

# The Seismic Shift in End-of-Life Care: Palliative Care Challenges in the Era of Medical Assistance in Dying

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## Abstract

**Background:** Concerns regarding personal, professional, administrative, and institutional implications of medical assistance in dying (MAiD) are of particular interest to palliative and hospice care providers (PHCPs), who may encounter additional moral distress and professional challenges in providing end-of-life (EOL) care in the new legislative and cultural era.

**Objective:** To explore PHCPs' encountered challenges and resource recommendations for caring for patients considering MAiD.

**Design:** Qualitative thematic analysis of audio-recorded semistructured interviews with PHCPs.

**Setting/Subjects:** Multidisciplinary PHCPs in acute, community, residential, and hospice care in Vancouver, Canada, with experience supporting patients who have made MAiD inquiries or requests.

**Measurements:** Interviews were deidentified, transcribed verbatim, and coded by four researchers using a common coding scheme. Key themes were analyzed.

**Results:** Twenty-six PHCP participants included physicians ( $n=7$ ), nurses ( $n=12$ ), social workers ( $n=5$ ), and spiritual health practitioners ( $n=2$ ). Average interview length was 52 minutes (range 35–90). Analysis revealed four broad challenges associated with providing EOL care after MAiD legalization: (1) moral ambiguity and provider distress, (2) family distress, (3) interprofessional team conflict, and (4) impact on palliative care. Participants also recommended three types of resources to support clinicians in delivering quality EOL care to patients contemplating MAiD: (1) education and training, (2) pre- and debriefing for team members, and (3) tailored bereavement support.

**Conclusions:** PHCPs encountered multilevel MAiD-related challenges, but noted improvement in organizational policies and coordination. Resources to enhance training, pre- and debriefing, and tailored bereavement may further support PHCPs in providing high-quality EOL care as they navigate the legislative and cultural shifts.

**Keywords:** bioethics; medical assistance in dying; Canada; hospice care; qualitative research; palliative care

## Introduction

IN ITS 2015 *Carter v Canada* ruling, the Supreme Court of Canada (SCC) struck down the criminal prohibition on assisting consenting and capable adults who have a grievous and irremediable condition in suicide.<sup>1</sup> The SCC ruled that such prohibition violated the *Canadian Charter of Rights*

*and Freedom*: it limits individuals' liberty rights to make decisions concerning their bodily integrity and security rights by leaving such individuals to endure intolerable suffering. In 2016, following the passing of Bill C-14 to amend the Criminal Code,<sup>2</sup> Medical Assistance in Dying (MAiD) became legal in Canada. Physicians and nurse practitioners can now assist eligible and consenting patients

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to die by clinician-administration or self-ingestion of lethal medication under specific safeguards. As of February 2020, over 13,000 deaths in Canada have been attributed to MAiD.<sup>3</sup>

Proponents believe MAiD is an important tool to promote patient autonomy and improve the quality of dying experience,<sup>4</sup> whereas others point out that MAiD paradoxically places control in physicians or nurse practitioners, who assess eligibility and provide the means.<sup>5</sup> Concerns regarding intersecting personal, professional, administrative, and institutional implications of MAiD have been a major topic of end-of-life (EOL) care.<sup>6–9</sup> Palliative and hospice care providers (PHCPs), who have been trained to accept death as a natural process, may encounter additional moral distress and professional challenges in the new legislative era with increasing medicalization and potentially hastening of death.<sup>10,11</sup> These concerns require important considerations of how institutions must support PHCPs in providing respectful and appropriate EOL care with this new legal option.

MAiD eligibility criteria and administrative processes continue to evolve,<sup>3</sup> including how multidisciplinary PHCPs navigate professional, ethical, social, and institutional considerations.<sup>12</sup> This study describes PHCPs' encountered challenges and resource recommendations using qualitative thematic analysis of semistructured interviews conducted with 26 PHCPs in Vancouver, Canada.

## Materials and Methods

### Study design

This qualitative interview study examined PHCPs' experiences and perspectives in providing EOL care after the legalization of MAiD. It explored challenges PHCPs face and resources that can support clinicians' work in providing person-centered EOL care. Ethics approval was granted from the university's Research Ethics Board. As MAiD coordination is a team endeavor, we used purposive sampling to recruit a range of multidisciplinary PHCPs across acute, community, residential, and hospice care with experience supporting patients who have made MAiD inquiries or requests. Recruitment materials were circulated through professional listservs, clinical presentations by the research team, and professional contacts. Utilizing maximal variation sampling technique to recruit PHCPs from various disciplines, positions, experience levels, and sites, interested prospective participants were contacted by a team member to confirm eligibility and given further information and consent materials before the interview.

### Data collection

Semistructured interviews were conducted in person or by phone/Skype between 2018 and 2019 in Vancouver by one of two researchers (A.H. and S.J.) with extensive experience in qualitative methods. The interview guide was developed based on a scoping review and informed by our research team's practice experience. It was piloted with three PHCPs with experience responding to MAiD requests and refined accordingly. Participants provided written informed consent and were assigned pseudonyms to protect confidentiality. Interviews were audio-recorded and transcribed verbatim. Field notes documented the recruitment and interview contexts as well as participants' speech and nonverbal behavior.

### Qualitative analysis

Our multidisciplinary research team with expertise in nursing, bioethics, and qualitative methods began inductive analysis with the initial data and constantly compared indicators, concepts, and categories. Early in the data collection process, two researchers (A.H., S.J.) analyzed the first three transcripts using open coding, identified emerging themes, and refined interview questions for further probes in subsequent interviews. To enhance validity, we utilized a constant comparative approach to systematically organize, compare, and understand the similarities and differences among participants' perspectives.<sup>13,14</sup> Four researchers (A.H., S.J., K.J., and C.N.) coded two transcripts independently to further clarify themes, subsequently compared and grouped into conceptual categories to form a coding scheme. Disagreements were resolved through team deliberation. We actively sought disconfirming examples, adding and revising categories 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>15</sup> and determination of data saturation, when no new themes emerged from further interviews.<sup>13</sup> Four transcripts were coded by at least two researchers to ensure intercoder reliability. Remaining transcripts were divided and coded by a single researcher. To promote trustworthiness of the analysis,<sup>16</sup> analytic memos recorded the researcher's self-reflections and critical analysis of the emerging ideas.<sup>17</sup> NVivo 12 software facilitated data management and analysis, and we adhered to the Consolidated Criteria for Reporting Qualitative Research checklist.<sup>18</sup>

## Results

The 26 PHCP participants included physicians ( $n=7$ ), nurses ( $n=12$ ), social workers ( $n=5$ ), and spiritual health practitioners ( $n=2$ ). Most participants, identified as female, had over 10 years of work experience, worked in secular institutions, and supported MAiD (Table 1). Average interview length was 52 minutes (range 35–90).

Thematic analysis identified four challenges associated with providing EOL care after MAiD legalization: (1) moral ambiguity and provider distress, (2) family distress, (3) interprofessional team conflict, and (4) impact on palliative care. Participants recommended three types of resources to support clinicians in delivering quality EOL care to patients contemplating MAiD: (1) education and training, (2) pre- and debriefing for team members, and (3) tailored bereavement support.

### Moral ambiguity and provider distress

All participants, regardless of their position on MAiD, expressed that providing EOL care after MAiD legalization is ethically challenging, despite following federal laws and patients' wishes. Although capable patients must initiate MAiD requests and express consent throughout the process, participants experienced varying degrees of moral uncertainty in navigating MAiD requests and providing such option:

*“Whether you feel it's moral or not is a personal battle, something that I still think about—from my first MAiD experience, straight through all of them... A small piece of it will always not sit with me comfortably.” (Participant #6, Nurse)*

TABLE 1. PARTICIPANT DEMOGRAPHICS

Characteristic	Qualitative study sample, n = 26
Gender, n (%)	
Male	3 (12)
Female	23 (88)
Age range, n (%)	
25–34	4 (15)
35–44	5 (19)
45–54	10 (38)
55–64	6 (23)
65–74	1 (4)
Role, n (%)	
Social workers	5 (19)
Nurses	12 (46)
Physicians	7 (27)
Spiritual health practitioners	2 (8)
Type of institution, n (%)	
Religious	9 (35)
Secular	14 (54)
Location, n (%)	
Community	1 (4)
Hospice	7 (27)
Hospital palliative care	9 (35)
Multiple sites	9 (35)
Work experience in years, n (%)	
<1	1 (4)
1–5	8 (31)
5–10	4 (15)
>10	13 (50)
Personal position on MAiD, n (%)	
For	16 (62)
Against	3 (12)
Conflicted/undecided	7 (27)

MAiD, medical assistance in dying.

*“At the beginning I thought having more options, the better for people. What I’m realising is that sometimes having that option, and either going through with it, or not being able to go through with it for whatever reason, causes suffering for the person passing away, for their loved ones, and for healthcare providers in general.” (Participant #4, Nurse)*

PHCPs reported patients’ ambivalence regarding MAiD and challenges in managing families’ access inquiries on patients’ behalf:

*“There was a case where we weren’t sure who was advocating for MAiD—if it was the patient or her family who brought this as an option and pressured her.” (Participant #6, Nurse)*

Other participants expressed distress about patients’ underlying reasons for requesting MAiD:

*“I have a lot of challenge with patients that ask for MAiD because they’re lonely and 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.” (Participant #10, Physician)*

PHCPs also raised concerns over procedural safety requirements, such as the 10-day waiting period, which can ironically impede patient well-being:

*“Sometimes you feel pressure to change your management... People refuse pain medications or medications to help them sleep because they’re fearful the medications will impact their ability to have MAiD. That’s hard for me because people aren’t receiving the benefit of palliative care and are arguably increasing their suffering while waiting for MAiD.” (Participant #12, Physician)*

**Family distress**

PHCPs discussed balancing their competing duties to care for the patient and support the family, while accepting the need to prioritize the patient’s wishes. Some families supported the patient’s MAiD decision but struggled with it. They grieved for their loss and that death occurred through MAiD. Families who respected the patient’s choice despite their own unease were particularly sad or angry of losing their loved ones in those circumstances:

*“It’s those moments when the families aren’t on board, when they’re struggling, when they’re unable to be in there, but they’re out here crying, when they’re very resistant or angry at their loved one for, you know, how could you? I think a challenge is, how to support family members that are resistant?” (Participant #13, Social Work)*

Some families hid their loved one’s MAiD decision from friends and relatives in fear of stigma and could not seek support, exacerbating their distress after the patient’s death:

*“The wife was very upset [MAiD] was being considered, but the husband was adamant. Because their normal support was their church, and there was a lot of stigma, it was almost done in secret. ... A lot of shame. It wasn’t a good death situation, in terms of how people will do down the road with bereavement.” (Participant #17, Social Work)*

**Interprofessional team conflict**

Negative encounters with colleagues due to MAiD-related disagreements created challenges for some participants. For example, different opinions regarding whether their institutions should provide MAiD onsite and where items for MAiD administration should be placed contributed to various levels of conflicts:

*“We’re a small unit. Just drawing up the drugs and getting them prepared is a point of conflict... Some staff don’t even want to see the drugs in the tray lined up, and that can be conflicting.” (Participant #4, Nurse)*

Some participants who supported MAiD reported conflicts encountering colleagues, who were conscientious objectors and allegedly went beyond passively disagreeing with MAiD to actively persuading patients to change their minds about MAiD:

*“One colleague knows that I have MAiD conversations all the time with patients. I’m very transparent about it. But after I have the conversation and I tell him, he will go in right after that and try to convince the patients otherwise.” (Participant # 20, Nurse)*

**Impact on palliative care**

Some participants discussed their or their mentors’ decades-long effort to combat public misconceptions that

palliative care would hasten death. They worried that the blurring role of PHCPs in MAiD might exacerbate this view:

*“People were already afraid to access our services before MAiD. They thought palliative care meant that we weren’t going to do anything. Dump them in a corner, DNR, do nothing, the whole works. People would cry coming in, until they actually understood what we’re here to do.” (Participant #1, Nurse)*

Others expressed concerns that the media focused more on MAiD access than palliative/hospice care access:

*“With the extensive media coverage about MAiD, it’s hard to educate the general public about the deeper joy of caring for each other.” (Participant #18, Physician)*

Participants also reported the challenging impact of being consumed by MAiD coordination while having less time for non-MAiD patients:

*“When MAiD first came in, our entire job was about MAiD... It was like we were expected to do debriefing, to be present,... our job, instead of being about palliative and end-of-life care, it was about being MAiD support.” (Participant #15, Social Worker)*

*“There was so much time sensitive coordination that my work ended up being much more focused on [MAiD] patients, at the expense of spending time with other patients and coordinating their care.” (Participant #2, Nurse)*

### **Education and training**

Participants recommended expanding MAiD education for PHCPs to clarify the complexities in the MAiD legislation (e.g., eligibility criteria, waiting period), institutional policies, and professional colleges’ and health authorities’ procedural requirements. They also proposed specialized training on MAiD communication:

*“There needs to be more education that patients’ wish of death statements aren’t necessarily really about MAiD. People panic when somebody says something like “can you just put me to sleep?” “Oh, you mean MAiD. Here, call the MAiD coordinator.” There needs to be more of an exploratory... “You said you want to go to sleep. Tell me more about that.” (Participant #17, Social Worker)*

Participants noted that despite their extensive training in EOL care discussions, MAiD requests felt like a “seismic shift” from their palliative care work. As a sensitive topic, MAiD can dramatically affect the patient-provider therapeutic alliance. Engagement in MAiD conversations requires guidance on what language or approaches can best support patients in the care pathway, from exploration of patients’ initial inquiries to grief support for families’ post-MAiD procedures. Suggested strategies included using patient actors and skilled interdisciplinary mentors to demonstrate effective MAiD discussions:

*“If you miscommunicate and impair your relationship with your patient, they may not trust you with this kind of sensitive information... We should have clinicians practice with simulated patients, and experts in communication can give feedback.” (Participant #24, Physician)*

### **Team and individual debrief**

Most participants reported that team debriefs were helpful in supporting staff by encouraging a welcoming space for dif-

ferent voices to come together and providing a platform for more conversations to understand and address provider distress. Participants recommended more frequent debriefs than currently offered (e.g., debriefs following all MAiD events):

*“Debriefing is one of the most valuable and accessible... Those are so useful at reviewing cases that are highly relevant because of direct practice. They give us the opportunity to review what went well, what could have gone better and how we can do better next time.” (Participant #6, Nurse)*

Individual debriefing for PHCPs to contemplate their own position, perspectives, and biases was deemed especially valuable for clinicians experiencing MAiD-related moral uncertainty or distress:

*“[MAiD] is different than other clinical protocols or clinical events. It’s also a personal piece. Each caregiver has to take the time to work through their own.... stuff in terms of ‘who am I, where are my weak points, where are my soft [points], where am I in this?’” (Participant #21, Spiritual Care Provider)*

### **Tailored bereavement support for families**

PHCPs underscored the lack of customized bereavement resources to support families after MAiD provisions. Some participants were uncertain of whether families’ grief following MAiD versus natural death differed; others suggested that grief after MAiD is qualitatively different, particularly given the highly politicized nature of MAiD and social norms:

*“I don’t know what it’s like to go to a support group, for people who say someone died a natural end-of-life death, versus their loved one died a MAiD death. How that will be taken in a group setting, when they’re talking about their loved ones, and one person, fought to the very end and your mom, she did MAiD... How those loved ones... are being accepted by the sort of grief, and support, and support services in the community.” (Participant #3, Social Work)*

### **Discussion**

While other studies have explored physicians’ and/or nurses’ views,<sup>19,20</sup> to our knowledge, this is the first Canadian qualitative study to provide an in-depth exploration of multidisciplinary PHCPs’ experiences with MAiD. As contemporary medicine—and MAiD in particular—requires multidisciplinary coordination and support, these professionals’ intersecting experiences and perspectives are also important to inform practice.

An overarching theme from our interviews emerged: echoing one survey study with PHCPs that reported inadequate psychological and professional support,<sup>21</sup> MAiD-related challenges abound at the system level, requiring institutional resources to help explore and respect patients’ true values and facilitate smooth processes along patients’ care pathway. These resources are needed to promote patients’ well-being and ease family and PHCP distress regardless of whether patients ultimately receive MAiD. While organizational policies and coordination have improved since 2016, equipping PHCPs with more procedural familiarity and administrative ease, these efforts compounded participants’ workload, paradoxically exacerbating some PHCPs’ distress and raising questions of the sustainability of MAiD-related services without additional resources.<sup>21,22</sup> With the new

federal reporting requirements now in place,<sup>23</sup> research on how these administrative tasks may further affect PHCPs' workload can inform resource requirement to ensure smooth processes and avoid burnout.

Participants' report of institutional changes since MAiD legislation reveals an evolving practice. Various religious organizations and palliative/hospice units that initially prohibited MAiD assessment or provision gradually lifted some restrictions.<sup>24</sup> PHCPs who considered MAiD one of various EOL care options welcomed improved access and associated services as part of patient-centered care. Others worried that providing MAiD services by PHCPs challenges the longstanding palliative care philosophy of relieving people's suffering without hastening death. Some participants accepted supporting roles for MAiD as an extension of good palliative/hospice care, but all participants disagreed with admitting patients to palliative/hospice units or facilities solely for MAiD, suggesting professional consensus that this might counter the specialty's focus to provide holistic care at EOL. As some participants reported their own changing beliefs regarding the role of palliative care in MAiD, and that people requesting MAiD are likely to have received palliative care,<sup>25</sup> more research on whether or how MAiD should be embedded in palliative care and opportunities for PHCPs to discern and reflect on one's moral intuition would help to clarify the conflicting messages regarding the role of palliative care in MAiD.<sup>26</sup> Further exploration of PHCPs' evolving roles and responsibilities may help health administrators and policy makers to achieve a clearer understanding of how palliative care can be best (re)structured, coordinated, and resourced in the new legislative era.

Our findings reveal that responses and coordination are highly variable for the evolving practice. Participants' reports of potentially subjective decisions regarding the waiting period, which were enacted to safeguard a new practice that remains ethically controversial,<sup>27</sup> warrant additional investigation for deeper understanding. As Canada explores whether MAiD eligibility should be extended to people with cognitive impairments,<sup>28</sup> research on professionals' experience in navigating the challenging terrain of respecting patients who may (soon) lack capacity to consent to or change their mind regarding MAiD may inform policies and practice. Other concerns around different interpretations regarding irremediable suffering was especially salient for participants who perceived patients' suffering to be partly results of their reduced sense of self-worth due to negative social norms about disability and terminal conditions. It highlights not only the difficulty PHCPs face in making subjective determination of irremediable suffering, but also raises ethical questions of whether offering MAiD to patients who struggle with a loss of self-worth without correcting the contributing negative social norms may medicalize suffering and perpetuate these norms while disguising MAiD as a tool to promote civil liberties.<sup>29</sup>

Some interviewees cautioned that access to beneficial palliative/hospice care and related social support remain uneven, and that the media focus on MAiD access has not been met with equal advocacy for expanding government investment in palliative/hospice care. These intersecting concerns raise questions regarding whether prioritization of MAiD access may mask the access inadequacy of palliative/hospice services, and whether MAiD is gradually considered by advocates a preferred rather than last resort strategy to ease patients' pain and suffering at the end of life. The de-

velopment of the Action Plan and Framework on Palliative Care by the federal government<sup>30</sup> and the Parliament's commitment to examine the state of palliative care in Canada in 2021 may inform the future direction of palliative care in the evolving legislative and social era.<sup>31</sup>

Interestingly, some participants held potentially inconsistent views regarding the moral nature of MAiD. Echoing a recent study of family caregivers' perspectives,<sup>32</sup> some participants expressed moral equivalency between MAiD and other EOL care options. Nonetheless, most participants thought bereavement for MAiD and natural death was different,<sup>33–36</sup> and recommended MAiD-tailored resources to help all stakeholders navigate the legislative and cultural shifts. Echoing the experience of nurses in another study,<sup>37</sup> varying levels of emotional weight and moral uncertainty were reported by all participants in navigating MAiD provision, indicating that MAiD was not perceived as a morally neutral practice.

### Limitations

PHCPs were recruited from one diverse urban area of Canada. They were mostly female (reflecting the demographic makeup of PHCPs), worked in secular institutions, and supportive of MAiD legalization. Thus, the transferability of our findings may be limited to PHCPs of similar demographics and/or working environments that are more open to MAiD provision. Since MAiD is legal with wide public support but remains a sensitive and morally unsettling practice in palliative care, it is possible that there might have been more reporting bias in how participants wanted to portray the practice in a face-to-face or phone/Skype interview compared to an anonymous questionnaire. Reports from PHCPs only represent participants' perceptions and recollection. Further research with patients and families regarding their experience may help to determine experience congruence among stakeholders.

### Conclusion

Our exploratory study with PHCPs revealed that MAiD-related challenges abound at the system level. Resources to enhance education and training, pre- and debriefing for team members, and tailored bereavement may support PHCPs in providing EOL care as they navigate the legislative and cultural shifts.

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### Author Disclosure Statement

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