

# How does Medical Assistance in Dying affect end-of-life care planning discussions? Experiences of Canadian multidisciplinary palliative care providers

Anita Ho , Joshua S. Norman, Soodabeh Joolae, Kristie Serota, Louise Twells and Leeroy William

*Palliative Care & Social Practice*

2021, Vol. 15: 1–14

DOI: 10.1177/  
26323524211045996

© The Author(s), 2021.  
Article reuse guidelines:  
sagepub.com/journals-  
permissions

## Abstract

**Background:** More than a dozen countries have now legalized some form of assisted dying, and additional jurisdictions are considering similar legislations or expanding eligibility criteria. Despite the persistent controversies about the relationship between medicine, palliative care, and assisted dying, many people are interested in assisted dying. Understanding how end-of-life care discussions between patients and specialist palliative care providers may be affected by such legislation can inform end-of-life care delivery in the evolving socio-cultural and legal environment.

**Aim:** To explore how the Canadian Medical Assistance in Dying legislation affects end-of-life care discussions between patients and multidisciplinary specialist palliative care providers.

**Design:** Qualitative thematic analysis of semi-structured interviews.

**Participants:** Forty-eight specialist palliative care providers from Vancouver ( $n = 26$ ) and Toronto ( $n = 22$ ) were interviewed in person or by phone. Participants included physicians ( $n = 22$ ), nurses ( $n = 15$ ), social workers ( $n = 7$ ), and allied health professionals ( $n = 4$ ).

**Results:** Qualitative thematic analysis identified five notable considerations associated with Medical Assistance in Dying affecting end-of-life care discussions: (1) concerns over having proactive conversations about the desire to hasten death, (2) uncertainties regarding wish-to-die statements, (3) conversation complexities around procedural matters, (4) shifting discussions about suffering and quality of life, and (5) the need and challenges of promoting open-ended discussions.

**Conclusion:** Medical Assistance in Dying challenges end-of-life care discussions and requires education and support for all concerned to enable compassionate health professional communication. It remains essential to address psychosocial and existential suffering in medicine, but also to provide timely palliative care to ensure suffering is addressed before it is deemed irremediable. Hence, clarification is required regarding assisted dying as an intervention of last resort. Furthermore, professional and institutional guidance needs to better support palliative care providers in maintaining their holistic standard of care.

**Keywords:** assisted dying, assisted suicide, autonomy, Canada, euthanasia, Medical Assistance in Dying, palliative care, qualitative research, suffering

Received: 12 May 2021; revised manuscript accepted: 25 August 2021.

## Introduction

Assisted dying is now legal for people who meet various criteria under certain circumstances in

Belgium, Canada, Colombia, Germany, Luxembourg, the Netherlands, Spain, Switzerland, as well as parts of Australia and the United States.

Correspondence to:

**Anita Ho**  
Centre for Applied  
Ethics, The University  
of British Columbia,  
227 – 6356 Agricultural  
Road, Vancouver, BC V6T  
1Z2, Canada

Bioethics Program,  
University of California,  
San Francisco, San  
Francisco, CA, USA  
[Anitaho.ethics@gmail.com](mailto:Anitaho.ethics@gmail.com)

**Joshua S. Norman**  
School of Medicine,  
University of California,  
San Francisco, San  
Francisco, CA, USA

**Soodabeh Joolae**  
Department of Pediatrics,  
The University of British  
Columbia, Vancouver,  
BC, Canada; Nursing  
Care Research Center,  
Iran University of Medical  
Sciences, Tehran, Iran

**Kristie Serota**  
Dalla Lana School of  
Public Health, University  
of Toronto, Toronto, ON,  
Canada

**Louise Twells**  
Faculty of Medicine,  
The University of British  
Columbia, Vancouver, BC,  
Canada

**Leeroy William**  
Supportive & Palliative  
Care Unit, Eastern Health,  
Melbourne, VIC, Australia

Austria and New Zealand both legalized assisted dying in 2020, with provisions coming into force in late 2021.

Eligibility, permitted circumstances, and authorized methods for assisted dying vary considerably internationally. In Canada, the 2016 Bill C-14 legalized Medical Assistance in Dying (MAiD), allowing not only physicians but also nurse practitioners to assist eligible and consenting adult patients with foreseeable death to die by clinician-administration or self-ingestion of lethal medication under specific safeguards. In March 2021, an additional criminal code amendment was passed by the Canadian Parliament with Bill C-7. This Bill expands the MAiD eligibility criteria, adding the inclusion of individuals whose death is not reasonably foreseeable, and those whose death is foreseeable but are at risk of losing the capacity to consent.<sup>1</sup>

Despite legalization, the relationship between medicine, palliative care, and MAiD remains controversial. With notable exceptions,<sup>2,3</sup> one complex and under-recognized issue in the empirical literature is how MAiD legalization affects end-of-life care discussions, particularly among palliative care providers (PCPs).<sup>4</sup> This is an important area for practice consideration, given that changes in end-of-life care discussions can impact ongoing delivery of care, as the direction of these conversations may affect whether palliative care and related social support services would be further explored with patients.<sup>5</sup>

This paper reports findings from interviews with multidisciplinary PCPs on how MAiD enquiries affect end-of-life care conversations. Despite the persistent controversies about the relationship between medicine, palliative care, and assisted dying, many people are interested in assisted dying. As the primary settings for MAiD administration in Canada are hospitals, patients' homes, and palliative care units, where PCPs who have been trained to accept death as a natural process are increasingly asked to be involved in MAiD conversations, their experience in navigating these discussions can inform practice, professional curricula, and policies to enhance PCPs' ability to provide holistic care in the evolving cultural landscape. The study was conducted before the passing of Bill C-7, and thus the findings presented here occurred within the context of the previous eligibility criteria, outlined in Bill C-14. Adhering to the Consolidated Criteria for Reporting

Qualitative Research (COREQ) guidelines,<sup>6</sup> we report PCPs' experiences, concerns, and recommendations in discussing MAiD as part of end-of-life care planning in the evolving socio-cultural and legal environment. The study was approved by the University of British Columbia (H18-03123) and University Health Network (18-6306) Research Ethics Boards. We explore how PCPs manage the tension between MAiD and the philosophy of palliative care, especially when a shared population may access both services.

## Methods

### Research question

As part of a larger qualitative study on PCPs' experiences in caring for patients who have enquired about MAiD,<sup>7</sup> we explored the perspectives of specialist palliative care clinicians on discussing MAiD with patients and families within routine end-of-life care planning.

### Study design

An exploratory qualitative study using in-depth, semi-structured interviews.

### Participants and recruitment

In Canada, multidisciplinary specialist PCPs need to navigate MAiD processes and experience various contact points for MAiD discussions.<sup>8</sup> Using purposive sampling, we recruited specialist PCPs who work in acute care ( $n = 26$ ), community care ( $n = 1$ ), hospice care ( $n = 7$ ), and multiple sites ( $n = 14$ ) in Vancouver and Toronto. All participants have had direct experience supporting patients who had enquired about MAiD. To assure maximum variation in our participants and to capture diverse perspectives, we recruited physicians ( $n = 22$ ), nurses ( $n = 15$ ), social workers ( $n = 7$ ), and allied health professionals (AHPs) ( $n = 4$ ) of varying experience levels. Recruitment materials were circulated through professional listservs, clinical presentations by the research team, and professional contacts. Interested participants were contacted by a team member to confirm eligibility and provide further study information.

### Data collection

The semi-structured interview guide was constructed based on a prior scoping review and

informed by our research team's practice experience. To ensure clear wording and smooth flow between questions, mock interviews were conducted with three PCPs with experience responding to MAiD requests. Their concerns were addressed, and the interview guide was refined accordingly.

Semi-structured interviews were conducted between 2018 and 2020 by one of three researchers (A.H., S.J., and K.S.) with extensive qualitative research experience. The interviews elicited participants' experiences engaging in end-of-life care discussions and care practices before and after MAiD became legal, their roles and responsibilities before and after the legislative change, and their experiences responding to general enquiries or formal requests for MAiD.

Interviews were recorded, transcribed, and analyzed using NVivo 12 software. Participants provided consent and were assigned pseudonyms, with identifiable information removed from the transcripts to protect confidentiality. Field notes documented the recruitment and interview contexts as well as participants' speech and non-verbal behaviors. The same interview guide was used for both sites.

### *Data analysis*

Interviews were analyzed using inductive thematic analysis, which has a descriptive and exploratory orientation.<sup>9</sup> Early in the data collection processes, two researchers (AH, SJ) analyzed the first three transcripts using open coding, identified emerging themes, and refined interview questions for further probes in subsequent interviews. To enhance validity and facilitate a reflexive process of continuing meaning-making,<sup>10</sup> we utilized a constant comparative approach to systematically organize, compare, and understand the similarities and differences among participants' perspectives as themes began to emerge.<sup>11,12</sup> Each research team member coded two transcripts independently to further clarify themes, subsequently compared and grouped into conceptual categories to form a preliminary coding scheme. Any coding that did not reach at least 90% agreement between coders was reviewed and reassessed by the researchers. Coding differences were resolved through team deliberation and better understanding of various codes. We actively sought disconfirming examples, adding and revising categories to form a final coding scheme to

accommodate the data adequately. The concurrent and iterative data collection and analysis facilitated comparison of new themes and categories with those previously established in the dataset<sup>13</sup> and determination of data saturation, when no new themes emerged from further interviews.<sup>11</sup> Four transcripts were coded by at least two research team members to ensure intercoder reliability of at least 90% agreement before dividing up the remaining transcripts to be coded by a single researcher. To promote trustworthiness of the analysis,<sup>14</sup> analytic memos recorded the researcher's self-reflections and critical analysis of the emerging ideas.<sup>15</sup>

### **Results**

Forty-eight participants from Vancouver ( $n = 26$ ) and Toronto ( $n = 22$ ) were interviewed in person or by phone. Average interview length was 53 minutes (range 30–97). Participants included physicians ( $n = 22$ ), nurses ( $n = 15$ ), social workers ( $n = 7$ ), and AHPs ( $n = 4$ ). Eight interviewees had served as MAiD assessors/providers; two received assessment training. (Table 1)

Inductive thematic analysis identified five notable considerations associated with how MAiD affected discussions in end-of-life care planning: (1) concerns over having proactive conversations about the desire to hasten death, (2) uncertainties regarding wish-to-die statements, (3) conversation complexities around procedural matters, (4) shifting discussions about suffering and quality of life, and (5) the need and challenges of promoting open-ended discussions.

### **Concerns regarding proactive conversations about the desire to hasten death**

Despite their general comfort in having proactive end-of-life discussions with patients, interviewees expressed trepidation about initiating MAiD conversations. These concerns arose even for participants who supported Bill C-14 and wanted to provide an open environment for patients to explore MAiD-related matters. Apprehensions were particularly salient among participants who perceived professional and institutional restrictions for MAiD:

We have end-of-life care conversations with everybody because that's our work. So, the conversation has not shifted. [But] the College of Nurses mandates that we're not allowed to initiate

**Table 1.** Participant demographics.

Characteristic	Study sample, <i>n</i> = 48
Gender, <i>n</i> (%)	
Male	9 (19)
Female	39 (81)
Age range, <i>n</i> (%)	
25–34	8 (17)
35–44	15 (31)
45–54	17 (35)
55–64	6 (13)
65–74	2 (4)
Role, <i>n</i> (%)	
Physician	22 (46)
Nurse	15 (31)
Social Worker	7 (15)
Allied health professional	4 (8)
Type of institution, <i>n</i> (%)	
Faith-based	13 (29)
Secular	32 (71)
Location, <i>n</i> (%)	
Community	1 (2)
Hospice	7 (15)
Hospital palliative care	26 (54)
Multiple sites	14 (29)
Work experience in years, <i>n</i> (%)	
< 1	2 (4)
1–5	12 (25)
5–10	14 (29)
> 10	20 (42)
Participation in MAiD, <i>n</i> (%)	
Assessor	8 (17)
Provider	5 (10)
Neither	40 (83)
MAiD, Medical Assistance in Dying.	

[MAiD] conversations. The only thing we can do is respond. (P5, Nurse)

Some participants also questioned the congruence between palliative care philosophy with MAiD, rendering wish-to-die discussions challenging for PCPs who want to explore the motivations behind patient requests. They expressed concerns that people with a strong desire to access MAiD may consider broader discussions as intrusive:

I've been talking about [wish to die] stuff for decades with people. "Why do you feel like you want to be dead?" "How can we make it better?" Just that it's all swept away now ... The law passed in June 2016, and by September 2016 at the [international] palliative care conference in Montreal, they had stats from xxxx University that patients were already saying to palliative care doctors, "get out of here, I don't want to talk to you, I just want to be dead." (P17, Physician)

Several participants reported disinclination to initiate MAiD discussions unless the patient has raised the topic:

I've initiated a discussion with the label of MAiD if they've identified a desire for hastened death and I'm exploring what that means ... I can't say I've introduced it as an option without some prompting from the patients that it might align with what they're looking for. (P32, Physician)

Some participants who were comfortable with various forms of end-of-life conversations nonetheless worried about upsetting patients by initiating MAiD discussions due to associated stigma:

One big difference is recognizing the potential individual perspectives or stigmas about MAiD. ... I don't ask, "Is it alright with you if I talk about how we can manage your pain?" But I think with MAiD it is important to get permission, because sometimes we've noticed people can be offended. (P45, Physician)

Participants also explained how the introduction of MAiD in end-of-life care discussions may disrupt the therapeutic relationship with patients and families:

It can change the course of the conversation that you're having. Like ...we're all discussing things where there's support surrounding the discussion,

and everybody is on the same page. And then they would talk about MAiD; the patient wants it and the family doesn't, and then a family member might leave the room and not be part of the conversation anymore, or becomes quite tense, or people close off the discussion. (P41, Physician)

### Uncertainties regarding wish-to-die statements

When patients appeared to be expressing a desire to hasten death, participants faced challenges in clarifying ambiguous statements:

I think people panic, when somebody says something like "can you just put me to sleep?..". You are thinking, oh my god, they want MAiD. The reality is, they're taking dexamethasone and they are so hyped that they literally just need something to help them sleep. (P15, SW)

A MAiD provider noted situations where non-palliative clinicians presumed and misunderstood patients' end-of-life care desires:

We get lots of referrals for patients who're wanting MAiD and it turns out that's not what they're asking for ... Now that MAiD is legalized, everything is "This patient wants MAiD" when really patient wants palliative care. (P47, Physician)

Participants also reported some patients being referred to palliative care only after having expressed a wish to die, and it was not until then that the patient's wish was clarified:

[MAiD] has drawn people to the attention of palliative care that wouldn't have got palliative care beforehand. And that's because they mention the dying word, or they mention the MAiD word. There was a guy who said, 'I want to die,' and it turned out that he just really didn't know his options. We talked to him for quite a while, and he was quite happy with palliative care. (P 24, Physician)

Others reported concerns about addressing wish-to-die statements without appearing to recommend MAiD or influencing patients' decisions:

When people say, "Life isn't worth living, I hurt so much, I can't wait until this is over. When is death coming?" Those kinds of statements are a bit harder to navigate ... and you don't want to say, "Well,

have you heard that I can help you die?" You have to be very careful how you talk about it. (P29, Physician)

### Conversation complexities around the MAiD process

Even when patients explicitly ask about MAiD, interviewees reported extra burdens and intricacies in explaining procedural logistics as part of end-of-life care discussions, especially in cases of institutional non-participation:

I had to use language with people in the beginning that ... they'd be moved [elsewhere] for the provision ... Patients will almost always stay here until the hour before they die. So, we've done all the work. The only thing that's not happening is the actual injection. (P5, Nurse)

Some participants also reported complexities in helping patients understand and accept the necessity of assessment and waiting period safeguard requirements:

It's hard when somebody comes in, and they're in pain. All they're doing is saying: "I want MAiD." But they don't understand that assessment process, and they want to die now. We're trying to explain to them while they're acutely suffering about how this process works, and they don't want to hear it. They get mad ... There are ways to help that suffering, especially once they've come up here with medications and stuff. I feel that's not necessarily the best time to make that decision, and they get frustrated because they don't want to go through that ten-day process. (P3, SW)

Other participants reported situations where patients had upcoming MAiD appointments and refused pain or sleep medications because they worried that the medications would affect their ability to consent to MAiD, rendering them ineligible. Due to these concerns, participants discussed the need to explore if MAiD is an end in itself or a means to an end for patients:

When somebody clearly had talked about "this is the way I want to end my life," I ask them this question. "If you're dying naturally, how important is it for you that you die from MAiD? Or are you ok for us to allow you to die naturally if it's clear that's what's happening?" (P14, Nurse)

Such discussions are important, especially since some families were reportedly upset when patients died naturally before the scheduled MAiD procedure, even when the death was peaceful:

There's been significant anger in instances from family members after [MAiD] didn't happen. That the one thing they wanted, the way that they wanted to go ... they had a natural death which is very comfortable, but it wasn't how they wanted to go and we've had some learnings around communicating how much time it takes to set these things up. (P46, Physician)

Since patients have the right to privacy and confidentiality, but families are often accompanying patients' end-of-life journeys, some participants reported challenges in navigating the physician-patient-family communication triad when patients wanted to keep their MAiD planning process a secret:

[MAiD] was something she wanted to do and she didn't want us to tell the [family] ... That's her right ... But we also felt tremendous conflict ... We spent so much time with her ... How was this going to be for her and how is this going to be for the [family]? ... She said, 'when I die you can tell them anything you want.' But she definitely did not tell them about the fact that she was planning for MAiD ... She was kind of transferring that on to us. Like, I'm done, I made my decision. You deal with it. And it was hard on all of us. (P2, Nurse)

Other participants who generally supported MAiD worried about the subjective interpretations of eligibility criteria and the implementation pathway for MAiD, and wondered if there should be a comprehensive exploration of all end-of-life care options before discussing MAiD:

Now I'm a little less positive, a little bit wary ... Some of my struggles go back to the question, did we explore all options? And then I battle with it, because why does it matter? If the person wants MAiD, why do I say we need to make sure we've explored every option to alleviate their suffering before they can practise their legal right to MAiD? I feel it should be the last option ... Whereas sometimes I don't feel it works that way. Maybe there're other things that could be done, but we shot straight to MAiD. (P4, Nurse)

### Shifting discussions about suffering and quality of life

As PCPs focus on promoting well-being and relieving suffering, some participants felt positive about

providing patients a sense of control by discussing MAiD as part of end-of-life care planning:

A lot of people have a tremendous sense of loss of control, and how [their illness has] decimated their life and their prospects over the future. I think having some control over how you die is having some control. It's a privilege to be able to tell your patients and their families what their options are and choosing what makes the most sense for them. (P45, Physician)

However, other participants reported the inadequacy of simply carrying out a patient's MAiD request without first addressing their psychosocial and existential suffering that might have prompted the request and supporting the patient accordingly:

He wanted MAiD because he was grieving [his wife's death] and didn't really have a lot more reason to live in his life, and he felt lonely. It wasn't really the suffering of his disease per se; it was the suffering of life ... I have a lot of challenge with patients that ask for MAiD because they're lonely and they're elderly and don't have a lot of social connections ... I would hope, as a society, we could figure out how to support people as much as we can, rather than kind of committing them down this pathway towards euthanasia. (P10, Physician)

Other participants also discussed their uneasiness when patients' suffering, which motivated MAiD enquiries, could have been managed by other palliative care and relational measures:

When people are in different stages and degrees of suffering, they look for the magic bullet which is MAiD. But they don't realize that better symptom management and open frank discussion between them and the families could really reduce their suffering. They may not require MAiD. (P9, Nurse)

Such discomfort is noteworthy, given that some participants perceived that MAiD legalization has ironically made it more difficult for PCPs to thoroughly explore patients' suffering and present various options that may ease such suffering:

Prior to [legalization], we had greater ability and time to deal with existential and emotional distress ... [Now] the ability to help people deal with their existential crisis through talking and reflection is severely constrained. Practically absent ... My being

forced by that [MAiD] question to say, “are you telling me that you want to implement the government guidelines that you want somebody to help you end your life?” Instead of saying, “that’s horrible, tell me more. What’s going on?” It constrains the discussion. I feel it underserves and inappropriately serves individuals in dealing with their suffering. (P37, Physician)

Illustrating such concern, another participant told a cautionary tale of how even though PCPs focus on finding ways to support patients to live as well as possible, for as long as possible, the MAiD option may paradoxically lessen discussions and efforts to promote patients’ quality of life:

I’m thinking of a recent patient who had MAiD. Our end-of-life care conversation was different . . . She was very matter of fact about having and wanting MAiD. I would’ve had more of a conversation about “what other activities would you like to do,” but because we knew she was having MAiD soon, it changed my role with her. I could’ve done more things with her. I could’ve been more involved with her care and end-of-life care journey. But because she was ending her journey at this point, those conversations weren’t had. (P30, AHP)

### The need and challenges of promoting open-ended discussions

In addressing MAiD as part of end-of-life care conversations, interviewees recommended having open, compassionate, non-judgmental, and exploratory discussions regarding patients’ end-of-life care goals and support them accordingly:

When I counsel patients who’re interested in MAiD, I try to present it as one of the many reasonable pathways they can take. I frame it not as charged and controversial, because I want them to be as objective as possible in their decision-making . . . I try to spend time to really understand what they’re saying. Often by sitting with people and talking, you can understand, is this someone who wants to sign a request form for MAiD? Or is there something else going on? I try to just tease out what they’re talking about and how we can support them. (P48, Physician)

Participants also noted the need to have iterative exploratory discussions to fully uncover potential psychosocial and existential concerns that may have prompted a wish to hasten death and address

them accordingly rather than focusing solely on MAiD:

During the MAiD process, from the time someone initiates the conversation to the time the provision is had or isn’t—someone dies or chooses against it or what have you—it’s never just one conversation. It’s multiple conversations; it has multiple layers with different family members with different coordination with [multiple people]. (P5, Nurse)

Other participants also recommended first making space to explore how a potential MAiD enquiry fits in the patient’s broader end-of-life care wishes:

If I’m in a consult and it seems like someone’s kind of, like, “I’m done. I’m ready to pass away,” then I explore that a bit. First to hear what they mean by that, and then just because I don’t want people to fall through the cracks. If they’re asking for MAiD and they’re not being explicit, I’ll be like, “Sometimes I work with people and they say something like that, it just means they don’t want antibiotics and medications to prolong life. They’re ready to allow for natural death. And I’ve worked with others when they say something like that, they want a doctor or a nurse practitioner to give them something to end their life on their own timeline.” You know, and then kind of suss that out. (P35, Physician)

## Discussion

### Main findings

As the compatibility of MAiD with medicine and palliative care remains contentious among PCPs,<sup>16–18</sup> and there is wide variation in the intensity and timing of palliative care involvement, our participants encountered various levels of discomfort in incorporating MAiD discussions as part of end-of-life care planning. Some interviewees believed that PCPs are uniquely skilled at holding complex end-of-life care discussions and are thus better equipped than non-palliative healthcare providers (HCPs) to explore all options with patients, including MAiD.<sup>19,20</sup> Others iterated the concerns noted by global palliative care associations,<sup>21</sup> worrying that PCPs’ involvement in MAiD may further blur the public perception of palliative care and erode trust in a specialty that commits to whole-person care by easing pain and suffering without hastening death.<sup>22</sup> This concern was particularly salient among participants with

more than ten years of practice experience in palliative care. They echoed other Canadian findings showing uneven palliative care access at individual, organizational, and population levels.<sup>23</sup> Some of these participants had long fought public misconceptions that palliative care would hasten death. They worried that the inclusion of MAiD discussions in end-of-life care planning, particularly in cases of late palliative care referrals that were initiated only after a patient's MAiD request, would reinforce that perception. Another Canadian study looking at inpatient palliative care code that identified patients who received or were referred to palliative care revealed that 76.8% of patients were only first identified as "palliative" in their final admission before death; for other patients receiving the designation before their final admission, nearly half were identified less than 2 months before death.<sup>24</sup>

Some participants in our study also cautioned that a gradual normalization of MAiD discussions, even if well-intended to promote patients' autonomy, may inadvertently move palliative care from being compassion-driven to process-driven.<sup>25</sup> This can have important social and practice implications, as a whole-person focus on patient emotions and suffering in their wider socio-relational context may allow HCPs to probe and clarify patient motivations, potential misconceptions, and needs, thereby providing tailored education and support. Whereas a process-focused approach that adopts a non-interventionist view of autonomy may result in MAiD requests being taken at face value. Subsequently, the current legal process may facilitate MAiD without fully understanding the broader patient decisional context and intersecting concerns, including whether they truly wanted MAiD if other support options were available.

#### *Implications for practice and policies*

To our knowledge, this is the first multi-site Canadian qualitative study to explore multidisciplinary specialist PCPs' experiences with MAiD discussions in the broader end-of-life care context. As PCPs continue to strive toward better holistic care and the easing of patient suffering, while many patients still lack early access to palliative care or adequate knowledge of the palliative approach,<sup>26</sup> the intersecting perspectives, concerns, and experiences of PCPs can inform practice.

Echoing empirical data from the United States, most participants reported waiting for patients to initiate assisted dying discussions,<sup>27–29</sup> partly stemming from their perceived legislative, professional, or institutional requirements.<sup>3</sup> Some of these requirements may have conflicted with each other, further complicating these difficult conversations. Moreover, PCPs are more accustomed to exploring the patient-initiated concerns with them, rather than unilaterally introducing MAiD into the conversation. Unlike the Australian legislation,<sup>30</sup> C-14 does not prohibit HCPs from initiating MAiD discussions,<sup>31</sup> although various professional colleges and organizations have communication protocols cautioning certain practices.<sup>32,33</sup> Some nursing regulatory organizations allow members to inform patients about MAiD *after* it is clear a patient is requesting information for MAiD (versus expressing a desire to die) but warn against appearing to be suggesting, recommending, advising, or inciting uptake.<sup>34,35</sup> HCPs and healthcare institutions can refrain from providing MAiD based on individual or institutional conscientious objections. Nonetheless, regulatory Colleges require physicians to provide enquiring patients with sufficient information and resources to enable informed decisions and effective referral.<sup>36</sup> These protocols serve as reminders of the delicate power dynamics that may accompany MAiD discussions in end-of-life care planning. Even when HCPs are discussing treatment options as objectively as possible, the mere introduction of MAiD in end-of-life conversations may inadvertently direct the discussion toward a medicalized pathway while neglecting various forms of social or community services that may ease patient suffering. As many religious organizations and palliative care units have eased some practice restrictions,<sup>37</sup> gradually allowing MAiD assessment or provision within their premises, clarity on institutional and professional protocols toward MAiD discussions would be important to guide care conversations and delivery. Lessons from other countries with longer histories with assisted dying may also help to navigate processes and promote smooth care management plans.<sup>38–40</sup>

The concerns of participants that initiating MAiD discussions may unduly influence patient decisions echo international findings. In Vermont, where clinicians have an affirmative duty to inform patients of the assisted dying option, some



HCPs chose not to initiate discussions due to worries about sending problematic messages, influencing patients' decisions, and damaging therapeutic relationships.<sup>41,42</sup> Family physicians in Switzerland noted three reasons for similar reluctance: managing their own emotions in helping patients end their lives, conflicts with their religious/moral values, and a perceived tension with their professional role.<sup>43</sup>

While some participants worried that initiating MAiD discussions might upset patients, other international studies, including a cross-sectional study in Italy with advanced cancer patients, show that many patients appreciate the exploration of their potential desire to hasten death by HCPs.<sup>44</sup> Findings from the United States, the Netherlands, and other countries also reveal that many patients want to confirm their assisted dying eligibility for psychological comfort,<sup>29,45</sup> even if they may not intend to seek the procedure.<sup>46</sup> Some wish to hasten death but lack knowledge of assisted dying being legal.<sup>41,42</sup> Others may have talked to relatives and await the opportunity to discuss with HCPs.<sup>31,47</sup> Internationally, assisted dying is discussed more than it is performed,<sup>48</sup> suggesting that many patients welcome or accept other holistic approaches and social services to ease their distress, whereas others may be more at risk of having unmet needs and unresolved suffering that prompt them to resort to assisted dying. Echoing a systematic review and meta-ethnography that included studies from Australia, Canada, China, Germany, the Netherlands, Switzerland, Thailand, and the United States,<sup>46</sup> our interviewees indicated that some enquiring patients were expressing despair and seeking relief rather than wanting to hasten death. Even though the World Health Organization and the Canadian Palliative Care Association recommend incorporating palliative care early in the course of illness and in conjunction with curative therapies,<sup>24</sup> some participants reported palliative care being consulted only after patients have endured extended periods of poor physical and/or psychological suffering, and sometimes only after a MAiD enquiry had been made. This highlights the need for early discussions and palliative care referrals to explore and clarify patients' broader contextual concerns, proclamations, motivations, values, and goals to help ease their suffering accordingly,<sup>49,50</sup> including many social services and evidence-based palliative care options.<sup>41,42</sup> Early and open discussions may strengthen therapeutic relationships and help PCPs to determine when they may need to

refer patients for additional specialist consultations or other supporting services.<sup>48,50</sup>

Nonetheless, some participants reported that MAiD legalization may have inadvertently constrained shared decision-making in the specialist palliative care setting, as offerings of palliative options that can ease suffering and facilitate peaceful natural death may be misconstrued as being paternalistic by patients who are only interested in MAiD. Even though a patient's desire to pursue MAiD does not necessarily mean that the person would lose eligibility for various services, some participants reported that patients' decisions to have MAiD deterred them from offering or discussing additional services. They also noted that MAiD discussions sometimes diverted care plans from the best whole-person care possible<sup>51</sup> to more mechanical or procedural matters. This may reflect how healthcare systems often focus on finding quick "magic bullet" physical solutions, rather than taking a more holistic public health approach focused on addressing the complex psychosocial and existential issues that contribute to trauma and suffering for patients and their families.

While patients can qualify for MAiD if their suffering is grievous and irremediable, Bill C-14 does not require patients to first consider palliative care or other support services to determine their effectiveness in alleviating suffering. Nonetheless, 82.1% of patients who received MAiD in Canada in 2019 reportedly received palliative care services.<sup>52</sup> In that year, 7,336 patients submitted a MAiD request, and 73.5% subsequently received a MAiD provision.<sup>52</sup> 54.6% of these recipients received palliative care for more than 1 month, whereas 39.2% of these recipients received palliative care for less than 1 month.<sup>52</sup> Out of the small number of 263 patients (3.6%) who withdrew their request for MAiD, 69 of them (26%) reported that they withdrew their MAiD request because they found palliative care measures to be sufficient, making up 0.94% of all MAiD requests.<sup>52</sup> As some interviewees perceived that patients were sometimes referred to palliative care too late, further chart review and documentation studies on how the timing and nature of palliative care involvement may impact MAiD requests are required.

Some participants perceived MAiD to be broadly permissible and raised concerns about its practical consequences,<sup>53</sup> since different responses exist

for multifaceted sources, expressions, or experiences of suffering.<sup>43,54,55</sup> They reported that most enquiring patients did not have severe refractory physical symptoms that required medical interventions. Rather, some were grieving or feared the loss of autonomy and control over their circumstances.<sup>56</sup> Others experienced a reduced sense of self-worth due to negative social norms about disability and terminal conditions,<sup>7</sup> or felt despair about lacking support services or being a burden on others.<sup>57</sup> The patient's wish to hasten death may thus be a reactive phenomenon intertwined with physical, psychosocial, and existential suffering that reflects a desire to retain control and spare others from burdens, raising complex social and ethical questions of using a lethal pharmaceutical means to address identity and relational angst.<sup>58</sup>

Shared decision-making at the end of life involves a complex interplay between the contextual environment and the decision-making triad of the patient, the clinician, and their social network.<sup>5</sup> As people live and experience illnesses and end-of-life journeys in relationships and communities, a clearer understanding of patient motivations in their personal and relational contexts by clinicians can facilitate discussions of available support and resources to meet these goals. Using semi-structured conversational guides to uncover the wider context of the patient's suffering early on as an upstream measure may help PCPs to build trust and clarify ambiguous statements,<sup>50</sup> explain the palliative care philosophy, and offer targeted treatments and support resources to address symptoms and suffering holistically. As a German study revealed, in strengthening therapeutic relationships with patients who express a desire to hasten death, PCPs can help to ease patients' suffering by generating hope and new perspectives through refocusing or activating patients' mental and social resources.<sup>59</sup>

The perspectives on MAiD conversations in the broader end-of-life care discussions reflect an ongoing tension for participants about the appropriate relationship between palliative care and MAiD.<sup>2</sup> Interviewees recognized that patients should not be abandoned or discriminated against because of their potential interest in MAiD. They strongly supported upholding patient autonomy and alleviating suffering, and recognized that these are values held in common between MAiD and palliative care.<sup>60</sup> Nonetheless, in the evolving

cultural landscape that may accept a wish to hasten death at face value while neglecting the socio-relational context of the request, some participants questioned whether "in the guise of autonomy, we are abandoning people" (P17, Physician).<sup>61</sup> The focus on autonomy, even if well-intended, may fail to see people in the context of their lived experiences, beliefs, health literacy, and social connections that affect their decision-making. The exploration of a person's end-of-life narrative also requires the depth of perspectives provided by family and friends, alongside the professional therapeutic relationships, to collectively attempt to understand that person. Our findings can inform policies, medical curricula, communication training, and practices to clarify what it means to truly promote patient autonomy and support holistic care regardless of whether patients are dying or will ultimately receive MAiD.

As Canada expands MAiD eligibility to individuals who are not at the natural end of their lives, but are experiencing severe suffering,<sup>1</sup> initiation and incorporation of MAiD discussions into clinical consultations may pose further challenges for all healthcare providers. PCPs have noted the increase in administrative workload to coordinate eligibility assessments and implementation, as well as the associated emotional burden in these processes.<sup>7,62</sup> Echoing our findings on the influence of family members and the social context on patients' MAiD decisions, evidence from the Netherlands also raised the importance of attending to the patient-physician-family triad.<sup>40</sup> Ideally, end-of-life discussions should be free from coercion, misinformation, and miscommunication. MAiD conversations are demanding experiences for all stakeholders, requiring clinicians to have exquisite skills in talking about end of life and in shared decision-making with patients and families, which are "neither commonplace nor included in existing curricula."<sup>39</sup>

The importance our participants placed on the ability of doctors to facilitate open end-of-life care discussions in trusting therapeutic relationships is well recognized in the international literature.<sup>39,63,64</sup> Regardless of legislative changes, early, respectful, and competent communication is essential to optimize responsive support to ease patients' suffering. Further research is needed to understand whether or how the

gradual normalization and potential expansion of MAiD may affect the roles and practices of HCPs, and how we can improve professional curricula to enhance HCPs' ability to engage in open and compassionate end-of-life care discussions in the evolving cultural and legal environment.

### Limitations

Qualitative research often forgoes generalizability in favor of in-depth explorations of a phenomenon. Our findings should therefore be interpreted in this light, rather than as a representation of how MAiD affects all end-of-life care discussions. Specialist PCPs were recruited from two diverse Canadian cities. They were mostly female (reflecting the demographic makeup of PCPs) and worked in secular institutions. The transferability of our findings may be limited to PCPs of similar backgrounds. As MAiD remains a contentious medical practice,<sup>65</sup> but is widely accepted among the Canadian public, there might have been reporting bias in how participants portrayed the practice in interviews compared to anonymous questionnaires. Since recruitment mostly relied on professional listservs, professional contacts, and snowball sampling, PCPs who were not exposed to these materials or whose work was unknown to the research team would have been excluded. Further research with patients and families regarding their experience may determine experience congruence among stakeholders.<sup>66</sup>

### Conclusion

Our study revealed that MAiD discussions as part of end-of-life care planning pose challenges, and requires education and support to enable compassionate health professional communication. It remains essential to address psychosocial and existential suffering, but also to provide timely palliative care to ensure suffering is addressed before it is deemed irremediable. Hence, clarification is required regarding assisted dying as an intervention of last resort. Furthermore, professional and institutional guidelines need to better support PCPs in maintaining their holistic standard of care, as they navigate the legislative and cultural shifts.


### Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was supported by St. Pau's Foundation (Palliative Care Fund).

### ORCID iD

Anita Ho  <https://orcid.org/0000-0002-9797-1326>

### References

1. Parliament of Canada, House Government Bill: C-7 An Act to Amend the Criminal Code (medical assistance in dying), <https://www.parl.ca/LegisInfo/BillDetails.aspx?Bill=C7&Language=E&Mode=1&Parl=43&Ses=2> (2021, accessed April 2021).
2. Brooks L. Health care provider experiences of and perspectives on medical assistance in dying: a scoping review of qualitative studies. *Can J Aging* 2019; 38: 384–396.
3. Selby D and Bean S. Oncologists communicating with patients about assisted dying. *Curr Opin Support Palliat Care* 2019; 13: 59–63.
4. Mathews JJ, Hausner D, Avery J, *et al.* Impact of medical assistance in dying on palliative care: a qualitative study. *Palliat Med* 2021; 35: 447–454.
5. Romo RD, Wallhagen MI and Smith AK. Viewing hospice decision making as a process. *Am J Hosp Palliat Care* 2016; 33: 503–510.
6. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349–357.
7. Ho A, Joolae S, Jameson K, *et al.* The seismic shift in end-of-life care: palliative care challenges in the era of medical assistance in dying. *J Palliat Med* 2021; 24: 189–194.
8. Fujioka JK, Mirza RM, McDonald PL, *et al.* Implementation of medical assistance in dying: a scoping review of health care providers' perspectives. *J Pain Symptom Manage* 2018; 55: 1564–1576.e9.
9. Miles MB, Huberman AM and Saldaña J. *Qualitative data analysis: a methods sourcebook*. 3rd ed. Thousand Oaks, CA: SAGE, 2014.
10. Srivastava P. A practical iterative framework for qualitative data analysis. *Int J Qual Method* 2009; 8: 76–84.

11. Corbin J and Strauss A. *Basics of qualitative research Techniques and procedures for developing grounded theory*. 3rd ed. Thousand Oaks, CA: SAGE, 2008.
12. Parry K. Constant comparison. In: Lewis-Beck MS, Bryman A and Futing Liao T (eds) *The Sage encyclopedia of social science research methods*. Thousand Oaks, CA: SAGE, 2004, p. 181.
13. Holloway I and Wheeler S. *Qualitative research in nursing and health care*. 3rd ed. Chichester: Wiley-Blackwell, 2010.
14. Shenton A. Strategies for ensuring trustworthiness in qualitative research projects. *Educ Inf* 2004; 22: 63–75.
15. Saldaña J. *The coding manual for qualitative researchers*. 3rd ed. London: SAGE, 2016.
16. Gamester N and Van den Eynden B. The relationship between palliative care and legalized euthanasia in Belgium. *J Palliat Med* 2009; 12: 589–591.
17. Dierickx S, Deliens L, Cohen J, *et al*. Involvement of palliative care in euthanasia practice in a context of legalized euthanasia: a population-based mortality follow-back study. *Palliat Med* 2018; 32: 114–122.
18. Herx L. Physician-assisted death is not palliative care. *Curr Oncol* 2015; 22: 82–83.
19. Buchman S. Why I decided to provide assisted dying: it is truly patient centered care. *BMJ* 2019; 364: 1412.
20. Downar J, Fowler RA, Halko R, *et al*. Early experience with medical assistance in dying in Ontario, Canada: a cohort study. *CMAJ* 2020; 192: E173–E181.
21. International Association for Hospice and Palliative Care. Global statements on euthanasia and physician assisted suicide, <https://hospicecare.com/policy-and-ethics/ethical-issues/statements-on-euthanasia-and-physician-assisted-suicide/#CPCA> (1997, accessed January 2021).
22. Waran E and William L. Navigating the complexities of voluntary assisted dying in palliative care. *Med J Aust* 2020; 213: 204–206.
23. Tanuseputro P, Budhwani S, Bai YQ, *et al*. Palliative care delivery across health sectors: a population-level observational study. *Palliat Med* 2017; 31: 247–257.
24. Tung J, Chadder J, Dudgeon D, *et al*. Palliative care for cancer patients near end of life in acute-care hospitals across Canada: a look at the inpatient palliative care code. *Curr Oncol* 2019; 26: 43–47.
25. Herx L, Cottle M and Scott J. The “normalization” of euthanasia in Canada: the cautionary tale continues. *World Med J* 2020; 66: 28–39.
26. Costante A, Lawand C and Cheng C. Access to palliative care in Canada. *Healthc Q* 2019; 21: 10–12.
27. Back AL, Starks H, Hsu C, *et al*. Clinician-patient interactions about requests for physician assisted suicide: a patient and family view. *Arch Intern Med* 2002; 162: 1257–1265.
28. Dobscha SK, Heintz RT, Press N, *et al*. Oregon physicians’ responses to requests for assisted suicide: a qualitative study. *J Palliat Med* 2004; 7: 451–461.
29. Quill TE, Back AL and Block SD. Responding to patients requesting physician-assisted death: physician involvement at the very end of life. *JAMA* 2016; 315: 245–246.
30. White BP, Willmott L and Close E. Victoria’s voluntary assisted dying law: clinical implementation as the next challenge. *Med J Aust* 2019; 210: 207–209.
31. Canadian Association of MAiD Assessors and Providers. Bringing up medical assistance in dying, <https://camapcanada.ca/wp-content/uploads/2020/01/Bringing-up-Medical-Assistance-In-Dying.pdf> (2020, accessed January 2021).
32. Brown J, Goodridge D, Harrison A, *et al*. Medical assistance in dying: patients’, families’, and health care providers’ perspectives on access and care delivery. *J Palliat Med* 2020; 23: 1468–1477.
33. Shadd P and Shadd J. Institutional non-participation in assisted dying: changing the conversation. *Bioethics* 2019; 33: 207–214.
34. College of Licensed Practical Nurses of Manitoba (CLPNM), the College of Registered Nurses of Manitoba (CRNM) and the College of Registered Psychiatric Nurses of Manitoba (CRPNM). Medical assistance in dying: guidelines for Manitoba nurses, <https://www.crnmb.ca/support/medical-assistance-in-dying> (2018, accessed January 2021).
35. Pesut B, Thorne S, Stager ML, *et al*. Medical assistance in dying: a review of Canadian nursing regulatory documents. *Policy Polit Nurs Pract* 2019; 20: 113–130.
36. Petropanagos A. *Conscientious objection to medical assistance in dying (MAiD)*. Royal College of Physicians and Surgeons of Canada, <https://www.royalcollege.ca/rcsite/documents/bioethics/5-3-1-case-e.pdf> (2017, accessed January 2021).

37. Shaw J, Wiebe E, Nuhn A, *et al.* Providing medical assistance in dying: practice perspectives. *Can Fam Physician* 2018; 64: e394–e399.
38. de Boer ME, Depla MFIA, den Breejen M, *et al.* Pressure in dealing with requests for euthanasia or assisted suicide. Experiences of general practitioners. *J Med Ethics* 2019; 45: 425–429.
39. Dees MK, Vernooij-Dassen MJ, Dekkers WJ, *et al.* Perspectives of decision-making in requests for euthanasia: a qualitative research among patients, relatives and treating physicians in the Netherlands. *Palliat Med* 2013; 27: 27–37.
40. Roest B, Trappenburg M and Leget C. The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review. *BMC Med Ethics* 2019; 20: 23.
41. Buchbinder M. Aid-in-dying laws and the physician's duty to inform. *J Med Ethics* 2017; 43: 666–669.
42. Brassfield ER and Buchbinder M. Clinicians' perspectives on the duty to inform patients about medical aid-in-dying. *AJOB Empir Bioeth* 2020; 11: 53–62.
43. Otte IC, Jung C, Elger B, *et al.* "We need to talk!" Barriers to GPs' communication about the option of physician-assisted suicide and their ethical implications: results from a qualitative study. *Med Heal Care Philos* 2017; 2: 249–256.
44. Porta-Sales J, Crespo I, Monforte-Royo C, *et al.* The clinical evaluation of the wish to hasten death is not upsetting for advanced cancer patients: a cross-sectional study. *Palliat Med* 2019; 33: 570–577.
45. Norwood F. *The maintenance of life: preventing social death through euthanasia talk and end-of-life care: lessons from the Netherlands*. Durham, NC: Carolina Academic Press, 2009.
46. Rodriguez-Prat A, Balaguer A, Booth A, *et al.* Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography. *BMJ Open* 2017; 7: e016659.
47. Stutzki R, Weber M, Reiter-Theil S, *et al.* Attitudes towards hastened death in ALS: a prospective study of patients and family caregivers. *Amyotroph Lateral Scler Frontotemporal Degener* 2014; 15: 68–76.
48. Voorhees JR, Rietjens JAC, Van Der Heide A, *et al.* Discussing physician-assisted dying: physicians the United States and the Netherlands. *Gerontologist* 2014; 54: 808–817.
49. Branigan M. Desire for hastened death: exploring the emotions and the ethics. *Curr Opin Support Palliat Care* 2015; 9: 64–71.
50. Kremeike K, Frerich G, Romotzky V, *et al.* The desire to die in palliative care: a sequential mixed methods study to develop a semi-structured clinical approach. *BMC Palliat Care* 2020; 19: 49.
51. Byock I. *A physicians quest to transform care through the end of life: the best care possible*. New York: Penguin Books, 2012.
52. Health Canada. First annual report on medical assistance in dying in Canada: 2019, <https://www.canada.ca/en/health-canada/services/medical-assistance-dying-annual-report-2019.html> (2020, accessed January 2021).
53. Blaschke SM, Schofield P, Taylor K, *et al.* Common dedication to facilitating good dying experiences: qualitative study of end-of-life care professionals' attitudes towards voluntary assisted dying. *Palliat Med* 2019; 33: 562–569.
54. Lees C, Gubitz G and Horton R. A retrospective review of medically assisted deaths in Nova Scotia: what do we know and where should we go? *J Palliat Med* 2021; 24: 1011–1016.
55. Oregon Health Authority. Oregon Death With Dignity Act: annual report for 2016, [https://www.deathwithdignity.org/wp-content/uploads/2017/03/2016\\_ORDWDA\\_Report\\_030717.pdf](https://www.deathwithdignity.org/wp-content/uploads/2017/03/2016_ORDWDA_Report_030717.pdf) (2017, accessed January 2021).
56. Li M, Watt S, Escaf M, *et al.* Medical assistance in dying—implementing a hospital-based program in Canada. *N Engl J Med* 2017; 376: 2082–2088.
57. Dees MK, Vernooij-Dassen MJ, Dekkers WJ, *et al.* "Unbearable suffering": a qualitative study on the perspectives of patients who request assistance in dying. *J Med Ethics* 2011; 37: 727–734.
58. Gudat H, Ohnsorge K, Streeck N, *et al.* How palliative care patients' feelings of being a burden to others can motivate a wish to die. Moral challenges in clinics and families. *Bioethics* 2019; 33: 421–430.
59. Galushko M, Frerich G, Perrar KM, *et al.* Desire for hastened death: how do professionals in specialized palliative care react. *Psychooncology* 2016; 25: 536–543.
60. Hurst SA and Mauron A. The ethics of palliative care and euthanasia: exploring common values. *Palliat Med* 2006; 20: 107–112.
61. Bickenbach J. Disability and life-ending decisions. In: Battin M, Rhodes R and Silvers A

(eds) *Physician assisted suicide: expanding the debate*. New York: Routledge, 1998, pp. 123–132.

62. Bouthillier ME and Opatrny L. A qualitative study of physicians' conscientious objections to medical aid in dying. *Palliat Med* 2019; 33: 1212–1220.
63. Waldron T, Carr T, McMullen L, *et al.* Development of a program theory for shared decision-making: a realist synthesis. *BMC Health Serv Res* 2020; 20: 59.
64. Royal College of Physicians. Talking about dying: how to begin honest conversations about what lies ahead, <https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead> (2018, accessed June 2021).
65. World Medical Association. WMA Declaration on Euthanasia and Physician-Assisted Suicide, <https://www.wma.net/policies-post/declaration-on-euthanasia-and-physician-assisted-suicide/> (2019, accessed May 2021).
66. Frolic AN, Swinton M, Murray L, *et al.* Double-edged MAiD death family legacy: a qualitative descriptive study. *BMJ Support Palliat Care*. Epub ahead of print 18 December 2020. DOI: 10.1136/bmjspcare-2020-002648.

Visit SAGE journals online  
[journals.sagepub.com/  
home/pcr](https://journals.sagepub.com/home/pcr)

 SAGE journals