDRC has purposefully selected cases that are "not representative of most MAiD deaths," and that "depict circumstances that often represent divergence from typical practice," and does so with the stated aim "to support continued improvement for how MAiD is provided in the province of Ontario.[25]" While this approach can be helpful, it can also lead to a skewed vision that is not characteristic of more typical clinical practice. The lack of consistent and accessible information in the other provinces/territories makes the issue of oversight difficult to study and debate. Greater transparency provides insight into what is going on in practice and why, which is an integral part of enabling public scrutiny and engagement and building public trust.

Fourth, when evaluating Canada's MAiD system, it is important to adopt a broader perspective of monitoring and oversight rather than limiting the focus to clinicians' regulatory compliance.[26] It is important to evaluate and review how all components of MAiD delivery work together, such as intake, care coordination, practitioner assessment, education and training supports, and bereavement resources. Each jurisdiction's local context shapes its MAiD model, including oversight, and even in the absence of formal oversight bodies, alternative accountability mechanisms must be in place. A key challenge, however, is that achieving and understanding this holistic view of oversight is difficult, given the diversity of actors and resources involved.

Finally, we pose the question: does MAiD warrant exceptional oversight? Should oversight differ from that of other high-stakes health care practices—such as cardiac surgery or palliative sedation—and if so, for how long? Are jurisdictions without MAiD-specific oversight mechanisms problematic? Does the lack of transparency in College complaints and decision-making influence our consideration of such questions? These are normative questions beyond the scope of this overview, which warrant further exploration.

Conclusion

Monitoring and oversight are central to ensuring transparency and accountability within Canada's MAiD system. They help build public confidence, ensure safe, high-quality care, and indicate whether the system is functioning as intended, or not. Monitoring and oversight should extend beyond clinical compliance to assess how the diversity of actors and system resources are performing as a whole. While it remains an open question whether MAiD should be exceptionalized within Canadian health care, greater transparency than currently exists would provide a more robust foundation for public debate and future directions.

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What Does an Ideal Model for Medical Assistance in Dying (MAiD) Coordination Look Like?

Sarah Broder, MD, FRCP
Marta Simpson-Tirone, RP, MTS

Introduction

Medical Assistance in Dying (MAiD) is a legal medical procedure in Canada governed by federal and in some instances, provincial laws. MAiD is permitted under strict legal and procedural safeguards for individuals who meet specific eligibility criteria.[1] When MAiD is done well, the MAiD team works not only to ensure that all federally legislated requirements are met in a timely, efficient, and effective manner, but also that the person requesting MAiD is kept at the centre of the care circle ensuring compassionate patient care is reflected throughout the process. The coordination of MAiD Care differs across provinces, territories, regions, and organizations within these areas. Some provinces have MAiD Coordination Centres (MCCs) where all MAiD requests filter through for the entire province. Other provinces have similar concepts but are regionally organised. There are some areas in the Canada where access to MAiD coordination depends on specific organisations individual MAiD response and whether or not they have MAiD teams with coordinators. Even the title attributed to these role(s) vary across and within these areas. MAiD Care Coordinator, MAiD Coordinator, Nurse MAiD Navigator are just a few examples of the various titles attributed to MAiD coordination in Canada. However, despite the differences, one common thread unites ideal MAiD Coordination: its essential and pivotal role in helping to reduce barriers to MAiD care. The authors of this paper advocate for the 'ideal' scenario, which would involve standardizing access to aspects of MAiD coordination across all provinces in the form of a MAiD Coordination Center (MCC). This ideal scenario would ensure access to consistent education, clinical leadership, interprofessional involvement, supportive data/quality improvement oversight initiatives, and the actual process of coordination for all involved in MAiD care. Ideally, giving all health care providers and patients involved in MAiD Care access to standardized supports while maintaining the flexibility to respond to the nuances of their specific region or organization. Acknowledging the need for localized coordination and provincial, territorial difference will ensure the diversity that exists across Canada's healthcare and within each region can be honoured.

Education

One of the most important roles of an ideal MCC is serving as a reliable place to ask for information about MAiD. Since social media can spread misinformation (and even disinformation) about MAiD, the MCC can act as a regional educational hub for all involved in MAiD. MAiD coordinators across the country manage a high volume of basic inquiries, addressing questions regarding the eligibility criteria for MAiD and guiding individuals on how to request an assessment for MAiD within their region. MAiD coordinators come from a variety of health care backgrounds, including nursing and social work, yet they are universally compassionate, patient-centred people who treat each requestor of information as a unique individual. Whether the request comes from a Health Care Provider or a Health Care Consumer, MAiD coordinators provide a safe space to ask questions, receive honest answers, and achieve an effective referral for assessment.

An exceptional MAiD Coordination Centre recognizes educational gaps that exist not only in the public, but also within the healthcare community. They help to fill these gaps with reliable, timely, and factual information. For instance, when MAiD first became available in British Columbia in 2016, coordinators at the

Interior Health region (IH) MCC recognized the need for an online educational brochure. Collaborating with a family member who had experienced MAiD, they developed a brochure[1] that provided information about the process from the patient's perspective, shared links to resources for the family, and explained what was going on behind the scenes. As legislation has evolved, so too have these resources. The MCC in IH was the catalyst to making this type of educational support a reality.

MAiD coordinators can offer support and expertise to clinicians new to MAiD, and facilitate mentorship by connecting them with more experienced MAiD providers. Within many areas, MAiD coordinators currently serve as the experts, as not all primary care clinicians have the appropriate scope of knowledge required to navigate evolving federally legislated eligibility criteria. The introduction of an MCC would ensure this support was available to all MAiD care providers.

Clinical Leadership

A Medical Director (MD) or Clinical Lead (CL) has a vital role as part of an ideal MCC. This individual should also serve as a MAiD assessor/provider and support the MAiD coordinator(s) in various ways throughout the coordination process. The MD/CL can lead educational initiatives, ensure effective recruitment/on-boarding and help create tools to support a sustainable workload. Creating sustainability for the health care providers involved in MAiD Care is an essential task as the number of requests for assessment have consistently increased year over year across Canada.[3] The MD/CL also brings an assessor/provider lens to the creation of MAiD policies and procedures at the organizational, regional, and even provincial levels.

Interprofessional Involvement

Wherever MAiD care takes place, the coordinator works to ensure the appropriate interprofessional team members are present, recognizing that each location has unique support needs. As an example, with 37.2 % of MAiD provisions occurring in private residences across Canada,[3] MCCs often facilitate nursing support for intravenous placement.[4] As a member of an Interprofessional team, one author can attest to the potential an Interprofessional team has to enhance the experience not only for patients in the various supports that can be offered, but also for assessors/providers. Access to interprofessional teams allows assessor/providers to consult with various health care professionals with more ease, bringing multiple specialty perspectives to the assessment when needed.

Another example of interprofessional collaboration is the process by which MAiD coordinators refer eligible and interested patients to the provincial organ donation service once fully approved for MAiD. The MCC then works with the patient, the provincial donation service, the hospital system(s) and the MAiD providing team to enable organ donation after MAiD provisions for those who are eligible and willing. Adding access to interprofessional supports and collaborations is an important component of an ideal MCC as it helps to further patient wishes.

Data/Quality Improvement Oversight

MAiD coordinators have the most comprehensive understanding of what is happening locally within their regions with respect to MAiD. However, to gain an overview across larger regions, it is paramount to compile information from multiple areas to compare how MAiD is provided, and to whom, within the individual regions, provinces and/or territories. Within British Columbia, for example, oversight occurs at both the regional health authority and provincial levels. All completed MAiD assessment paperwork is collated and reviewed, creating a detailed data set. This is possible because MAiD coordinators input all relevant data into their regional MAiD databases and crosscheck with the province to ensure that all documentation is provided for review. This process enables both regional and provincial comparisons regarding who is accessing MAiD for end-of-life care, and the underlying medical problems of those individuals. When one health authority stands out, with respect to one aspect of MAiD Care or lack of access to MAiD care this data analysis process enables a more thorough review. Using the data collected by the regional health authorities, British Columbia can determine where to focus additional education, and when to involve more clinicians. Without the MCC in BC, that collates information across a region, conducting this level of detailed analysis would not be possible. Therefore, an ideal MCC should have the capability to collect and analyze regional data to support quality improvement initiatives at the local, regional, and provincial/territorial levels. Collecting this information would allow an ideal MCC to revise their resources in order to make the necessary adjustments to clinical care for example.

Act of Coordination

Some communities and acute care hospitals have their own triage/referral systems for managing MAiD requests as they come in.[5] These systems allow patients to move seamlessly through the MAiD process, interweaving MAiD into the organization's existing policies and procedures. Coordinators functioning in these scenarios work directly with patients, providing consistency of care for them and their family throughout the MAiD pathway. However, for the average person wanting assessment for MAiD, this mosaic of MAiD care can be a daunting challenge, especially for those unfamiliar with the healthcare system within which they are receiving care or those receiving care in a setting where MAiD coordination is not already established. The ideal MCC would include a, centralized referral mechanism and secure medical record storage for all required MAiD documentation. This would ensure a standardized process for tracking MAiD requests, as requestors move between community and hospital settings. Everyone supporting the process would know where the information is stored and could review it as needed. Additionally, the ideal MCC would also maintain a directory of MAiD assessors, providers, and experts available for consultation in each area. Local coordinators could upload documentation and request as much, or as little, support throughout the process as needed.

British Columbia is close to achieving a fully coordinated system for MAiD assessments, with 73% of all MAiD requests managed through the five regional health authority-based MCCs.[6] Within each MCC, the MAiD coordinators review the requestors' paperwork, such as their MAiD request form, for completeness. The MAiD request is then triaged/prioritized based on underlying medical problems and readiness to move forward. The MCC contacts the primary care provider to determine if they are willing to serve as either the first assessor or the prescriber (often known as Primary Assessor in other areas of the country). If the primary care provider declines to take on one of these roles, the MCC refers to a list of other health care providers within the community who are willing to take on requests outside their own practice. The coordinator then assembles the necessary assessors to review the request and conduct eligibility assessments. If expert opinion(s) are needed to support a provider's decision, the MCC will provide advice on which experts to approach.

Each step within the MAiD coordination process presents its own unique challenges. A centralized MCC, accessible to all assessors, providers and patients would help ensure that all patients have better access to assessment and that assessors and providers have standardized access to support. This is particularly an issue in remote and rural communities where MAiD assessors may be scarce. An ideal MCC could help arrange for video-assisted assessments, for example. In some regions of Canada, MCCs fund assessor travel to rural and remote regions, making MAiD a viable option for end-of-life care regardless of location. Currently, travel support is not consistent across the country due to provincial variations in funding.

Conclusion

MAiD coordination plays an important role in helping to diminish barriers for MAiD care. The authors believe that a MAiD Coordination Center should have reliable education, clinical leadership, interprofessional involvement, data/quality improvement oversite initiatives, and the coordination process itself built into the standard design. Ideally, all MAiD assessors, providers/prescribers, and coordinators would have access to the support of a MCCs while maintaining the flexibility to respond to the nuances of their specific region or organization. This approach acknowledges the need for localized coordination and provincial differences, ensuring diversity across Canada's healthcare is honoured in the pursuit of excellent MAiD Care.

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Is Structural Marginalization Driving Medical Assistance in Dying (MAiD) in Canada? Interpreting Observational Data, Social Context, and Regulatory Reports

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Abstract

This article analyzes current data on Medical Assistance in Dying (MAiD) in Canada, focusing on the interpretation of observational and demographic measures. It explores how structural marginalization is used as a proxy for vulnerability, and considers what this might tell us about decisional capacity and voluntariness in MAiD choices. Drawing on population-based datasets and case reviews, the analysis reveals that by every available measure, MAiD recipients are more socioeconomically privileged, with better service access and a better dying experience than that of the broader population. These findings refute common claims that marginalization and vulnerability drive MAiD requests, and challenge the idea that marginalization is undermining voluntariness in people who request MAiD. This review aims to clarify what current data can and cannot tell us about MAiD in practice, emphasizing the need for nuanced interpretation to guide future MAiD health policy and law.

Introduction

Since its legalization in 2016, Medical Assistance in Dying (MAiD) has become a focal point of discussions around end-of-life policy, ethics, and clinical practice in Canada. Much of the debate has focused on the potential risks posed by legalizing MAiD, in particular to "vulnerable" populations. Central to this debate is the use of observational data to support or refute assertions that vulnerable populations are disproportionately affected by MAiD. This paper examines the available data sources and metrics, offering an analysis of what Canadian data reveals about MAiD recipients, their characteristics, their experience with their illness, and their interactions with the healthcare system.

Framing a Research Question – Data Does Not Answer Moral Questions

Before designing any sort of study, it is important to clarify the research question. In MAiD, common research questions might include:

- "Are certain groups of people (e.g., structurally marginalized people) more or less likely to access MAiD than others?"
- "To what degree are people receiving MAiD for the intended purpose (e.g., relief of refractory suffering, exercising autonomy)?"
- "To what extent are MAiD providers meeting the expected standards of practice (e.g., complying with the law, improving the patient experience)?"

Note that these research questions can be answered objectively, and differ from sociopolitical questions about whether MAiD is morally acceptable, or whether the potential for abuse is sufficient justification for prohibiting MAiD entirely. These latter questions cannot be answered empirically; even 100% adherence to safeguards and universally positive experiences for all stakeholders would not, by itself, establish that MAiD is morally "correct". Nonetheless, advocates sometimes feel that their moral arguments might carry more weight if they could find data that would put MAiD in a favourable or unfavourable light. Hence, much of the debate around MAiD has involved attempts to answer moral questions with an appeal to data, or attempts to align empirical observations with a pre-existing moral perspective on MAiD (a confirmation bias).

Observational Data and the Importance of Appropriate Comparators

Most MAiD research relies on observational data, information that describes populations and events, and identifies associations between exposures (e.g., income, diagnoses) and outcomes (e.g., MAiD). The data may include purely demographic values that describe a population (e.g., age, sex, race, illness), or area-based indices that describe aggregate socioeconomic characteristics of a person's postal code. In addition, some datasets incorporate patient-centred outcomes (e.g., pain control, or whether individuals died in their place of choice).

Understanding the limitations of observational research is important, as many conclusions about MAiD recipients rely on observations and correlations that are vulnerable to misinterpretation. One common pitfall is the use of inappropriate comparators, or none at all, yielding spurious conclusions caused by "cohort effects".[1] In MAiD research, a common "cohort effect" occurs when a characteristic appears more prevalent among MAiD recipients than in the general population, which can be interpreted as driving MAiD. This inference is problematic because MAiD recipients are predominantly people with incurable chronic or terminal illnesses, the large majority of whom are over age 65.[2] Thus, we would expect any characteristic associated with advanced age and chronic or terminal illness to be more common among MAiD recipients than in the general population, independent of whether they request or receive MAiD. Before interpreting the link between this characteristic and MAiD, it is essential to compare its incidence in a group similar to MAiD recipients, such as people with chronic or terminal illness who die naturally, differing only in their decision not to receive MAiD. Put simply, the goal is to identify factors associated with receiving MAiD, rather than factors associated with conditions that make people eligible to receive MAiD.

Using Structural Marginalization and Vulnerability as a Proxy for Potential Concerns about Decisional Capacity and Voluntariness in the Context of MAiD

The legalization of MAiD aims to offer people the ability to choose and to respect their autonomy and provide relief from intolerable suffering for those with serious and incurable illnesses. To that end, each person requesting MAiD undergoes two independent assessments of their eligibility, as well as their decisional capacity, with an emphasis on ensuring that their request is truly voluntary. However, if people pursue MAiD not out of a voluntary decision, but due to undue influence, whether from caregivers or correctable societal factors (e.g., poor support services, poverty), then the goal of MAiD legislation is undermined. While there are accepted processes for determining capacity and voluntariness, these assessments inherently involve subjective, decision-specific judgment by the assessor. There is no definitive, objective method to prove decisional capacity or voluntariness in MAiD or any other medical decision.

While "vulnerability" can be defined in various ways,[3] for the purpose of MAiD research and policy, we will define it to mean a diminished ability to advocate for one's own needs. People considered "vulnerable" are felt to be more vulnerable to the influence of factors that may undermine their voluntary decision-making. Vulnerable people are at elevated risk of receiving treatments that they *do not* want, as well as being at elevated risk of not receiving treatments that they *do* want.

Although the terms "vulnerability" and "marginalization" are used commonly and interchangeably in academic and non-academic discussions, they represent distinct concepts. *Structural Marginalization* refers to a condition of reduced power, generally as a result of sociodemographic characteristics such as race, income, education, disability, or geographic location.[4] Marginalization is a valuable concept in academic contexts because sociodemographic factors are often objectively measurable (unlike vulnerability, capacity, or voluntariness) and can be used to describe populations. Marginalization and vulnerability are related but not equivalent concepts; people from marginalized populations are at greater risk of vulnerability, but structural marginalization does not equate to vulnerability (nor vulnerability to marginalization) in every individual case.

To sum up, this discussion rests on a chain of logic. We are primarily interested in voluntariness and decisional capacity, two elements that cannot be measured objectively (at either the individual or population level). However, if there were a consistent pattern of people accessing MAiD as a result of external, correctable societal factors (e.g., poverty, poor service provision, or outright coercion) rather than through truly voluntary requests, we would expect these influences to disproportionately affect vulnerable populations. As a result, we would expect to see an over-representation of structurally marginalized populations among MAiD recipients.

We Should Not Assume that Marginalized or Vulnerable People are Decisionally-Incapable, and We Do Not Protect Vulnerable Populations by Limiting Their Options

There are two critical points to remember here. First, if MAiD decisions are truly voluntary, we should expect to see MAiD use across all demographic groups, including marginalized ones, with relatively similar rates. There may be valid reasons to observe variations in incidence of MAiD among some groups—for example, some ethnic or religious groups may be less accepting of MAiD, or some illnesses may produce greater suffering than others. However, in an equitable system where true voluntariness was respected, we would still expect people from marginalized groups to be receiving MAiD.

Second, we must guard against the notion that people who are vulnerable or marginalized are incapable of making voluntary decisions, or that limiting their choices is the best way to protect them. The appropriate response to concerns about voluntariness is to perform additional assessments to determine the influence of external or correctable factors, or to provide resources that support voluntary decision-making or address specific factors identified during a comprehensive assessment. By contrast, restricting a person's voluntary decision-making serves to confirm and compound their vulnerability.

What Does the Data Reveal About Marginalization Among MAiD Recipients?

The collective data about MAiD indicates that for virtually every relevant metric, MAiD recipients are *less* marginalized (and often far less marginalized) than the appropriate comparator. One large Ontario study has shown that MAiD recipients are more likely to belong to the highest income quintile than those who died of natural causes (24.9% vs. 15.6%).[5] A subsequent study, which adjusted for various demographic and illness factors (e.g., diagnosis and sex, among others) found that Ontarians in the lowest income quintile were 39% less likely to receive MAiD compared with those in the highest income quintile.[6] Supporting these findings, the 2023 federal report showed that MAiD recipients were overrepresented in the highest income quintile, and underrepresented in the lowest income quintile, relative to the general population of natural decedents.[2]

When comparing postal code-based indices of marginalization, which consider multiple socioeconomic factors, a similar pattern emerges. According to the 2023 annual federal report, MAiD recipients were significantly less likely to reside in areas classified within the most marginalized quintile (i.e., 20%) for economic dependency, which includes indicators such as unemployment and reliance on government benefits. Only 10% of MAiD recipients resided in these areas, compared with 30.6% of natural decedents. Similarly, for situational vulnerability, which reflects factors such as indigenous identity, homes in need of repair, and education level, approximately 14% of MAiD recipients come from the most marginalized quintile, versus 20.5% of those who died naturally.[2] Notably, these findings echoed those of a provincial report from Ontario, which used comparable, but not identical, measures of marginalization.[7]

Other demographic indicators are similarly reassuring. MAiD recipients are less likely to be institutionalized (6.3% vs. 28%) and more likely to be married than natural decedents.[5] Additionally, the federal report also showed that 96% of MAiD recipients identified as white, compared to 86% of community-residing seniors. Indigenous, East Asian and other racialized groups were markedly underrepresented among MAiD recipients compared with the average among seniors.[2]

"Track 2" MAiD Recipients

Recent federal and Ontario reports have included data specifically focused on MAiD recipients from "Track 2"— people without a reasonably-foreseeable natural death. This group typically includes those living with chronic illnesses, though some cases are due to injuries (e.g., spinal cord injuries). While Track 2 MAiD accounts for only a small proportion of MAiD cases overall (approximately 4% of MAiD, or <0.2% of all deaths),[6] concerns have been raised by some advocates about the potential for disproportionate marginalization among Track 2 MAiD recipients. Again, the data do not support these concerns, and largely show the opposite. The federal reports show that Track 2 MAiD recipients exhibit similar patterns to Track 1 MAiD recipients in terms of economic dependency and situational vulnerability, meaning they tend to be more privileged and less deprived than natural decedents.[5] In terms of income, Track 2 MAiD recipients were found to be essentially equivalent to natural decedents. These findings are particularly notable because Track 2 recipients, given that they generally have chronic illnesses and would have longstanding disabilities, would be expected to have a greater degree of marginalization by both measures on average.

There are slightly more women than men among Track 2 recipients (58% vs. 42%). However, this is consistent with the epidemiology of populations with chronic conditions associated with frailty and not an issue of gender-related inequity: women are more likely to develop such conditions, but less likely to die from them compared to men.[8] As a result, across age groups, women are more likely than men to be alive, but also more likely to be living with chronic, debilitating illness. Additionally, conditions commonly associated with Track 2 MAiD requests, such as chronic pain, also show a higher prevalence among women.[9] Therefore, the female predominance observed in Track 2 MAiD is consistent with the underlying health conditions driving these requests, and is unlikely to be a purely gender-driven issue, or any reflection on vulnerability differences between men and women as it relates to MAiD.

Is it Normally Difficult to Find an Association Between Marginalization and Poor Health Outcomes?

When interpreting MAiD data, it is important to appreciate the strong correlation between *natural* mortality or poor service provision and forms of marginalization such as income or education, and how clearly these relationships are shown in observational research. For example, Tjepkema et al. showed that between 2011 and 2016, Canadians (both men and women) in the lowest income quintile had age-standardized premature mortality rates that were 2.5 times higher compared with those in the wealthiest income quintile.[10] Similarly, Canadians who had not completed secondary school experienced age-standardized premature mortality rates nearly 2.5 times higher than those who had completed postsecondary education. In 2014, Statistics Canada estimated that the mortality gap between the poorest and wealthiest Canadians accounted for 40,000 deaths per year.

Low income is also associated with poorer service provision. In Canada, the poorest quintile is significantly less likely to receive Palliative Home Care services,[11] less likely to be seen by specialists[12] (and seen by fewer specialists when they are), and more likely to experience long wait-times for care[13] compared to the wealthiest quintile.

In other words, the effect of structural marginalization on natural mortality and service access is profound and consistently evident in observational studies. It is therefore particularly notable that MAiD data does not follow this trend. Instead, MAiD consistently appears to be less common among structurally marginalized groups and more prevalent among people within privileged groups.

Palliative Care and the Patient Experience

Our federal reports include information on whether MAiD recipients received palliative care services and the duration of that care before death. In the most recent report from 2023, approximately 75% of MAiD recipients required and received palliative care, and among them, approximately half received it for more than a month before they died.[2] Conversely, only 2.8% were identified as needing palliative care services but not receiving it, and in only six cases out of 15,343, assessors reported that palliative care services were required but not accessible. While there is room for improvement, these figures objectively describe a population with a high level of palliative care involvement. Access issues appear to be rare and isolated. By contrast, a recent Canadian Institute for Health Information (CIHI) report suggested that fewer than 60% of Canadians overall receive palliative care before death, and when they do, it is often provided for less than one month before a natural death.[14] Notably, natural deaths tend to occur weeks or months later than MAiD deaths on average, suggesting that MAiD recipients often receive palliative care earlier in their illness trajectory than natural decedents. Although these assessments are subjective, they echo the objective findings showing that the populations with the highest incidence of MAiD, such as white persons, those who are more affluent, and people with cancer, are also the populations known to receive the highest quality palliative care.[15]

We also have data on the experience and quality of death among MAiD recipients from the Canadian Longitudinal Study on Aging (submitted for publication), a cohort study that enrolled 50,000 Canadians between 2011 and 2015 (prior to the legalization of MAiD) and has continued to follow them through periodic health questionnaires. For participants who died, a post-death interview was conducted with their next of kin, which included information about their end-of-life experience and decision-making processes. Among the 937 participants who died between 2016 and 2021, 25% had considered MAiD, and 7% received it. People who considered or received MAiD were reported to have a significantly higher quality of death experience, as reflected in a greater sense of "peace with dying," dying in their preferred location, a higher degree of dying with "dignity maintained", and dying without pain. While this was an observational study and cannot establish causation, meaning we cannot determine whether MAiD directly led to a better quality of death experience, or whether people experiencing a higher quality of death were more likely to choose MAiD for reasons not captured in the study. These findings strongly refute the idea that Canadians are turning to MAiD out of desperation because of poor experiences with healthcare.

Subjective Drivers of MAiD Requests

The federal reports also include insights into the types of suffering experienced by MAiD recipients. Notably, people can select multiple types of suffering (on average, they select three), and are not required to indicate which form of suffering is the main driver of the request. This approach is appropriate, given that suffering is inherently multifactorial and its relative severity is difficult to quantify. However, opponents of MAiD have raised concerns about two causes of suffering (loneliness and the feeling of being a burden on others), implying that these are reversible social phenomena and therefore are not a legitimate basis for MAiD.

These arguments are problematic for two reasons. First, as mentioned above, we need to compare the prevalence of this type of suffering among MAiD recipients with that of the general population who are not requesting MAiD. National surveys of Canadians over age 65 (who account for 85% of MAiD recipients) report significant loneliness in 19–24% of respondents,[16] with prevalence increasing with age. In comparison, 21% of Track 1 MAiD recipients and 47% of Track 2 recipients reported loneliness.[2] In other words, Track 1 recipients, who account for 96% of all MAiD cases, actually experience lower rates of loneliness than would be expected in a random sample of Canadian seniors with average health. While loneliness is more common among Track 2 recipients, the data challenges the assumption that MAiD is being driven by social suffering. For self-perceived burden, numerous surveys of terminally ill people admitted to palliative care facilities (and not requesting MAiD) show that as many as 65–70% feel that they have become a burden to others.[17] Among MAiD recipients, this sentiment is reported by 45% (Track 1) and 49% (Track 2) individuals. In other words, these figures are lower than expected for people with advanced or terminal illnesses.

The second issue with these arguments is that they imply that certain forms of suffering are due to factors external to the patient, and therefore distinct from disease-related suffering, which is accepted as a legitimate reason for requesting MAiD. In reality, people form social connections around shared interests and activities. When illness deprives a person of the ability to perform activities that they enjoy or value, it frequently leads to the loss of their social circle. Loneliness has many contributing factors and is increasingly recognized as a serious public health problem worldwide.[18] However, in the context of advanced or terminal illness, loneliness is strongly linked to the illness itself and the functional decline it causes. It is not something that is addressed by simply providing additional companionship or encouraging new interests. By the same token, the sense of being a burden on others is a common emotional response among people who rapidly lose the ability to perform activities of daily living as a result of an illness. This distress is caused by the impact of an illness on their sense of identity, and is distinct from being made to feel like a burden by others. Their distress is not due to a lack of assistance with their activities of daily living, or that their caregivers are making them feel like a burden. Their distress is caused by the need for assistance with activities that they previously managed independently. Again, this form of distress is deeply linked in the illness experience and cannot be addressed simply by providing additional supports; Canada's federal report from 2023 suggested that only five MAiD recipients (out of more than 15,000) required supportive services that they were unable to access.[2]

Exceptions and Anecdotes

The large observational studies and reports discussed above strongly refute the idea that structural marginalization is a major driver of MAiD requests. However, this does not exclude the possibility of exceptional cases where marginalization may play a role. In particular, media reports have highlighted exceptional or controversial MAiD cases—such as those involving allegations of housing insecurity or inadequate disability support. These stories are difficult to analyze because they often rely on only allegations, and lack access to medical records or input from the providers and assessors who were involved in the case due to confidentiality constraints. In general, these cases fit into one of three categories.

The first category includes reports that have been refuted by regulatory bodies or by the patient themselves. There are many that fit into this category, but the most prominent case would be that of "Sophia" (a pseudonym), a woman with multiple chemical sensitivities. Media reports suggested she was requesting MAiD because she could not access medically-safe housing.[19] However, after the story appeared, Sophia herself wrote a letter refuting it, clarifying that while she had struggled to obtain medically-safe housing, her condition continued to deteriorate even after suitable accommodations had been found. Her remaining housing option was living in a "bubble" environment where she would be isolated from friends and family.[20] She declined that option for reasons of quality of life and chose MAiD instead. A multidisciplinary MAiD Death Review Committee reviewed the case and the majority of members concluded that "other housing arrangements would not have led to a resolution of her suffering."[4]

The second category includes lapses in pre-MAiD care that are mistakenly portrayed as a choice between receiving appropriate care and opting for MAiD. A notable example is the case of Mr. Normand Meunier,[21] who was quadriplegic from a previous motor vehicle accident. He presented to his local Emergency Department with signs of an infection, but was not provided with a pressure-relief mattress, resulting in him spending 90 hours on a stretcher while waiting for a hospital bed. This led to the development of a severe pressure sore which was resistant to medical and surgical management. Faced with a terminal condition, Mr. Meunier requested MAiD rather than wait for a natural death. Although this case is currently under review by a Coroner's inquiry, media reports and opponents of MAiD have cited it as an example of someone receiving MAiD rather than standard of care treatment. However, Mr. Meunier's decision to request MAiD came only after the consequences of a lapse in standard of care had already occurred. The presence or absence of MAiD as an option had no bearing on the incident that caused his fatal condition.

The third category encompasses cases where there may be legitimate differences in perspectives about whether a MAiD request was caused by a lack of available supportive care for independent living, or a medical deterioration that made independent living an unrealistic option. A representative example is the case of Yves Belair, a 69-year-old man born with severe physical disabilities and complex medical conditions due to cerebral palsy.[22] Despite these challenges, he was able to complete postsecondary education and became a prominent advocate, leaving behind a legacy of resources to support university students with disabilities. In his later years, however, his multiple medical conditions had worsened to the point that he could no longer be safely cared for in his home even with having more than 28 hours of supportive services per week, and assistance from three close friends who provided supplemental support on a volunteer basis. Frequent hospital admissions became necessary, and rather than face institutionalization in a complex care facility, he requested MAiD. Yves Belair maintained that he requested MAiD because his social support system had failed him. Meanwhile, his friends believed that his condition had deteriorated to such an extent that no level of support could have sustained him at home, and that he no longer enjoyed any quality of life. Ultimately, this case reflects a matter of perspective. It also underscores the reality that there are limits to the amount of resources that can be provided in a home setting, and that the need for support is clearly driven by the progression of illness.

Conclusion

This article examined the use of observational data on MAiD in Canada, how structural marginalization is used as a proxy for vulnerability, and how these factors might provide insight about decisional capacity and voluntariness in MAiD-related decisions. Drawing on population-level data and case reviews, the analysis reveals that MAiD recipients are more socioeconomically privileged, with greater access to services and a better dying experience compared to the broader population across all available measures. While these findings do not resolve moral debates about whether MAiD is a “good” thing, or whether the potential for misuse is sufficient to justify criminalization, they clearly refute the notion that MAiD is being driven by marginalization or inadequate service provision on any substantial level in Canada. Although exceptions may exist, the anecdotal cases cited to support this claim rarely stand up to scrutiny.

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