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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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