Importance of investigating vulnerabilities in health and social service provision among requestors of medical assistance in dying

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Canada's medical assistance in dying (MAID) policy

Canada is one of several jurisdictions in the world that permit MAID, for persons meeting certain criteria.[1] Unlike other jurisdictions allowing MAID such as the Netherlands, Canada does not explicitly require that MAID be a last resort, meaning that persons can be eligible for MAID even if there are reasonable, standard treatments or resources that would make their suffering tolerable but are inaccessible due to lack of availability, extended wait times, financial insecurity, or other reasons.[2] The recently released *Model Practice Standard* states only treatments available to requestors need be discussed in informed consent for MAID.[3] It is true that the document leaves the door open to practitioners to send a MAID requester back to providers who offer services that could alleviate their suffering, however it is not a requirement and, as the accompanying *Advice to the Profession* acknowledges, a person is eligible even if the lack of access to existing remedies is due to "systemic barriers".[4(p.12)] For many persons in Canada, therefore, MAID will be more accessible than standard treatments and remedies.

Minimizing instances of MAID due to lack of access to adequate care and resources is an uncontroversial goal. But such a goal requires identifying situations of vulnerability, i.e., the places of mismatch between the resource needs of MAID requestors and the availability of needed resources within the Canadian health care system. MAID annual reports provide the characteristics of those who received MAID (mostly Track 1 MAID deaths (i.e., where natural death is reasonably foreseeable) in the currently available data as the removal of reasonably foreseeable death criterion did not occur until March 2021).[5] Some studies have also examined the characteristics of those accessing MAID as well as the relationship between various health services and MAID in Canada.[6–10]

These studies generally show those receiving MAID tend to be of higher socioeconomic status, which aligns with sociodemographic characteristics of MAID seekers in other countries,[11] where the majority of MAID cases are also for the terminally ill.[11,12] Because those with higher socioeconomic status are typically better at navigating complex systems, including palliative care,[7,13] potential health care need-availability mismatch among them may appear to be of little concern. However, further investigation is warranted for several reasons. First, these results are not fine grained; it is not clear, for example, even among those with higher socioeconomic status, whether factors such as wait times for procedures affect requests. Second, for Track 2 MAID (i.e., where natural death is not reasonably foreseeable), socioeconomic and other factors may play a greater role, so that what we know from Track 1 (i.e., where natural death is reasonably foreseeable) may not be applicable. Third, without comparing the socioeconomic characteristics of MAID requestors across provinces and territories, we cannot rule out their impact on MAID requests in different health care delivery contexts. The investigation of potential health care need-availability mismatch is particularly important against the backdrop of a substantial increase in MAID deaths in Canada: from 1108 deaths in 2016 to 13,241 deaths in 2022, a 12-fold increase in 6 years, a much faster pace than other MAID countries.[11,12,14]

MAID is a controversial ethical issue that can be analyzed in different ways. One could ask, for instance, whether a case of MAID can ever be acceptable. Such a framing is about the morality of MAID; it is an

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important but insufficient consideration for assessing MAID as a policy issue. This paper identifies the aspects of the Canadian health care system that are particularly relevant for minimizing cases of MAID due to lack of needed resources and types of data necessary for further investigation (Table 1). Although we cover MAID overall, we pay special attention to MAID for persons whose sole underlying condition is mental illness (now scheduled to be permitted in March 2027), as timely access to adequate mental health care is often considered limited in Canada.[26]

Potential for mismatches between health care need and access among potential MAID requestors

Track 1. Maid for persons whose death is reasonably foreseeable

Main conditions for MAID deaths in 2022 (of which 12,778 or 96·5% were Track 1) were cancer (63%), cardiovascular disease (19%), respiratory conditions (13%), and neurological conditions (13%) (a person can have multiple conditions).[5] Recipients tended to be older than the average Canadian (77·0 vs. 41·7 years); male (representing 51·4%) (MAID annual report 2022)[5]; and, as discussed above, with higher socioeconomic status.[7,8]

Potential health services concern

Wait times. In principle, since Medicare offers "medically necessary" physician and hospital services free of charge at the point of service, Track 1 MAID requesters should have received or been offered all medically necessary physician and hospital services. However, ongoing wait time problems in many jurisdictions in Canada[15] raise a concern for potentially hastened or even unnecessary MAID requests (e.g., if the request precedes confirmatory diagnostic procedures). For example, whereas 96% of patients meet the wait time benchmark for radiation therapy in Canada

Potential health services concerns
Among MAID for persons whose death is reasonably foreseeable (Track 1)
Wait times[15,16]
Drug coverage[17,18]
Palliative care services[5,19,20]
Inequitable health care use[21–23]
Among MAID for persons whose death is not reasonably foreseeable (Track 2)
Among persons with chronic physical non-terminal illnesses and disabilities
Availability of social services[5,24,25]
Quality of available social services[5,24,25]
Among persons with mental illness
Insurance coverage for mental illness[26]
Navigation of complex system[26]
Wait times[26]
Costs to access privately funded services[26]
Stigma[26]
Treatment for personality disorders[27–30]
Treatment refractory depression[30–33]
Trauma-informed care[34–37]
Inequitable gender-based impact of under- resourced mental health system[38]
Data need and challenges
Needs
Careful routine monitoring of MAID requestors and recipients supported by:
• Consistent and standardized individual-level data collection on their sociodemographic and socioeconomic information and drug and private insurance status
• Individual-level data linkage with social and health administrative data (e.g., physician billings, hospitalization, home care) and cancer registry
• Area-level data linkage with health and social services supply and access wait times
Challenges
• Administrative data typically held separately within each province and territory
• Little coordination of data between health and social services sectors
• Area-level wait time information only available to specific procedures (e.g., hip replacement) at a large area-level (e.g., province)

Table 1: **Potential health services concerns and data need and challenges**

as a whole, only 79% and 85% of patients meet benchmarks in Nova Scotia and British Columbia, respectively.[15] With persistent wait time issues, especially heightened due to the COVID-19 pandemic,[16] there is an urgent need to examine care episodes and patterns prior to MAID deaths as individual-level MAID death data become widely available.[39] Furthermore, it would be important to examine any correlation between wait times or access issues and MAID prevalence both by patient characteristics and by geographic area.

Drug coverage. The longstanding unfulfilled attempts to establish national pharmaceutical insurance mean drug coverage is a hodgepodge of public and private financing with wide coverage variation across 14 federal, provincial, and territorial health systems (1, 10, and 3 systems, respectively).[17,18] Unaffordability of necessary out-of-hospital drugs due to the lack of or insufficient drug insurance could be of concern for potentially hastened or unnecessary MAID requests. Accordingly, there is a need to track drug insurance status of MAID requesters.

Palliative care services. According to the 2022 MAID report, 77·6% of persons with MAID deaths received palliative care services, but for 12·5% of persons with MAID deaths, palliative care services were not accessible when needed.[5] While a recent report examining palliative care use and access in Ontario, Alberta, British Columbia, and Yukon shows no difference in palliative home care access between urban and rural/remote residents in 2021–22,[19] an Ontario study reports a persistent socioeconomic gradient in the receipt of palliative care services at the neighborhood level in 2009–2016.[20] Careful monitoring of a gap in access to palliative care services is necessary.

Inequitable health care use. Whereas those who die by MAID to date tend to have higher socioeconomic status, a large body of literature on access to health care shows that access, utilization, and quality of health care are often socioeconomically graded.[21] Canadian studies show that those with higher socioeconomic status can navigate complex health care systems, especially specialist care, better than their counterparts,[22] and wait times are graded by income.[23] As mentioned above, the socioeconomic gradient of palliative care is at best mixed.[19,20] Inaccessibility of necessary drugs most acutely fall into those with lower, but not the lowest (where governmental subsidies kick in), socioeconomic status.[18] Furthermore, focusing on inequity, the scope must extend beyond typical socioeconomic measures of education and income, in particular, race/ethnicity, sexual orientation, and geography. It is important to observe carefully if MAID requestors remain, even among Track 1 patients, people with social advantage or MAID becomes a "health care option" among those with social disadvantage who bear the brunt of health care challenges.

Track 2. MAID for persons whose death is not reasonably foreseeable

Chronic physical non-terminal illnesses and disabilities

In 2022, 463 MAID cases (or 3.5% of the total) pertained to track 2.

The topic of decisions on MAID requests influenced by disability is important to consider given the high rates of disability among the Canadian population. About one in five Canadians over the age of 15 report having one or more disabilities.[40]

According to the 2022 MAID annual report, 36·8% of MAID recipients overall (tracks 1 and 2) required disability support services, of whom 89·5% used services.[5] Whether disability supports were required is "unknown" for 23·2% (n = 3041) of MAID recipients overall.[5] Among those who used services, the extent, quality or sufficiency of disability support is not reported on. The data also do not allow us to determine how many individuals had long term disabilities as opposed to recent illness or trauma. The data only report those who required disability supports for 6 months or longer. It is also unclear how many individuals with long term disabilities received Track 1 MAID. Among Track 2 cases, 53·8% (n = 249) required disability services, and 92·8% (n = 231) received them.[5] Given that this cohort is not at the end of life, the rise in numbers requiring disability supports suggest that disabled persons may be seeking MAID purely on the basis of their disability and potentially due to the lack of sufficient or appropriate supports as the anecdotal evidence seems to suggest.[24] The public controversies related to disability and mental health often revolve around quality or quantity of disability supports as much as the simple availability of services. Currently, no data on quality or sufficiency of services are collected. Case reports and anecdotal information suggest that forced institutionalization due to a lack of home care support and a lack of sufficient and/or appropriate disability supports have been a motivating factor in a number of Track 2 cases.[25,41]

Mental illness

MAID when mental illness is the sole underlying condition is scheduled to become legal in March 2027. The mismatch between need and access is great because much of the care for mental illness is not publicly covered in Canada. For instance, the Canada Health Act does not guarantee coverage of services prescribed by a physician but provided by another health care specialist, such as a psychologist or therapist.[27] Even if a public insurer covers (or partially covers) such services, they will not necessarily be free at the point of service. Private

insurance plans are more likely to cover psychotherapy services but will often leave a substantial portion to the patient, often through a stopgap measure such as a ceiling on expenses covered that falls short of the needs of someone with severe or chronic illness. Psychosocial rehabilitation services (e.g., vocational rehabilitation, supported education, and supported housing) are often—not always and not always sufficiently—covered by the public sector and the not-for-profit private sector for people with severe and persistent mental illness.

Thus, longstanding concerns about MAID for mental illness stem from several factors that affect those with mental disorders, including individual circumstances (such as unstable housing and lack of employment opportunities), self-perception (internalized stigma), and histories of negative interactions with health services that intersect with structural vulnerabilities to create barriers to care.[26,42(p.11),43] Challenges in navigating complex systems to access appropriate and available service, long wait times, costs to access privately funded services, and stigma in seeking and receiving care are particularly problematic in seeking treatment for mental illness.[24,26] Despite the expansion of early intervention services in specific populations in recent years, missed opportunities for early intervention increase the likelihood of worsening symptoms and functioning, with increased risk of crisis and need for emergency services, and contribute to poor outcomes, including disruption to relationships, educational and/or occupational attainment, and risk of suicidality.[44] Furthermore, relationships between the availability of MAID and the incidence and attempts of suicide call for careful examination.[45]

Some specific health services concerns among those who may request MAID where mental disorders are the underlying reason

Personality disorders. Personality disorders are very common among those who die by suicide,[42] and by MAID.[28,42] Individuals with personality disorders face particular challenges in accessing appropriate services due to stigma (including from health professionals) and the need for often lengthy treatment with specialized services that may not be publicly funded or adequately covered by private insurance.[29] Furthermore, there may be insufficient availability of clinicians with requisite skills to evaluate MAID requests from persons with psychologically complex personality disorders.[30]

Treatment refractory depression. Although "treatment resistant depression" (TRD) is often used as a paradigm case of irremediable mental illness,[31] it has no standard definition,[30] and the evidence base regarding irremediability is sparse. The best longitudinal studies of such patients show that treatment resources are crucial: the majority of persons with well-documented TRD enter remission but require high quality longitudinal specialty care including inpatient services.[32] Further, emerging therapies such as ketamine, psychotherapy assisted psychedelics, and targeted transcranial magnetic stimulation show promise, but they may create further instances of mismatch between resource needs and availability.[33]

Trauma-informed care. Canadians report high rates of lifetime exposure to traumatic events, with long-term negative consequences for physical and mental health and additional challenges in meeting often complex mental health care needs.[34,35] Trauma history is common in those seeking MAID for mental disorders.[34] Despite recommendations to recognize and address trauma as an important risk factor for poor mental health outcomes, particularly among marginalized groups,[36] there is a lack of consistency in the definition of trauma-informed care or its uptake in practice.[37]

Inequitable gender-based impact of under-resourced mental health system. Women seek and receive psychiatric MAID at approximately 2–3 times the rate of men,[38] likely reflecting the fact that women have higher incidence of conditions and experiences that put them at risk of desire for death, such as depression, personality disorders, and history of trauma.[38] If MAID for mental disorders becomes legal, it will be important to track this gender-based disparate impact on persons seeking psychiatric MAID.

Conclusion

MAID is a controversial practice that can polarize opinions. However, there should be no controversy about aiming to minimize instances of persons who seek MAID as a "health care option" faced with the lack of access to standard health and social services. Such an aim will require identifying sources and points of mismatch. This paper outlines some of the potential areas of mismatch between health care needs and health care availability among MAID requesters. Our analysis suggests a need for careful, routine monitoring supported by sufficient data collection (e.g., consistent and standardized data collection on sociodemographic and socioeconomic information of those who requested and died of MAID), individual-level data linkage of MAID data with social and health administrative data (e.g., physician billings, hospitalization, home care) and cancer registry, and area-level data linkage with health and social services supply and access wait times. Such data collection and linkage are formidable and require concerted effort, beyond individual research projects, as most of these data are separately held by provincial and territorial governments and across health and social services sectors. In light of the rapidly growing uptake of MAID in Canada and scheduled expansion to persons whose sole underlying condition is mental illness in

March 2027, the need is urgent to ensure MAID does not become a de facto "health care option" in Canada in lieu of access to needed care.

Contributors

All authors contributed to the generation and development of the main arguments in the paper and the acquisition and examination of the facts presented. All authors contributed to the writing and approved the final version of the paper.

Declaration of interests

We declare no competing interests.

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