

Perspectives of Canadian health leaders on the relationship between medical assistance in dying and palliative and end-of-life care services: a qualitative study

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Abstract

Background: Medical assistance in dying (MAiD) was legalized in Canada in 2016, but coordination of MAiD and palliative and end-of-life care (PEOLC) services remains underdeveloped. We sought to understand the perspectives of health leaders across Canada on the relationship between MAiD and PEOLC services and to identify opportunities for improved coordination.

Methods: In this qualitative study, we purposively sampled health leaders across Canada with expertise in MAiD, PEOLC, or both. We conducted semi-structured interviews between April 2021 and January 2022. Interview transcripts were coded independently

by 2 researchers and reconciled to identify key themes using content analysis. We applied the PATH framework for Integrated Health Services to guide data collection and analysis.

Results: We conducted 36 interviews. Participants expressed diverse views about the optimal relationship between MAiD and PEOLC, and the desirability of integration, separation, or coordination of these services. We identified 11 themes to improve the relationship between the services across 4 PATH levels: client-centred services (e.g., educate public); health operations (e.g., cultivate compassionate and proactive leadership); health

systems (e.g., conduct broad and inclusive consultation and planning); and intersectoral initiatives (e.g., provide standard practice guidelines across health care systems).

Interpretation: Health leaders recognized that cooperation between MAiD and PEOLC services is required for appropriate referrals, care coordination, and patient care. They identified the need for public and provider education, standardized practice guidelines, relationship-building, and leadership. Our findings have implications for MAiD and PEOLC policy development and clinical practice in Canada and other jurisdictions.

The relationship between the practice of medical assistance in dying (MAiD) and palliative and end-of-life care (PEOLC) in jurisdictions where both are available has been variable and sometimes tenuous.¹ Although many PEOLC services and physicians in Canada are engaged in MAiD,^{2,3} national palliative care societies in Canada and elsewhere have not endorsed this practice.³⁻⁸ Meanwhile, demand for both MAiD and PEOLC has grown in Canada in recent years.⁴⁻⁶

Adults in Canada with a grievous and irremediable medical condition and a “reasonably foreseeable death” have been able to legally pursue MAiD since 2016.⁷ Eligibility for MAiD was extended in March 2021 to include people without a fatal or terminal condition.⁸ A further extension was planned for

March 2024, to allow MAiD to be available to people whose sole underlying condition is mental illness.^{9,10}

From 2016 to 2022, 44 958 people in Canada chose to end their lives through MAiD.¹⁰ In 2022, MAiD accounted for 4.1% of all deaths in Canada.¹⁰ The frequency of MAiD in Canada has increased by 20%–30% annually since its introduction.^{6,10-12} This practice is expected to grow as eligibility for MAiD has broadened to include people whose death is not “reasonably foreseeable.”^{8,13} Although a framework and action plan for PEOLC in Canada has been developed,^{14,15} the introduction and growth of MAiD in Canada has occurred without clear policies or guidelines in relation to its concurrent delivery with PEOLC.^{16,17} Further, there has been a lack of consensus on how MAiD and PEOLC services

should relate to each other in practice.¹⁸ This policy gap has posed challenges for the collaborative planning of both services to ensure optimal delivery.^{19–28}

Our aim was to understand the perspectives of health leaders in Canada with expertise in MAiD, PEOLC, or both on the relationship between MAiD and PEOLC services and to identify opportunities for improved coordination. Whereas previous research has focused on the perspectives of patients and caregivers,^{29–31} we focused on health leaders who have roles in developing and modifying policies about MAiD or PEOLC.

Methods

Study design and setting

We have published the protocol for this qualitative study elsewhere.³² We conducted interviews with health leaders across Canada with expertise in MAiD, PEOLC, or both and who have been involved in developing policy or modifying practice. Our study has fulfilled the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Appendix 1, Section 1, available at www.cmaj.ca/lookup/doi/10.1503/cmaj.231241/tab-related-content). To protect participant confidentiality, we did not report potentially identifying information.

The research team consisted of people from diverse career stages (trainees, early, mid-, and senior career), ethnicities (self-identifying as White, Asian, and other), gender (female and male), and place of birth (Canada, China, and Scotland). All team members lived in Toronto, Canada, during the completion of this research, and were living in Canada when MAiD was introduced. The research team was multidisciplinary, with expertise in health policy, health services, bioethics, psychiatry, palliative care, and clinical and health psychology. The research team also included PEOLC-only providers as well as PEOLC and MAiD providers, and held diverse views on the optimal relationship between PEOLC and MAiD.

Reflexive practices that maximized the rigour of our findings included the publication of the research protocol before data collection, refinement of the interview guide by team members, having 2 coders of data, an open discussion of themes, and reflection on the team's positionality during team meetings. We identified potential participants through recommendations from team members, based on their large national professional network, and through snowball sampling.

Study framework

We chose the Integrated Health Services (PATH) framework³³ to guide our analysis, because of its focus on understanding multiple levels of the potential integration of health services and its demonstrated ability (through use in case studies) to guide recommendations for services.^{34–37} This framework was valuable in examining the relationship between MAiD and PEOLC services and in understanding considerations for coordinating these services on 4 levels: client-centred services (we used “client-centred” rather than “patient-centred” because this is the terminology of the PATH framework), health operations, health systems, and intersectional initiatives. The PATH framework guided the development of questions included in the interview guide and data analysis.

Participant sampling and recruitment

We purposively sampled 19 participants to optimize representation of leaders with knowledge and expertise in MAiD, PEOLC, or both, as well as experience developing and modifying MAiD or PEOLC policy or managing large PEOLC teams. We employed snowball sampling to recruit 17 additional participants (Appendix 1, Section 2). We sent prospective participants an email invitation to participate in the study.

Data collection

We conducted semistructured interviews from April 2021 to January 2022, and collected sociodemographic characteristics of the interviewees. The development of the interview guide is described in the protocol (Appendix 1, Section 3).³² We conducted and audiorecorded interviews using a videoconferencing online platform. We used respondent validation during the interviews and checked emerging themes with interviewed participants to ensure the accuracy, validity, and generalizability of the findings.

Data analysis

We transcribed interviews verbatim using an online machine transcription service (Temi.com). An independent rater (E.T.) verified and deidentified transcripts before adding them to NVivo 12 for qualitative data analysis (NVivo, QSR International, version 12).

We analyzed data using conventional content analysis methodology.³⁸ Two authors (G.K.S., E.T.) conducted the initial open coding independently. After analyzing 10 transcripts, we compared and categorized codes and developed them into an initial coding scheme. We applied these codes to new transcripts and revised accordingly. We added further categories to reflect nuances and novel issues in the data. We used systematic comparative analysis to identify differences and similarities among participant accounts. Iterative analysis continued until data saturation was reached. To minimize bias, 2 research team members (R.N. and G.R.) reviewed codes and themes. We discussed codes until there was consensus.³² Similar to Jarvis and colleagues,³⁹ we used an inductive approach to examine participant experiences and attitudes regarding MAiD and PEOLC to develop the coding framework, and subsequently a deductive approach to examine themes using the PATH framework. We include quotes, even for single words, in the interpretation to emphasize how themes are grounded in participants' own words.

Ethics approval

The study was approved by the University Health Network Research Ethics Board (No. 19-5518).

Results

Participant characteristics

We conducted 36 interviews. Most participants self-identified as White (83%), female (72%), and nonreligious, agnostic, or atheist (53%) (Table 1). Central Canada was most represented, with a substantial minority (31%) of participants, and 2 were from Quebec (6%). Most participants had a health professional role (64%),

Table 1 (part 1 of 2): Demographics of study participants

Characteristics	No. (%) of participants n = 36
Age, yr	
20–29	2 (6)
30–39	2 (6)
40–49	7 (19)
50–59	13 (36)
60–69	8 (22)
70–79	1 (3)
Prefer not to answer	3 (8)
Gender	
Female	26 (72)
Male	9 (25)
Gender fluid	1 (3)
Ethnicity	
White	30 (83)
Indian or South Asian	2 (5.5)
First Nations	2 (5.5)
East Asian	1 (3)
Prefer not to answer	1 (3)
Religion	
None, agnostic, or atheist	19 (53)
Christian	10 (28)
Jewish	3 (8)
Islamic	1 (3)
Spiritual	1 (3)
Prefer not to answer	2 (5)
Region	
Central Canada*	11 (31)
National	10 (28)
Western Canada	6 (17)
Atlantic Canada	5 (14)
Territories	2 (5)
Prairies	2 (5)

in addition to roles in other sectors. Leadership roles included medical and nursing division heads, program directors and managers, presidents or CEOs of nongovernmental societies or associations, lead government policy analysts, scientists with expert specialization in MAiD or PEOLC or both, and chairs of advisory committees.

Most participants (64%) were supportive of the legalization of MAiD. Those who were against, or neutral, generally accepted people's right to make their own decisions. Interviews lasted on average 56 minutes.

Table 1 (part 2 of 2): Demographics of study participants

Characteristics	No. (%) of participants n = 36
Years of professional experience	
2–5	1 (3)
6–10	4 (11)
11–15	3 (8)
16–20	6 (17)
21–30	15 (42)
31–40	5 (14)
≥ 41	1 (3)
No answer	1 (3)
Sector (leadership role)†	
Health professional	23 (64)
Administrative	20 (55)
Academia	18 (50)
Not-for-profit	17 (47)
Government	8 (22)

*Two participants (6%) were from Quebec.
†Some participants indicated holding multiple roles across sectors.

The optimal relationship between MAiD and PEOLC

Participants noted that MAiD remains a relatively new practice in Canada and that more time is needed to adjust its relationship with PEOLC and other health services. They reported that there has been “improvement” and “better communication” in the relationship between practitioners of these services over time: “Initially it really felt like 2 separate worlds, and that was a bit of a challenge and barrier to good patient care in some ways, but that’s getting much, much better. There is better communication for sure.”

Participants expressed diverse views about the optimal relationship between MAiD and PEOLC (Table 2). Nevertheless, there was an overall recognition that some degree of cooperation is required for appropriate service referrals, care coordination, and prioritizing patient care.

Some felt that MAiD and PEOLC had distinct and often incommensurable goals and suggested that they should be separate services. They expressed concern that integrating the services could cause patients to be confused about the respective roles of these services. Some suggested that the burden of clinical care at many centres limited the capacity of PEOLC providers to dedicate time and effort to formally coordinating or integrating MAiD and PEOLC services.

In contrast, other participants believed that MAiD and PEOLC should be fully integrated and described MAiD as an “extension” or “continuity” of PEOLC. They emphasized that PEOLC is a shared goal of both services, and some suggested that the ideal integration would be individual clinicians providing both services.

Table 2: Optimal relationship between medical assistance in dying and palliative and end-of-life care

Optimal relationship*	Illustrative quote
Separated	<p>“They should be made separate because I believe that there are different indicators, nuances that are followed once you go down either of those paths.”</p> <p>“It’s not something that we wish to have tacked on to palliative care, because we feel that the 2 are completely separate. The goal and mission of palliative care is not MAiD.”</p> <p>“That’s where I see keeping these 2 things separate is important, because it allows for the continuation of the type of dying that we’ve done for the rest of humanity’s existence [...] The reason they need to remain separate right now is there’s too much confusion.”</p>
Integrated	<p>“My personal view is that I would like it if there were more palliative care physicians providing MAiD and that it was more of an integrated [model]. I see it as an extension of palliative care, not a stand-alone. Having said that, I certainly don’t see it as a replacement for palliative care. I really see MAiD as a mode of death on your final day of life, not a continuum of care per se [...] I see it as an addition to palliative care, but not, as I said, a replacement for it. I do hope that there will be more crossover going forward.”</p> <p>“Because we’re a small community, and family physicians kind of do everything here, the same people that were showing up to do MAiD are the same people that are providing palliative care. So there’s no specific palliative care group to consult. We’re all providing palliative care within our practices. And certainly, I would say we probably have a fairly large overlap between people who are interested in palliative care and people who are interested in providing MAiD, because I think we just see it as an extension or a continuity of service or just one of the things that’s available within the service.”</p> <p>“For some people, it works profoundly well because they do both. You’ve got people like Colleague A and Colleague B and they’re palliative care providers who do MAiD. It’s glorious because that’s where the person’s getting the full menu and they’re getting what they want.”</p>
Coordinated	<p>“I don’t know that they need to be integrated. I just think they need to be on the table — how do we make sure that everybody’s talking about all the options along the way and making sure that people are having the ability to make the best choice for them regardless of where they physically are, or what treatment they’re physically undergoing?”</p> <p>“There’s a lot of similarity, and I think as long as there’s collaboration and an open relationship, like a collaborative relationship, I don’t necessarily think they need to be merged together or coordinated differently. I just feel like for MAiD, we need to see palliative care [providers] as a key stakeholder, and for palliative care, we need to see MAiD providers as a key stakeholder, and keep that open and look at ways or other ways that we can be more collaborative.”</p> <p>“It has to be coordinated in as much as we have to know what each other is bringing to the service of this patient. So, yeah, separate but coordinated, or distinct but collaborative, I think is kind of a bit of a universal model for any — multiple providers coming around a person and their family. Right? Whether you’re talking about providing a surgery and a medical consultation, or MAiD and a palliative consultation or whatever: that mantra has served health care well.”</p> <p>“I think that there have been some pretty powerful, influential voices that have been able to speak to how palliative care and MAiD can work together. And they don’t have to be 2 separate things or 2 separate options. They can be part of a continuum, and people who access MAiD can also access palliative care and probably should be accessing palliative care if they are eligible for MAiD; it’s likely that palliative care would also be helpful for them from a social, psychological, emotional and of course, pain management point of view.”</p>

**Separated care* involves no established arrangement for palliative and end-of-life care (PEOLC) and medical assistance in dying (MAiD) professionals to come together. *Integrated care* represents the highest degree of collaboration and communication among PEOLC and MAiD professionals. PEOLC professionals who practise integrated care work alongside MAiD professional colleagues and team members in hospitals, primary care settings, and other specialty health care practices. Providers may be both PEOLC and MAiD professionals. *Coordinated care* involves an arrangement where PEOLC and MAiD providers come together voluntarily and share the responsibility for providing care. These are distinct services, and provider involvement is coordinated through referrals and consultation.

Some participants advocated for these services to be coordinated, as this would be the best approach to allow teams to support their shared patients, prioritize patient care, respect patients’ wishes, facilitate open communication, and improve service access. Participants also acknowledged that some patients who are eligible for MAiD would not necessarily require PEOLC, particularly with anticipated changes to the legislation regarding MAiD and mental illness.

Enhancing relationships between MAiD and PEOLC services

Participants described ways to enhance relationships between MAiD and PEOLC, which we have organized into themes across

the 4 PATH Framework levels (Figure 1): client-centred services (1), health operations (5), health systems (4), and intersectoral initiatives (1). Representative quotes for each theme are included in Table 3.

Client-centred services

Educate patients and public

Participants advocated for greater education for patients and the public about MAiD and PEOLC (e.g., roles and boundaries of each service). This was recognized as challenging, given what participants viewed as a “death-denying culture,” in which open discussions about death and dying are associated with stigma or discomfort.

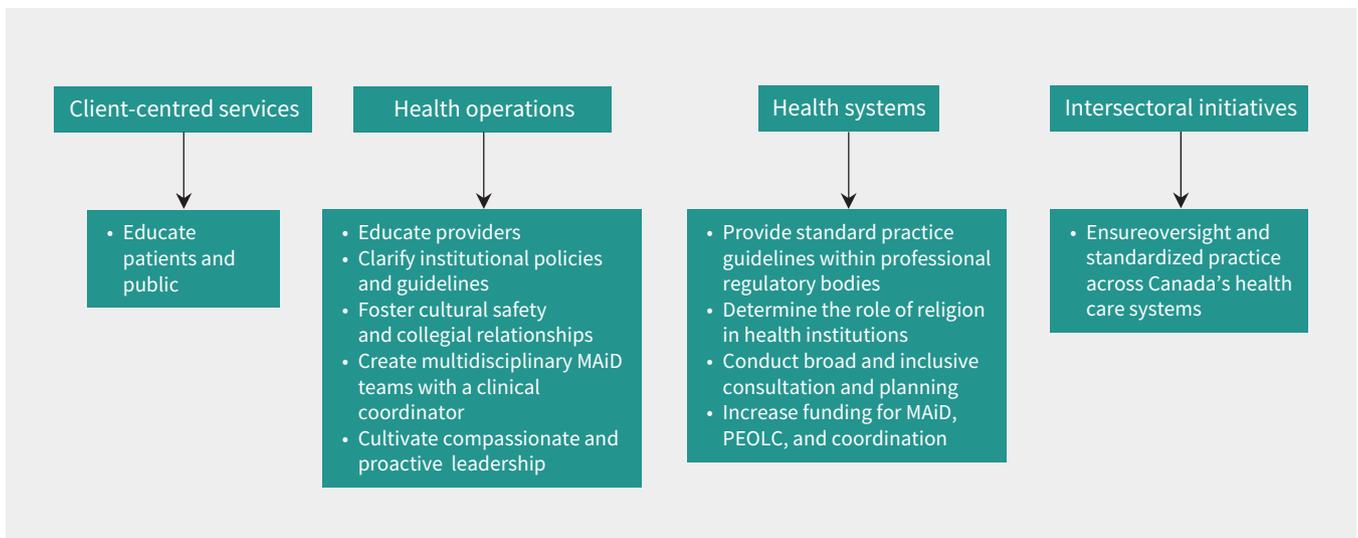


Figure 1: Overview of themes, by PATH level. Note: PATH's framework describes the relationship of services on 4 levels: a) client-centred services, focusing on clients, families, and the broader community; b) health operations, focusing on the planning and delivery of services; c) health systems, focusing on coordination at the regional, provincial, and national level, which includes broader governance and capacity issues; and d) intersectoral initiatives, including intersection with more than 1 system. Note: MAiD = medical assistance in dying, PEOLC = palliative and end-of-life care.

Health operations

Educate providers

Participants described the importance of educating and training MAiD and PEOLC providers about both services, to help shift any “barriers” or “misunderstandings on both sides.” They suggested that this would better equip providers with the “skills and tools” to have informed and comprehensive discussions on PEOLC with their patients.

Clarify institutional policies and guidelines

Some participants expressed frustration with the lack of clarity about policy or guidelines regarding the relationship of MAiD and PEOLC services. Some indicated the need for clearer institutional policies, particularly regarding access and effective referral. In the absence of clear guidelines, participants described the potential for some providers to “project” their personal beliefs onto patients by refusing to refer patients, ultimately creating “barriers” and “doing harm” to patients.

Foster cultural safety and collegial relationships

The importance of “mutual respect” and clear “communication” between MAiD and PEOLC teams resonated with many participants. They acknowledged the overall emotionally challenging nature of PEOLC, the “controversial” relationship between MAiD and PEOLC, and the resultant “tension,” “trepidation,” and “uncertainty.”

Participants emphasized the need to support the “autonomy of the provider,” the “choice to opt out,” and the experiences of “uncertainty” and “moral distress,” particularly in those who conscientiously object to MAiD. However, some noted that a minimum professional requirement should be to “put their patient’s need first” and to “refer” or “transfer” patients to MAiD, regardless of personal beliefs.

Those involved in MAiD described the “difficult” and “isolating” nature of MAiD work. Some disclosed feeling “not valued,” like a “target,” and “in the firing line,” and described “disrespectful” and “painful” experiences from some colleagues for being a MAiD assessor or provider. Considering this, participants noted the importance of fostering “cultural safety” and described feeling “lucky” when there was a respectful relationship between teams within their organizations. They expressed that the opportunity to be “in the same room” and to have “open,” “two-way dialogue” allowed both teams to acknowledge their shared value of patient-centred care. When present, collegial relationships were described as helpful in facilitating referrals and coordinating treatment for patients. Greater contact and trust between MAiD and PEOLC providers and teams was reported to facilitate increased communication and collaboration, alleviate fears, and “demystify” misunderstandings.

Create multidisciplinary MAiD teams with a clinical coordinator

Participants emphasized that having a dedicated multidisciplinary MAiD team was helpful in facilitating a comprehensive understanding of patients’ needs, streamlining MAiD service delivery, and coordinating efficient referrals between related services. Participants described the importance of having a clinical coordinator to act as the “point of contact” for patients and health care providers, and to direct patients to the service that matches their needs. Having a single MAiD team was also described as important for enhancing “peer support” and developing a “community of practice.”

Cultivate compassionate and proactive leadership

Participants acknowledged the role of “significant,” “proactive,” and “influential” leaders in setting the tone for the relationship between MAiD and PEOLC. Some believed that leaders who conveyed strong opposition to the views of others or did not provide

Table 3 (part 1 of 5): Themes and selected quotes by PATH framework level

Level*	Theme	Illustrative quote
A. Client-centred services	Educate patients and public	<p>“We’re still a very death-denying culture and people just don’t know very much about MAiD or palliative care. And so there really could be better education for the general public on both.”</p> <p>“How can someone know what they want when they don’t even know what’s available to them, or what it is? So a public education piece is important as well — what are my options?”</p>
B. Health operations	Educate providers	<p>“I think training and education is essential [...] There needs to be training of all providers. I don’t think it’s the MAiD providers. I think it’s all health care providers need to understand exactly what hospice palliative care can do. By the time it gets to the MAiD provider, I think it’s probably often too late.”</p> <p>“I do think that physicians would benefit from some sort of discussion guide or some supports on how to address the issue. If it comes up, if there is a situation where they do feel like it might be an option, how to raise that. So I think there needs to be some support around that. So it’s not just leaving physicians on their own to have those conversations. I think if they feel supported by their colleges, their institutions, we might be at a better place for that.”</p> <p>“I think there’s misunderstandings on both sides. There’s misunderstandings about MAiD, there’s misunderstandings about palliative care. I think for a lot of clinicians not involved with MAiD, they don’t really understand — not only like the medical and the legal side of things, um, in terms of like eligibility and safeguards and what an actual assessment looks like. I think some people think that it’s just a decision a clinician comes to easily, which is not the case.”</p>
	Clarify institutional policies and guidelines	<p>“It’s the consistency. It’s actually developing policies and mandating how palliative care works in conjunction with MAiD. I’m assuming from looking from the ground level that there isn’t a lot mandated there in terms of how those 2 pieces are supposed to interact together. So I think actually establishing some policies around that and then making sure that the patient and their families and organizations like us are aware of what those policies are.”</p> <p>“There are obvious examples where an institution’s policies to preclude the assessment or someone’s — even the determination of eligibility, makes it extremely difficult for that person and their caregivers, their families and the professional care team around them. And there have been discussions, there have been policies and so forth and institutional policies and otherwise, regional health authorities and so forth that can get in the way of people, I think even, even determining their own eligibility for such a service, so what can be done to stretch that a little bit further and to make sure that everyone’s needs are addressed?”</p> <p>“Where it’s very important to have different regions and different agencies and even different providers within those agencies have autonomy, there needs to be some standardization. [...] If somebody has their own personal belief system and their own barriers to accessing MAiD, which is totally understandable and totally respectable, but there should be, in my opinion, a standardized insistence, a legal requirement that their job is then to hand off to somebody else who can handle it [...] and I think there needs to be some legal enforcement around people who create barriers.”</p>

“explicit communication” created barriers for collaboration. Some described that having “open-minded” and “compassionate” leaders who were “committed” to “respecting” all views helped to ensure that “the whole system can function overall together.”

Health systems

Provide standard practice guidelines within professional regulatory bodies

Participants described a need for greater “clarity” of boundaries, standards, and regulation within their professional regulatory bodies regarding the relationship between MAiD and PEOLC services, while maintaining “flexibility.” They also noted tension between the importance of “a policy of noncompulsion” (i.e.,

not requiring any physician to be involved in the delivery of MAiD) for providers while ensuring availability of MAiD to patients through physicians making an effective referral.

Determine the role of religion in health institutions

Participants acknowledged the “complex” and “polarizing” relationship between MAiD and PEOLC, particularly in institutions influenced by religion (e.g., in funding, history, or governance). They were divided on whether faith-based, publicly funded institutions should be exempted from providing MAiD. Some expressed concern about the religious institutional barriers for patients who consider MAiD and regarded the requirement to transfer patients who seek MAiD out of religious institutions as “disgusting,” “cruel,” and “unnecessary.”

Table 3 (part 2 of 5): Themes and selected quotes by PATH framework level

Level*	Theme	Illustrative quote
B. Health operations (cont'd)	Foster cultural safety and collegial relationships	<p>“I really think the first step is getting people in the same room. I really do. I think if you put the palliative care teams and the MAiD docs in the same room and just have a respectful conversation, that is the first step everywhere, because there’s so much in common. So, so, so, so much in common.”</p> <p>“I think we have quite a good relationship with our palliative care teams in Province X. I think partially, I mean, at least in the City X area, like I used to work there, so I know all of them and they know that I’m not like a crazy person just wanting people to have MAiD, like they know that I understand what palliative care is, because I feel like that was some of the fear that people would just be getting MAiD left, right, and centre. But I think it helps for them to know that I understand and value palliative care and integrate that into part of the care coordination [...] So if we saw patients who we thought might benefit from palliative care and sent them a referral, they’re like, wow, this is great — like this is how it should be working. And so that’s improved our communication. I’ll often call the palliative team to give them an update. They call me all the time to give me updates.”</p> <p>“I think that that trust is important because if you’re a palliative care clinician and your patient wants MAiD and you don’t know who’s on the other end of the line, or who’s over there coordinating this, or who’s involved, there’s just a lot of fear that people will get the wrong information, or that they’ll somehow be coerced, or that people won’t think to refer someone to palliative care when they should have, or those kinds of things. Once you know people and you realize that they’re compassionate and they’re caring and they’re really just trying to meet the need of the person who’s asked for this service, I feel like that fear goes away.”</p>
	Create multidisciplinary MAiD teams with a clinical coordinator	<p>“Having a palliative care person embedded right within the MAiD team, I think would be helpful. And having that would be somebody who could have that big picture perspective on, are we doing all we can to alleviate people’s suffering? Are there pieces or gaps that we could be addressing in terms of services that might help alleviate suffering? And I know most of the patients I talk to who’ve requested MAiD don’t know about palliative sedation as an option. And so I always introduce that as an option. [...] So again, you’d have that palliative care expertise right within the MAiD team that could serve a bunch of different purposes.”</p> <p>“One singular team, I think that would be good from a couple of perspectives. I think it would be good for consistency in terms of service delivery, but I also think that it would be good for support within that team because I’ve had the opportunity to connect individually with some of the doctors and their team members who go out and perform MAiD. And it’s a beautiful service that they provide, but I’m sure it weighs on them and I’m sure it’s difficult in its own way. And so having their own team member who consistently does this, and that would allow them to develop their own internal supports and have peer support as well. So I think that that would benefit everybody.”</p> <p>“I think the multidisciplinary team works well because hopefully they get expertise, and they have multiple perspectives in terms of disciplinary affiliations.”</p>
	Cultivate compassionate and proactive leadership	<p>“There’s the right combination of the right people at the right time who started this journey in 2016, all of the health authorities, the provincial government, everybody, the nondenominational — everybody wanted to be a part of that MAiD conversation, if not for ‘how do we do MAiD in the right way,’ for ‘how do we make sure that the whole system can function overall together?’ And there was a good ingredient mix of the people in the leadership [...] just having a system and leadership committed to making this a continuum experience was really critical.”</p> <p>“There may have been room for more explicit communication around what the plans were [...] and more effort could have been made to engage us directly and let us know that our concerns would be addressed.”</p> <p>“They weren’t necessarily leaders with portfolio, but they were recognized leaders and who had done this kind of work before, around other contentious issues. So folks who are highly principled and always maintain that compassionate focus were able to create this policy and procedure. Other stuff was built in. So yeah, it’s a multidisciplinary team that you know works and then they — what was the other one you said, but they weren’t the important — they were consequences of them, of the leadership and compassionate culture.”</p> <p>“I was impressed at our department. [...] They were pretty proactive about saying, ‘we have no idea how many people, if any, are actually going to request this, but we will make it available.’”</p>

Table 3 (part 3 of 5): Themes and selected quotes by PATH framework level

Level*	Theme	Illustrative quote
C. Health systems	Provide standard practice guidelines within professional regulatory bodies	<p>“What works well, I think is, for every group, whether it be a unit or a service or whatever, to have an open conversation about how they feel about MAiD and to agree that they need to prioritize patients. And so they as a group have a responsibility to ensure that MAiD is available in a seamless way. Not every individual has a responsibility. And I think that’s a really important shift and that’s how they approached it in [province]. And I think it’s why it’s worked so well is, the profession feels that it as a profession has an obligation with respect to MAiD, but no individual physician does.”</p> <p>“Policy wise, I think governments need to maintain a policy of noncompulsion. They don’t make us do it, protect the conscience rights — but even there, with conscience rights policy, I think they’ve taken a good step in saying that yes, every doctor has a right to refuse to participate. However, that right is limited by your obligation to tell your patient where to go, to get the information.”</p> <p>“It’s very challenging to develop policy of such a personal nature when every story is different. So you need to have standards, criteria, procedural safeguards, or standards within the practitioner regulatory stream around delivery. But there should be a recognition that not everyone is the same in terms of how they can tolerate suffering. And so there needs to be a recognition that there has to be some flexibility as well.”</p>
	Determine the role of religion in health institutions	<p>“I think just the philosophy sort of behind the 2 is one of the biggest challenges that whether they can coexist in the same facility. Teaching hospitals that are not sort of religiously based may be able to embrace both services, if we can couch it in those terms, more freely than others that have a religious affiliation, or have had in the past, and sort of carry on that philosophy or approach to providing services. So some places have divested or diverged in terms of where and how those services would be provided; others are under the same sort of umbrella or roof, either physically or philosophically.”</p> <p>“I think there’s a lot of great palliative care programs that are housed in religious-affiliated health care facilities. And then people are stuck with, well, I want palliative care, I need palliative care, but I also might want MAiD, so what do I do? Do I like not go to this institution because I know that when it’s time for me to have MAiD, I’m going to be moved around or I’m going to be denied access, or it’s going to be too difficult for me to go through the process? I’m afraid to bring it up because I don’t know what the reaction will be. Will I be treated differently if I talk about MAiD in a facility that I know doesn’t allow it on site? So I think that’s an issue that ties into the institutional barrier piece.”</p> <p>“I think it should be a matter of choice for the hospice palliative care. If they feel that they don’t have the supports in place to support that, it should be their choice. I think that they have to refer, but I don’t think that they should be forced to do something like that or have those dire repercussions. There’s lots of services that cannot be done in hospice that could be done in the hospital. So why is that any different?”</p> <p>“I obviously felt that Health Authority X behaved very unreasonably there. They adopted a very heavy-handed, legal approach rather than being pragmatic and communicating. And the hospice’s perception was that we don’t have a problem with MAiD at all. We have a MAiD-providing hospital, literally the other side of the car park [...], so you can easily have a patient who’s been in the hospice, who if they decide they want MAiD, can easily be taken next door to have MAiD provision. So the hospice staff were not saying we’re against MAiD. They’re just saying, ‘we think it’s better for our patients if it happens elsewhere, otherwise people will associate coming to the hospice with being killed and it’ll be a destination for people to go to be done away with.’ And we don’t want that to be the perception. It wasn’t really a religious thing, I don’t think.”</p>

Others emphasized the importance of faith-based institutions maintaining the right to refuse to provide MAiD. They noted the negative impact that providing MAiD would have on their ability to maintain donor funding and therefore to provide quality care within their institutions. They also indicated that patients could be “easily” transferred elsewhere to receive MAiD. They disagreed with “heavy-handed” approaches or being “forced” to provide MAiD, and they likened MAiD to other services that some institutions do not provide.

Conduct broad and inclusive consultation and planning

Participants emphasized the importance of broad consultation and planning in facilitating the relationship of MAiD with PEOLC. They highlighted the need to have the “right” people at the table in a “respectful” way from the planning stage to ensure that the “whole system can function together.” Participants described this as an opportunity to have “complex conversations,” amplify diverse voices regarding MAiD (e.g., “It’s not so much [being in] the same room as who gets to speak”), and address concerns.

Table 3 (part 4 of 5): Themes and selected quotes by PATH framework level

Level*	Theme	Illustrative quote
C. Health systems (cont'd)	Conduct broad and inclusive consultation and planning	<p>“It’s the complete failure [not] to allow for the Indigenous voice to be part of the decisions that had been made. And those decisions have rendered a rather unfortunate series of confusion, complications, or other implications on the Indigenous community or the Indigenous client. [...] Who are you gonna invite to the table? [...] Are you going to bring in the health director, the nurse, the doctor, the social worker, or even the religious orders, the chaplains, the deacons, everybody who needs to be brought to the table, everybody who touches, or has something to do with somebody’s life? And that also includes the youth voice. The youth tend to be the forgotten sector. And I said, unless you prepare the youth properly, they are the ones that are gonna look after us. [...] We need to provide them with the information so that they will have enough ammunition in the struggle of what’s going to be coming.”</p> <p>“So with good wisdom, the leaders of our system said, look, we need to collect people who have different views about this, from all spectrums, as you talked about earlier, so that we get it as right for many people in Canada. It’s not just by advocating for or advocating against — how do we help those people; it is now gonna be a legal thing. We need to put it in place.”</p> <p>“You need to have the right people around the table. And I think people who have a vested interest in, who are strong enough to withstand the rigours of having these complex conversations need to be at the table to voice their opinion so that we can come up with the best solution that fits all, because one approach or the other is like, it’s just not going to fit everybody. And you’re not going to be able to make 100% of the people happy 100% of the time, but you do what’s in the best interests of as many as you can, so that we’re not exclusionary, we’re not discriminatory in delivering these kinds of services ...”</p> <p>“I get the sense there wasn’t really any preparation for it. [Laughs]. It sounds like most of the team just said, ‘I’m interested in this,’ it was handed to someone as, you’ll be the contact person for MAiD, and then eventually just kept growing and it became too big for them.”</p>
	Increase funding for MAiD, PEOLC, and coordination	<p>“It’s boring to keep hearing everything reduced to money, but the reality is [laughs], we’ve got to fund the system. If we want good degrees of coordination, then you have to have funding in place. Because at a coordinator level, you need some consistency in services. And we don’t have that critical funding for palliative care in any setting, not just hospice. And so you don’t have equitable service, equitable access. So how do you coordinate a service when you’re not sure if all of the providers in a certain region don’t have the ability to do palliative home care because they don’t have any nurses available who are trained properly?”</p> <p>“I don’t know the specifics on how many hours they can bill for it, but most of them say it’s very much not reflective of the work involved. Because I think the billing is more so just for when you’re there doing the assessment and when you’re there doing the procedure. So it doesn’t include reviewing the case file, calling the family practitioner to get more information, writing the orders for the IV insertion and the meds, and like all the other pieces that they’re involved in. Most have said that the payment thing isn’t really a big barrier for them, because it’s not generally why they’re doing it. But it just adds to kind of the suckiness of it and not feeling valued.”</p> <p>“I think there’s possibly a bit of resentment in the palliative care field that MAiD has received attention and funding that palliative care has been struggling for, say, 20 or so years to obtain in order to be recognized for what it does and get the appropriate funding that it needs.”</p> <p>“We’re not well resourced for assisted dying in terms of our assessors. Often, the reality is that a patient might ask for MAiD, they might only have a week left in their natural life, and we can’t get them assessed because we just don’t have the resources for it.”</p>

Increase funding for MAiD, PEOLC, and coordination

Participants noted the “fixed pie” of resources in a “system under stress” and reported competition for funding and resources between MAiD and PEOLC services. They discussed a need for greater funding for PEOLC. The “attention” and “funding” that MAiD has received in recent years was described as a potential “threat” to PEOLC, ultimately negatively affecting the relationship between services. Participants noted that there is

inadequate funding to allow for service “coordination,” “consistency in services,” and equitable access to care, which made achieving a coordinated relationship between hospice MAiD and PEOLC services challenging. Others expressed the need for more support for “dedicated” time for providers involved with MAiD. They also advocated for greater funding for a clinical coordinator to provide strong administrative and navigation support for patients and other health care providers.

Table 3 (part 5 of 5): Themes and selected quotes by PATH framework level

Level*	Theme	Illustrative quote
D. Intersectoral initiatives	Ensure oversight and standardized practice across Canada's health care systems	<p>"I think because we live in such a large country and united under the federal government in one way, but then so chopped up because of the provincial, territorial health differences, and then adding in more complications of long-term care homes and their own policies and such from province to province: it's adding some additional complications. I don't think there's one solution or one event that will change everything. It seems like because of how things are structured and the different places where people at end of life could be — hospital, hospice, long-term care or retirement home, wherever — that's causing some problems."</p> <p>"I do believe that there's an opportunity for the federal government in particular to show more leadership. [...] There's this great disconnect where, on the ground, I know with the hospices, it's like, well, what are our rights? What are the legislative nuances from province to province?"</p> <p>"It would be great if just nationally they could say, like, here's the legislation. It's that translation between legislation and operationalization and it seems to have to go through a number of different steps and everybody seems to have to have their finger in it. And if we can say it's national legislation, I don't know, I just don't understand why there needs to be this, then okay, now we get to the provinces and the territories and they have to translate it for themselves. And then they have to come up with their own thing. Like, if we made it national, except I know that if we tried to make it national and nationally, they go like, okay, here are all the forms. And here's the process. Each province and territory would probably go, that's not going to work for us. We're special. So I don't know if there's an answer to that."</p> <p>"In Canada, the health care services and actually the administration of justice is carried out at the provincial and territorial level, they have the responsibility for it. The federal role is a bit more circumspect in that our role is to share information, to support research, to create policies, yes, but in the broad sense where, for instance, the framework on palliative care in Canada, our aim was to create as broadly as possible, so that provinces and territories and organizations and individuals and other advocates for improved care at end of life could see themselves in it and could take the relevant parts and say, all right, to apply that, to apply that approach in our area, we would need to do this."</p> <p>"I know in some provinces, all the MAiD requests are handled in a centralized way. And then oftentimes there's a palliative care team that's feeding into this centralized provincial system as well. So I imagine those places, it's probably much easier to have those discussions. And then the same with hospitals — there's a MAiD team and a palliative care team, having those sit-downs. But then I think there's some provinces where things are a little less centralized or not everybody is going through a centralized system and it might be more difficult to have those conversations about how to take one person, one patient, and ensure that they're getting the access to everything that they need access to, when it is more, like, patchworky."</p>

Note: IV = intravenous, MAiD = medical assistance in dying, PEOLC = palliative and end-of-life care.
 **Client-centred services* refers to focusing on the needs of clients, families, and the broader community, such as considering clinic hours to improve access, more efficient referral systems, or access to services to enhance care. *Health operations* refers to health operations planning at the organization level, focusing on the delivery of services (by ministries of health, nongovernmental or local organizations, and private-sector agencies) and the allocation of resources, time, money, or expertise. *Health systems* refers to coordination at the national level that includes broader governance and capacity issues, such as joint planning of the policies, processes, and infrastructure that make up the overarching health systems. *Intersectoral initiatives* refers to initiatives that include intersection with more than 1 system (such as the health and legal systems).

Intersectoral initiatives

Ensure oversight and standardized practice across Canada's health care systems

Participants reported a “disconnect” between the introduction of the MAiD legislation in Canada by the federal government and the “operationalization” of MAiD at the level of health systems. Some expressed their preference for a unified national approach that shows “leadership” and “direction” about the needed infrastructure to “standardize” MAiD practices (e.g., forms), clarify “legislative nuances,” and provide guidance on the optimal relationship between MAiD and PEOLC. Some participants expressed their wish for a “uniform approach for oversight” and a “centrally coordinated”

system to maintain “consistency” across the country. However, some noted this would require a “balancing act” to allow for “flexibility” for inherent differences in patients’ wishes and needs across jurisdictions. Conversely, others believed that the federal role should be more “circumspect,” to allow for autonomy in service delivery at provincial, territorial, and institutional levels.

Interpretation

This national qualitative study of the perspectives of health leaders regarding the relationship of MAiD and PEOLC in Canada revealed divergent views about the optimal relationship between these services. However, leaders recognized, overall, that a

collaborative relationship of some kind is required for appropriate referrals, care coordination, and patient care. Accordingly, a “distinct but collaborative” approach to the concurrent delivery of MAiD and PEOLC may be the most feasible approach at present, especially as MAiD eligibility has been extended in Canada to include people without a terminal condition.^{8,13} Because MAiD criteria in Canada no longer stipulate a “reasonably foreseeable death,” MAiD is now accessible to patients who may not receive or require PEOLC.⁸ Therefore, it is possible that health leaders’ perspectives about the optimal relationship between MAiD and PEOLC services will change. It is planned that some patients with mental illness will be eligible for MAiD after March 2024; the optimal relationship between MAiD and psychiatric services will require careful consideration.⁹

The findings of our study highlight the philosophical and practical challenges involved with the integrated delivery of MAiD and PEOLC services in Canada. The views of some of those we interviewed contrast with recent assertions that service integration is the “gold standard” to prioritize patients’ needs, improve access to and quality of services, and improve the overall effectiveness and efficiency of health care systems.^{40,41} Although more than three-quarters of patients in Canada who received MAiD also received palliative care,¹⁰ there have been complaints from patients and families who were told they would no longer be able to access PEOLC services after requesting MAiD.⁴² Furthermore, the transfer of patients desiring MAiD who are receiving care in institutions with strong objections to providing MAiD is often perceived as suboptimal and impractical.⁴³ The preference of most participants in our study was for a coordinated, rather than fully integrated, relationship between MAiD and PEOLC. A similar coordinated approach is in place in countries such as Belgium, where MAiD and palliative care services coexist in “a largely unproblematic and even synergistic way.”⁴¹

Our study also identified key considerations to enhance the relationship between MAiD and PEOLC, which we organized using the PATH framework (Figure 1). Although this framework offered a systematic approach to guide our study design and analysis, most of the themes generated were at the *health operations* and *health systems* levels; only 1 theme was generated on client-centred services. This may be because we interviewed health leaders who operate in these realms and the interview guide focused on these areas. The themes generated would likely have been different if we had interviewed other participant groups (e.g., patients and caregivers).

Health leaders in this study emphasized the need for greater patient, public, and provider education about MAiD and PEOLC to reduce misunderstandings about both services and their current and future relationship. This is consistent with previous research that identified public education on MAiD and palliative care as an important health priority,⁴⁴ along with increased specialized training in MAiD communication.^{18,45} Many PEOLC curricula have begun incorporating training on assisted dying.^{46,47} Moreover, a national MAiD curriculum aimed at health care providers is currently in development in Canada,⁴⁸⁻⁵⁰ and may also serve to address this need. Public education campaigns that

help to clarify who is eligible for MAiD, how to request MAiD, and where to find information could direct the public to a user-friendly and dependable website, which has nuanced information for the public across different Canadian jurisdictions. There should also be greater effort to provide education tailored for the patient population that is eligible for MAiD. A recent environmental scan of available resources for patients considering MAiD in Canada indicated that few educational resources have adequate understandability and actionability, particularly for patients with low health literacy and those who are not proficient in English or French.⁵¹

Across multiple PATH levels, the need for clarity and standardization in institutional policies, operationalization of MAiD, and practice guidelines within professional regulatory bodies was emphasized. A more consistent approach across jurisdictions may help to ensure a uniform standard of care and consistent practice, compliance with legal requirements, and clarity on the concurrent delivery of services, while allowing for flexibility and autonomy at the provincial, territorial, and institutional levels. Health leaders also highlighted the importance of compassionate leaders to ensure a respectful relationship between services and the fostering of cultural safety and collegial relationships. Facilitating communication that focuses on the common goals between MAiD and PEOLC teams (e.g., patient-centred care) is critical to improving the relationship between providers of these services.

Finally, consistent with previous findings,^{17,52,53} inadequate funding of PEOLC in Canada was also identified in this study as a challenge for both services and for the coordination of care. For example, health leaders expressed concerns about timely and equitable access to both services, and the perceived competition for limited resources. Although some health leaders may perceive funding for PEOLC and MAiD as competing, this view may arise because there are substantial needs and insufficient funding in both areas. Currently, it is not clear whether or in what way the attention to MAiD has affected resources provided to PEOLC.

Limitations

The data we collected were cross-sectional, and health leaders’ opinions and attitudes may evolve over time. Despite our purposeful sampling, there was an overrepresentation of participants identifying as White and those located in central Canada. There was an underrepresentation of participants from Quebec, even though we offered to conduct the interview in English or French. This may limit the generalizability of our findings, especially given the novel role Quebec played in leading the provision of MAiD in Canada.

Our study was not comprehensive in interviewing all key parties, although the views of patients, caregivers, and the public have been previously investigated.^{29-31,54} Although we had anticipated that health leaders who supported MAiD would be more willing to participate in the study,³² diverse views on MAiD were evident in the responses. Further research with representative samples of health leaders and with quantitative methods is needed to better understand attitudes toward MAiD and its relationship with PEOLC.

Conclusion

This study highlights the wide-ranging views held by health leaders regarding the optimal relationship between MAiD and PEOLC in Canada. However, there was overall recognition that some degree of coordination between MAiD and PEOLC is required for optimal patient-centred care. In Canada, where MAiD eligibility has been extended to include people without a terminal condition, options are needed for patients to be able to access MAiD-only services, PEOLC-only services, and both MAiD and PEOLC services. In this study, health leaders identified the need for public and provider education, standardization of practice guidelines and oversight, relationship-building, and leadership. These findings have implications for improving MAiD and PEOLC policy development and clinical practice across Canada and informing policy in other jurisdictions.

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