

Exploring experiences with denial of Medical Assistance in Dying services in Canada: A qualitative study with care seekers and their families

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Abstract

Background: Although Medical Assistance in Dying (MAiD) is legal in Canada with established safeguards, it remains a complex and often contested issue with significant barriers to patient access. However, professional obligations on the requirement for an effective referral differ by province and regulator in Canada leading to some providers denying MAiD services or referrals based on their personal beliefs.

Methods: We conducted 28 semi-structured in-depth interviews with patients or their family members who had been refused MAiD services since its legalization, to document their experiences with denial.

Results: Participants reported that refusing providers frequently cited ineligibility, which they perceived as reflecting narrow interpretations of the eligibility criteria. Their multiple coexisting illnesses resulted in cumulative suffering, which they felt was not understood appropriately even though intolerable suffering is one of several requirements for MAiD. Denials also stemmed from systemic barriers in application and approval processes, lack of decisional capacity, mental illness as the sole underlying medical condition (MI-SUMC), and institutional or provider refusals rooted in religious beliefs or personal discomfort. These denials led to emotional distress, disempowerment, and increased suffering for patients and families. Participants recommended clearer policy guidance and consistent implementation, legalization of advanced requests, inclusion of MI-SUMC, capacity building and training for health professionals, and requirements ensuring providers fulfill their obligations.

Conclusions: As MAiD legislation and policy continue to evolve in Canada, it is essential to address these barriers to access to ensure that patients receive the services to which they are entitled in a patient-centred and timely manner.

1. Background

Medical assistance in dying (MAiD), provided by physicians and nurse practitioners, became legal in Canada in 2016 [1]. Eligibility criteria include requirement that patients be competent adults with a grievous and irremediable medical condition, alongside safeguards to ensure the service is provided safely and ethically. In 2021, new legislation revised the eligibility criteria, such as removing the requirement of reasonably foreseeable natural death, include a minimum 90-day assessment period for those without a reasonably foreseeable natural death, and eliminate the 10-day reflection period as well as option for waiver of final consent for those with a reasonably foreseeable death. Further current exemption of mental illness as the sole underlying medical condition (MI-SUMC) in the criteria is scheduled to end in March 2027 [2–5]. From 2016 to 2024, the total number of MAiD deaths in Canada was 76,475, with 16,499 reported in 2024 alone [6]. MAiD offers individuals the right to autonomy and the choice to die with compassion and dignity.

However, MAiD remains a complex and often controversial issue, with barriers to access and provision [7–9]. For example, each province has their MAiD Care Coordination Service to help patients and

providers navigate services, however these services are variable. Ontario's MAiD coordination service are a centralized point of entry to help with navigation, but clinicians often manage records themselves. Alberta provides a truly centralized MAiD coordination service with a single point of entry where administrative teams gather records and manage logistics for clinicians.

Although literature around MAiD addresses ethical, policy, and legal dimensions, there is limited research around the experiences of being refused or denied MAiD and its consequences. This study aims to address this gap by exploring participants' experiences with refusal or denial of MAiD services in Canada. While belief-based denials motivated the study, we did not limit participants to those who believed their denial was based on religious beliefs.

2. Methods

We conducted semi-structured, in-depth interviews from March to July 2024 with care seekers or their family members who experienced refusal or denial of MAiD services in Canada.

2.1 Eligibility

To be eligible for the study, participants had to have been refused MAiD services since its legalization in June 2016, be sufficiently fluent in English or French to answer interview questions, and have access to a telephone, Skype, or Zoom. We also included family members of people who have received MAiD care after being initially denied.

2.2 Compensation

We offered interview participants a CAD40 (USD30) gift card as appreciation for their time.

2.3 Recruitment

We employed a multi-modal community-based recruitment strategy that included working with Dying With Dignity Canada's and Abortion Rights Coalition of Canada's members and supporters to distribute study information through established networks, asking early participants to refer others to us, and posting ads on social media such as Reddit. Potential participants sent an email to the study team to express their interest. We confirmed their eligibility via email exchanges and then set up a mutually convenient time for the interview.

2.4 Data collection

We carried out the interviews, which lasted an average of 60 minutes, in English over the phone or via audio-Zoom. We audio-recorded the interviews with participants' permission. AD conducted all interviews and undergraduate research assistants carried out the transcriptions. During the interview, we reviewed the consent form with the participant, answered any questions, and obtained oral consent. We developed an interview guide specifically for this study based on prior literature, documented policy debates and discussion with our community partner. The interview guide included open-ended questions

about the participants' demographic information, background, and health history. We then turned to a series of questions about the circumstances surrounding the participants' desire for MAiD and the participants' experiences with MAiD denial. We ended the interview by asking participants' opinions on how MAiD services could be improved. We adjusted the phrasing of the questions when interviewing family members but retained the same domains of inquiry (Appendix S1).

2.5 Data analysis

We analyzed the data for content and themes using an iterative process of inductive and deductive techniques [10]. AD and OA developed a codebook and used ATLAS.ti to manage data. We organized our results by domains of inquiry included illustrative quotes to elucidate our findings. We also present several narrative vignettes in order to provide thick description of participants' lived experiences [11, 12]. The quotes and vignettes represent the perceptions of the patients and family members and reflect how they experienced their care and denial. While some accounts may contain factual inaccuracies, they are presented as participants lived experiences rather than independently verified facts.

2.6 Ethical considerations

The University of Ottawa's Social Sciences and Humanities Research Ethics Board approved this study. We used pseudonyms that were either chosen by our participants or assigned by our study team, and removed or masked any personally identifying information to maintain participant confidentiality. Study procedures we conducted in accordance with the Declaration of Helsinki.

3. Results

3.1 Sample characteristics

We interviewed a total of 28 participants for this study, including individuals from Ontario (n = 10), British Columbia (n = 7), Alberta (n = 7), Quebec (n = 3), and Manitoba (n = 1). Of these, 18 participants spoke about the denial of MAiD for a family member, while 10 discussed their own experience of being denied. The average age of those denied MAiD was 69.7 years, with a range from 29 to 97 years at the time of the interview or death. The majority of those denied MAiD were white (n = 24), followed by Black (n = 2), and Indigenous or Métis (n = 2). Table 1 presents a detailed breakdown of demographic characteristics of the individuals denied MAiD in this study.

Table 1
Demographic characteristics of in-depth interview participants in a study dedicated to denial of MAiD in Canada (N = 28).

Demographic characteristic	n (%)
Age of patients (years)	(n = 10)
21–40	2 (20)
41–60	5 (50)
61–80	2 (20)
81–100	1 (10)
Age of family member* (years)	(n = 18)
21–40	2 (11)
41–60	4 (22)
61–80	12 (67)
Pronouns	
He/Him	9 (32)
She/Her	18 (64)
They/Them	1 (4)
Race	
White	24 (86)
Black	2 (7)
First Nations, Inuit & Métis	2 (7)
Province	
Alberta	7 (25)
British Columbia	7 (25)
Manitoba	1 (4)
Ontario	10 (36)
Quebec	3 (10)

*Family member includes son, daughter, spouse, mother, father, mother-in-law, friend, and grandchildren.

Note

3.2 Health history

Our participants reported a history of chronic and degenerative illnesses, which included cancer, amyotrophic lateral sclerosis (ALS), strokes, fibromyalgia, diabetes, Parkinson's disease, rheumatoid arthritis, spinal stenosis, chronic obstructive pulmonary disease (COPD), chronic pain, and various mental health disorders.

They emphasized how these interacting illnesses and comorbidities compounded their suffering and accelerated the decline of their health. This is exemplified by Penny, a 67-year-old white woman from Quebec, who described that her mother who was denied MAiD in 2021 lived with many different conditions, including arthritis in her spine and hips, and COPD from years of asthma, and later developed a bowel obstruction following surgery. She painted the cumulative impact of these illnesses on her mother's health: "Her quality of life was pretty poor...my mom said 'I don't want to live.' This isn't a life... her whole life force wasn't as strong. Pain and mobility were severe enough."

Similarly, participants identified a range of mental health conditions, including depression, post-traumatic stress disorder (PTSD), anxiety disorders, bipolar disorder, and suicidal ideation. In addition, several individuals reported concerns related to cognitive decline, which encompasses issues such as dementia, Alzheimer's disease, and progressive memory loss. These cognitive and mental health challenges not only contributed to their suffering but also served as significant barriers to accessing MAiD.

Detailed participant characteristics further illustrate the reasons for denial (Table 2).

Table 2
Year of refusal and type of denial in a study dedicated to denial of MAiD in Canada (N = 28).

Characteristic	n (%)
Year of refusal	
2016–2018	10 (36)
2019–2021	7 (25)
2022–2024	11 (39)
Percieved type of denial	
Not meeting eligibility criteria	4 (14)
Lack of decisional capacity	7 (25)
Belief-based care denial	6 (21)
Mental health illness	10 (36)
Reason unclear/undisclosed	1 (4)
Self or family member reported	
Self	10 (36)
Family member**	18 (64)

3.3 Reasons for seeking MAiD

Our study participants shared varied reasons for applying for MAiD. The primary reason for seeking MAiD was a desire for dignified death, often accompanied by a fear of future suffering and the loss of autonomy. This was illustrated by Bree, a white 49 year old woman from Ontario who was first denied in 2022.

[I woud like to] have a dignified death - and it doesn't have to be public and, you know...I can plan things out and I can plan a date, and it can be peaceful with nonviolence. And it won't traumatize others.

Participants expressed wanting to avoid unbearable or chronic suffering and wanting to have control over the timing and setting of their death. This burden was described by John, a 35-year-old Indigenous man from British Columbia who was denied MAiD in 2016.

I have abdominal migraines; it is kind of like getting food poisoning regularly. So, like very severe cramping, diarrhea, vomiting, and it lasts for a long time, and it comes in like outbreaks. It would last for 3 months; I could not go places or do things, and I would be in a lot of pain and nausea.

Other participants also described a fear of future cognitive and functional decline, particularly the prospect of institutionalization and losing the ability to make or communicate decisions about their care. Karen, a white 63-year-old woman from Alberta whose mother was denied MAiD in 2017, described her mother's motivation for requesting the procedure.

Mom never had confusion, and she never developed dementia, that I recall. However, she knew that if she developed dementia, she would not be approved for MAiD. So that was very much what influenced her decision to seek MAiD when she did.

Another participant was Puck, a 69 year old man from Winnipeg whose mother was denied MAiD in 2018. He and his wife shared the story of his mother's final years living with dementia, and her reasons for seeking MAiD (Fig. 1). They emphasized the need for health care workers to adopt greater sensitivity and flexibility in such cases, ensuring that patients with dementia are not excluded from compassionate end-of-life choices.

Dave from British Columbia (72 years old), recounted the journey of his mother, a Romanian Canadian retired special education teacher and Auschwitz survivor, who died in her late 80s. He had assisted his mother with her MAiD request due to her declining health and prolonged suffering but experienced denial in 2018 (Fig. 2).

3.4 Experience of the MAiD application process

Our participants often described considerable challenges navigating the MAiD application process. Some participants reported a lack of clarity about where or how to initiate the process, while others attempted to bypass providers they believed would object, only to encounter institutional barriers requiring formal referral. A few respondents explained how providers' hesitations stalled their application process. Kasei, a 78-year-old white woman from Ontario denied MAiD in 2016, shared her experience.

I repeatedly reached out to everyone involved—the social worker and the doctors—and brought it up at various medical appointments. Additionally, the hospital was unclear about the process for obtaining MAiD, which raised a red flag.

Several participants tied the issue of hesitant providers to geography. It may be more difficult to find providers for MAiD in rural and remote geographies, where religious denials may be more prevalent, highlighting the inconsistency in the availability of MAiD services across Canada. Maria, a 63-year-old white woman from Alberta, explained this while sharing about MAiD denial for her husband in 2021.

Particularly in my province, in the remote area that I'm in, they need to get their act together. They need to realize that not everybody lives in Edmonton or Calgary...I think checking your religious bias at the door is a very, very difficult thing to do. Even though people think they do it, they do not. And I think they should really be vetted to see whether they're a suitable assessor.

Many also described bureaucratic barriers, such as administrative or paperwork delays, which meant the patients' conditions deteriorated while waiting for a slow-moving system. For example, Blair, a white 71-year-old woman from Quebec whose spouse was denied MAiD in 2018, said:

The consent process, the paperwork, everything, and the application to begin with, and the paperwork had to be done before he got so bad that he could not consent. The process was stalling us. It was more a process of passive refusal than of active.

Although almost all participants were frustrated by the application process, two participants mentioned that the application form in itself required simple information about the applicants' profile, health history, and reasons for seeking the procedure. One participant said she called the Ontario MAiD helpline, and an agent assisted her in filling out the form: "I googled and found the number on Google, I called them, and they helped apply over the phone."

Samantha's story illustrates the experiences of navigating the MAiD application by phone in Ontario (29-year-old Black woman, denied MAiD in 2024) (Fig. 3).

3.5 Reasons for denial of MAiD

The reasons for denial described in this section are based on participants' or family members' accounts and may not reflect providers' reasons for denying MAiD. Some denials occurred before Bill C-7, while others may have reflected ongoing legal limits related to mental illness as the sole underlying condition, lack of decisional capacity or the absence of permitted advance directives. While some denials may therefore have been legally appropriate, the findings below reflect how participants' understood and experienced these denials.

i. Not meeting the eligibility criteria

Participants in our study experienced denials in accessing MAiD services for a variety of reasons. One of the reasons mentioned for the denials was not meeting the eligibility criteria, and suggestions from the participants that the denials may be due to a narrow interpretation of the criteria. Most often, patients were deemed "not sick enough" for MAiD. Here are two scenarios described in that context.

Samantha, a 29-year-old Black woman from Ontario with mental and other complex physical health conditions who was denied MAiD in 2024, said:

...they rejected my application, told me they would be closing my file, that same week that I filed the application, and that I could try again in the future if I want to...your situation basically needs to get worse...my health needs to be declining more...If the people on the MAiD line are saying I'm not sick enough... then what am I supposed to do?

Blair, a white 71-year-old from Quebec and common law partner of a patient denied MAiD in 2018, with a very rare blood disease and severe ADHD, echoed this denial due to not meeting the eligibility criteria.

They did establish that the palliative care hospitals wouldn't take him because... none would say he is terminal. If he was considered terminal, how soon would that diagnosis apply?

ii. Lack of decisional capacity

The majority of participants were assessed by a psychiatrist to determine their decisional capacity. Their reasons for denial were related to patients' perceived lack of decisional capacity and their assessment of competence. As Puck, a 69-year-old white man from Manitoba, said to underscore his mother's refusal in 2018:

You had to answer the questions on the spot, and if your dementia had progressed to the point where you could no longer respond, you would be denied. Even though we had the advanced care directive with us, it did not make a difference.

Also, some respondents expressed confusion about how the process for assessing competence was conducted by a psychiatrist before approving MAiD. Peter, a white 72-year old from Alberta whose wife was denied MAiD in 2018, shared his disbelief about his wife's assessment.

She was deemed to be mentally incompetent by the psychiatrist assessor... like an hour before, she read the application to the witnesses... read every clause and then signed it...later, the assessor said, she was no [longer] competent. She was more competent then, than I am right now.

iii. Belief-based care denial

Physicians' "conscientious objection" rooted in religious beliefs acted as a key barrier for patients to gain access to MAiD. This often prevented them from getting referrals to other providers. Further, institutional religious affiliation was raised by many participants who had distressing interactions with staff at these hospitals, often requiring a transfer to another facility, as showcased in the story of Beth's mother (Fig. 4).

Eighty-seven-year-old Ella, from Ontario, lamented that she wished she could change her respirologist, whom she had been seeing for years for her chronic lung condition. One day in 2016, she saw a sign on his desk that said something to the effect of: "Based on religious conviction, I don't support MAiD, so don't ask me for permission or involvement." Regrettably, Ella was unable to change her specialist due to a scarcity of such qualified professionals within the health care system.

Furthermore, respondents held the view that a physician's behavior to withhold referrals was seen as gatekeeping of integral health care. A few respondents opined that doctors or healthcare providers actively obstruct patients from obtaining the care they need and deserve, which they found unacceptable. Death and dying are integral parts of health care and these participants firmly believed that if providers find it challenging to set aside their religious beliefs, it's important and required to refer the individual to someone who can assist them.

iv. Mental health illness

Repeatedly, participants shared how they were denied MAiD based on the current legal exclusion of mental illness from the eligibility criteria, regardless of the patient's rational and autonomous choice to seek the procedure. Most participants expressed disappointment and anger at being denied due to federal restrictions on MAiD for MI-SUMC. Tony, a white 56-year-old man from Ontario denied in 2020, shared that he sought MAiD due to his incurable, treatment-resistant suffering. He has a long history of depression, diabetes, heart disease, and post-selective serotonin reuptake inhibitor (SSRI) sexual dysfunction.

I was extremely disappointed and angry to be denied, and it was evident that the decision-makers do not understand mental health. They lack awareness of the level of suffering that individuals experience. Their assumptions are misguided, and they clearly do not have enough knowledge about mental health, particularly regarding treatment-resistant, chronic, and ongoing mental health issues.

Anathema's story (Fig. 5) illustrates his mental breakdown struggles and difficult MAiD journey.

3.6 Consequences of being denied

Several consequences follow denial for MAiD; the denials made patients and their caregivers feel disempowered and took a harmful psychological toll on them. Participants described that the patients felt not just anger, frustration, betrayal, and humiliation, but also increased suffering and sometimes emotional shutdown. Most participants highlighted that anger was a very common emotion expressed after their denial. Peter, a 72-year-old white man from Alberta, shared about his wife's denial in 2018.

Oh! She was angry, oh, she was angry! Never seen her that mad in her whole life! I was pretty damn angry too. I still am. You know, like, it was none of [the doctor's] business. She was asked to help Betty with anxiety, which sure as hell didn't help, and the witnesses were just absolutely flabbergasted. This was just an hour after they were there; this woman had said she was mentally incompetent.

Likewise, their family members and caregivers were also angry and frustrated. All respondents mentioned that they experienced a long-lasting emotional burden from the denial. Maria, a 63-year-old white woman from Alberta, reflected on her husband's experience with MAiD denial in 2021 due to providers 'discomfort' after an initial approval.

I thought the guy was completely unhelpful, no compassion, no empathy. I don't believe he listened to what we were saying. Both of us felt angry, hurt, heartbroken, and frustrated. My husband was concerned, thinking, "If I am not approved for MAiD, how am I going to handle this myself?"... I'm still really angry.

Some participants turned to suicide after being repeatedly denied MAiD. Nina, a 30-year-old woman from Alberta, recounted the devastating experience of her 57-year-old mother's suicide following repeated MAiD denials (Fig. 6).

3.7 Suggestions to improve MAiD services

Participants shared that even though MAiD is legal in Canada, it is not readily available in practice. They called out for a clear policy and its implementation. Providers also need to fulfil their legal obligations and adhere to their professional codes of ethics, especially as there is a lack of willing health professionals who can administer MAiD. Capacity building and training for health professionals were highlighted.

In cases of conscientious or religious-based objections from institutions or providers, participants suggested that healthcare providers should be required to give referrals to others to provide the needed service. A 30-year-old white woman, Hailey from Alberta, shared about her father's MAiD denial experience in 2023.

The subtle hypocrisy of it all is quite striking. It feels controlling when it comes to people's bodies, particularly regarding MAiD. Allowing your clients to suffocate to death is incredibly dehumanizing and degrading, especially because of the provider's belief and fear of going to hell. This situation highlights the manipulation surrounding the act of affirming their beliefs. They should just refer clients to another person.

Due to a lack of understanding of mental health illnesses, several respondents mentioned the need to expand MAiD eligibility to include mental health conditions. Some participants also emphasized the need for the law to allow advance requests and disallow post-approval objections once MAiD is approved, and have a legal procedure to register the approved document so that MAiD wishes can be executed as per the clients plans. Seventy-six-year-old Tom from British Columbia made this suggestion after experiencing his wife's denial due to her lack of decisional capacity from dementia.

When MAiD is approved, a specific process must be followed to register those documents...Legal representation is crucial to ensure that plans are in place, preventing us from becoming trapped in an undesirable situation later.

Also, to address and assist with situations of trauma and suicidal ideation after experiencing MAiD denial, a few participants suggested the need for patients and their families to receive professional counselling, as well as support from groups such as bereavement and post-traumatic groups. As Nina, a 30-year-old white woman from Alberta, emphasized:

I believe it's nearly inevitable that if someone seeks MAiD and is turned down, they may resort to suicide instead. It's crucial to provide resources and support to prevent this from happening.

4. Discussion

Despite being a legal and regulated process designed to respect patient autonomy while safeguarding vulnerable individuals, MAiD remains a highly debated topic with unclear and inconsistent

implementation. Our qualitative study reveals that MAiD denial is shaped by factors beyond just medical eligibility. These factors include the complexity of cumulative illnesses, suffering from mental health conditions, systemic barriers in application and approval, and institutional as well as provider biases. Our participants or their family members were denied MAiD due to their perception of a narrow interpretations of the eligibility criteria, lack of decisional capacity, belief-based care denials, and MI-SUMC. As a result, denial was experienced as emotionally distressing, disempowering, and prolonging suffering.

A central finding was that participants described their suffering as cumulative from multiple chronic and degenerative illnesses, increasing the burden of their suffering. Many, including those denied before Bill C-7, reported a perception that the MAiD assessments did not adequately take into account the cumulative nature of their conditions and focused more on the foreseeability of death, overlooking their quality of life. The desire to relieve their suffering and to avoid further suffering was a strong motivation for seeking MAiD, as was the desire for autonomy over making their own decision about their life and dignity at the end of their lives. These motivations are consistent with findings from first year of MAiD legalization in Canada [13, 14]. Our study contributes to the understanding of this suffering, which has been reported among MAiD requestors despite receiving palliative care [15]. Assessors need to be critically reflective about the patient's suffering history and elicit these stories with a high degree of skill and ample time [16]. Quality improvement processes are essential for developing a patient-and family-centered MAiD program that is both accessible and respectful of dignity [7].

Our participants also described making a rational, thoughtful decision about seeking MAiD, but most also described loss of capacity as the reason they were given for the denial of MAiD. These narratives illustrate that decisions made to request MAiD are not irrational or impulsive. Evidence already shows that MAiD is unlikely to be driven by social or economic vulnerability [15]. Although practice standards have been made available, denial in our study was perceived by participants as rooted in interpretations of MAiD eligibility criteria that were perceived to be too strict around terminality and capacity to make decisions about end-of-life. This was evident in our participants' interpretation of their assessments as being subjective and dismissive.

This calls for a need to educate clinicians and connect them to guidance and training documents created to support them in their assessments [17]. These would prevent the eligibility criteria from being interpreted too broadly or narrowly and reduce the inequality created when MAiD assessors and providers interpret the law differently [18]. Moreover, these interviews suggest that advance requests need to be considered during policy development, so that legal pre-authorization for MAiD can prevent refusal in cases of compromised mental competence at a later stage. There may also be a need to increase awareness among patients and family members to make distinctions within eligibility criteria since misinformation about the nuances of MAiD eligibility is common among the public [19].

Refusal to provide MAiD care or referrals extends patients' suffering, highlighting the emotional and psychological consequences of denial. Participants reported feeling angry, helpless, and frustrated, and

families additionally reported long-term distress over not being able to access MAiD as the patients desired. The weight of these consequences suggests a need for support services following a denial, which was emphasized by participants when we asked how MAiD services could be improved. Crucially, this need for support services for families extends beyond cases of denial, as many families deal with the significant challenges in navigating the bereavement experience [20].

Another theme was the role of institutional and provider-level barriers, including belief-based care denials on the basis of religion or moral objection by hospitals based on institutional faith-based policies or individual providers who were unwilling to refer patients. Several participants also reported “passive refusals” as the MAiD application process lacked clear information or was slow. These refusals led to difficulty and inequities in access, particularly in remote communities where the choice of providers is limited. While Canadian law and professional policy permits physicians to refuse to provide MAiD based on their moral or religious beliefs, referral obligations vary by province, with only some jurisdictions like Ontario and Nova Scotia requiring an effective referral, that is a timely referral to a non-objecting, available, and accessible provider or agency [1, 21–23]. Although often described as “conscientious objection,” this practice has been critiqued as “belief-based denial of care” when providers refuse to provide or refer for a legal, patient-requested service within their scope of practice [22, 24–30]. Biomedical ethicists have called for the protection of patients from such denials, particularly in reproductive health care and MAiD [30]. To address this within the current legislative context, clearer referral processes, better patient navigation, and provider education about professional obligations, appear warranted.

Finally, the exclusion of MAiD MI-SUMC for eligibility is set to expire in March 2027. Although, the parliamentary committee began meeting in March 2026 and are due to submit their report on this exclusion in October 2026, there remains a possibility that this may be delayed further. Besides, the planned review is focused primarily on provincial readiness rather than revisiting the legislation itself. This evolving context adds further complexity to access for many patients, as they felt a lack of recognition for their psychiatric diagnosis and had feelings of invalidation when trying to apply for and access MAiD. Given the mentions of suicide as the alternative to MAiD when denied for MI-SUMC, these requests should be considered in the context of suicidality [31]. Our participants called for mental health conditions to be treated as legitimate grounds for MAiD, supported by clear and compassionate safeguards. Such patient and family lived experiences are crucial to guide MAiD MI-SUMC policy and practice. However, this remains challenging due to limited international precedent, as only a few countries have allowed MAiD, and even then, it is under highly restricted criteria. This study contributes to the growing literature on this complex issue. As Canada continues to lead the path in MAiD and its MAiD framework evolves, addressing MAiD MI-SUMC as an eligibility criterion will be particularly challenging, requiring careful policy development, clinical guidance, and ethical oversight.

4.1 Limitations

Our study was designed to interview self-selected individuals and their families who experienced MAiD denials; thus, we did not capture experiences of those who were unaware of MAiD as an option. Qualitative research, by nature, is intended to understand experiences and beliefs and not to provide generalizable or representative findings. The multi-modal recruitment employed in our study and inclusion of participants from five provinces gives us confidence that the themes are transferable, but we caution against using our findings to represent broader trends. This is particularly important for capturing provincial differences in MAiD policy implementation since provinces vary widely in their policies requiring referrals. Most of our participants identified as white, and all were Anglophone, including those from Quebec. Future research would benefit from the inclusion of people across ethnic groups and Francophone and other language-minority populations. Finally, future research should also explore providers' perspectives on the decision-making and denial of MAiD to give a more comprehensive view of the issues discussed here.

5. Conclusion

The findings reflect the complex interplay of cumulative health illnesses, systemic inconsistencies, provider and institutional values, and lack of support after denial. These findings call for a system that is clear and consistent across settings as well as more compassionate, providing psychosocial support to patients and their families.

Abbreviations

- ADHD
Attention—deficit/hyperactivity disorder
- AI
Artificial intelligence
- ALS
Amyotrophic lateral sclerosis
- ARCC
Abortion Rights Coalition of Canada
- CAD
Canadian dollar
- CAMAP
Canadian Association of MAiD Assessors and Providers
- COPD
Chronic obstructive pulmonary disease
- CPSO
College of Physicians and Surgeons of Ontario
- MAiD
Medical Assistance in Dying
- MI

SUMC—Mental illness as the sole underlying medical condition

- N

Total sample size

- n

Number of participants in a category

- PTSD

Post—traumatic stress disorder

- SSRI

Selective serotonin reuptake inhibitor

- USD

United States dollar

Declarations

Ethics approval and consent to participate

The University of Ottawa's Social Sciences and Humanities Research Ethics Board approved this study. All participants provided oral informed consent to participate in this study. We used pseudonyms that were either chosen by our participants or assigned by our study team, and removed or masked any personally identifying information to maintain participant confidentiality.

Consent for publication

Not Applicable

Competing interests

The authors declare no competing interests.

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Author Contribution

AD and AMF conceived the study and designed the protocol. AD carried out the data collection. LSM, ARK, HLAS, and MJP carried out the transcription of interviews. AD and OA synthesised the data and

wrote the first draft of the paper. AD, AMF, JA, HL critically revised the successive drafts of the paper. All authors approved the final version to be submitted.

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Data Availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declaration of Generative Ai and Ai-assisted Technologies in The Writing Process

During the preparation of this work, the authors used ChatGPT to assist with improving the readability and language of the manuscript. The use of this tool was limited to language refinement and all content, analysis, and interpretations remain the sole responsibility of the authors. After utilizing this tool, the authors carefully reviewed and edited the content as needed and take full responsibility for the accuracy, integrity, and originality of the published article.

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Figures

Puck's mother lived to age 87, and died from complications related to severe dementia. Throughout her life, she had lived multiple health challenges, including arthritis, experienced an accident that left her reliant on a leg brace, and had recurrent urinary tract infections and dehydration associated with her dementia.

As her dementia progressed, she moved into a transitional care home. Her general health remained unstable from a back surgery, and her cognitive decline became increasingly severe. When the family raised the topic of MAiD, she expressed agreement, viewing it as a dignified end of life option.

Puck and his wife felt that her suffering, compounded by advancing dementia, warranted a more compassionate approach to end life care. For them, MAiD represented a way to prevent prolonged distress and loss of dignity.

Figure 1

Puck's story of his mother

Over the years Dave's mother endured multiple health concerns, including heart disease, respiratory complications from previous tuberculosis, bowel cancer, vasculitis, and progressive hearing and vision loss. Despite these conditions, she was remained resilient. As her health deteriorated, she became increasingly exasperated and fatigued. For her, MAiD represented a way to end her suffering with dignity.

Dave first attempted to help her access MAiD in Switzerland, but logistical barriers made this impossible. They then pursued MAiD in Canada, with support from Dying With Dignity Canada. The initial evaluation with a cardiologist ended in refusal. In Dave's view, the physician was inexperienced with MAiD assessments and adhered rigidly to eligibility criteria, unwilling to take ethical or legal risks. A second evaluation with a respirologist was, in his opinion, dismissive, shaped by preconceived notions and prejudgments about MAiD.

Frustrated but determined, Dave and his family continued working with Dying With Dignity Canada's physician network. After several meetings, they connected Dave and his mother with a physician in Montreal who agreed to provide the procedure in November 2018.

Figure 2

Dave's mother's story

When Samantha first reached out to the MAiD referral line, the process felt both bureaucratic and impersonal to her. The intake began with requests for her health card number, personal details, and the names and clinic addresses of her family doctor, specialists, and psychiatrist.

The coordinators explained that her providers would be contacted to verify her diagnoses. She was also asked where she would prefer to die—at home or in a hospital—since location influences eligibility. Strangely for Samantha, despite living in a large Ontario city, her location was flagged as a barrier.

For Samantha, the follow-up calls felt narrowly focused on her physical health conditions. When she tried to disclose her mental health history, the coordinator bluntly dismissed it, stating that mental illness could not currently legally justify MAiD in Canada. Instead, they proceeded to ask for details about her chronic pain and gastrointestinal diagnoses, including the names and addresses of the physicians involved.

Another barrier quickly emerged: a direct referral from her family doctor was required. Knowing her physician's strong pro-life stance, she realized this would be a significant barrier. Attempting to bypass her family doctor left her feeling stuck, underscoring how systemic rules and personal beliefs can be a barrier in access to MAiD, even when the choice is meant to be hers.

Figure 3

Samantha's story

Beth's mother, a 92-year-old white schoolteacher living in a small village in British Columbia was diagnosed with arthritis and aortic stenosis. Her cardiologist issued her a pacemaker after she had episodes of fainting and falls. Her family doctor later prescribed an intensive diuretic regimen. Eventually, she had fluids accumulating in her lungs, and to Beth it felt like her mother was near the end. She had lived in an assisted living care home since her diagnosis, and they could not do much to help her when her situation got worse. She was taken to the hospital to get the fluid in her lungs drained.

Before going to the hospital, she and her children had discussed and agreed on pursuing MAiD. In 2018, her son helped with the application process and a physician at the hospital confirmed her eligibility. Although she could have undergone the procedure at the hospital, the MAiD doctor recommended a 10-day waiting period to order the necessary products for the procedure. Beth's mother did not like the hospital setting. She expressed her desire not to stay in a specific room at the hospital during the waiting period and requested to be moved to a hospice.

The MAiD doctor informed her children that she could not undergo the procedure at the hospice because it is a faith-based facility. He suggested that she either remain in the hospital or return home. But Beth's mother was adamant about staying at the hospice while she waited.

The MAiD doctor came to reassess her condition, and her mind was sharp and clear, confirming that she still qualified for the procedure. She needed to be transferred back to the hospital or home for MAiD; however, the doctor at the hospice warned that she could die during transportation.

At this time, she was experiencing considerable pain, but the staff kept insisting that she was in God's hands. They sedated her for comfort, as she became very frustrated and agitated when she awoke. Beth felt that the medication only prolonged her dying process by keeping her asleep. Eventually, she died in the hospice setting.

Figure 4

Beth's mother's story

Anathema is a 60-year-old gay French Canadian from Quebec who lives in Vancouver was denied MAiD in 2022. He described living with mental health disorders, including antisocial personality disorder and borderline personality disorder. He reported a major mental health breakdown and said he had very little social support and no income.

He was paired with a therapist from the Friendly Call program of the Red Cross, who reached out to him by phone. However, after three sessions, the program ended. He also connected with a peer navigator at the Canadian Mental Health Association. However, this was also temporary. He applied for income assistance because of his disability but was turned down. He described a broad pattern of social exclusion due to his sexual orientation, including rejection from community groups and organizations he had tried to join.

Anathema attempted suicide several times. On one occasion, he slashed his wrist and ended up in the intensive care unit of a Catholic hospital. After that, he went for suicide follow-up and education and met with a counselor who helped him a great deal.

Later, he decided on MAiD and applied for the procedure. He filed his application via email and attached his medical file. He got an email back that his MAiD request was denied because his mental health conditions did not meet eligibility under the law. Anathema expressed significant anger and did not feel he received any compassion. He believes the system lacks resources and finds it difficult to be listened to and heard. He suggested that access to MAiD could be improved by incorporating better measures for sexual orientation and increasing the accessibility of basic support services. He also stated that removing the influence of religion would help improve access to MAiD.

Figure 5

Anathema's story

Nina's mother lived for many years with alcoholism, depression, and anxiety. In 2022, a work-related injury left her with chronic pain and the devastating realization that she could no longer continue her career as a health care aide—a role that had given her purpose and identity. She told Nina, *"They said, even if you have a shoulder replacement, you're not going to be able to work as a health care aide anymore."* This loss deeply affected her mental health.

Beginning in October 2022, she applied for MAiD multiple times. Each application was denied, primarily because her request was rooted in mental health concerns, which were not recognized as valid grounds for MAiD approval. With every rejection, her mental state deteriorated further. In February 2023, after repeated denials and feeling she had no other options, Nina's mother died by suicide.

Her death shattered Nina and her sister. Nina believes MAiD could have offered her mother a more peaceful passing compared to the trauma of suicide. Her story underscores the urgent need for stronger mental health supports and follow-up care for individuals denied MAiD, to prevent people from being left with no support or compassionate pathways for care in crisis.

Figure 6

Nina's mother's story

Supplementary Files

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