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Palliative care providers' roles in medical assistance in dying decision-making triads with patients and families: A qualitative analysis

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Abstract

Objectives. Research on medical assistance in dying (MAiD) decision-making indicates that family members and close friends are often involved in making decisions with patients and their care providers. This decision-making model comprising patients, family members, and palliative care providers (PCPs) has been described as a triad. The objective of this study is to understand PCPs' experiences engaging in MAiD-related decision-making triads with patients and their families in Canada.

Methods. Semi-structured qualitative interviews were analyzed using interpretive description.

Results. We interviewed 48 specialist PCPs in Vancouver (26) and Toronto (22). Interviews were audio-recorded, professionally transcribed, and coded using a coding framework. PCPs take on 5 notable roles in their work with family members around MAiD. They provide emotional support and counseling, balance confidentiality between patients and families, provide education, coordinate support, and mediate family dynamics.

Significance of results. PCPs take on multiple roles in working with patients and families to make decisions about MAiD. As patients and families may require different forms of support throughout the MAiD pathway, PCPs can benefit from institutional and interprofessional resources to enhance their ability to support patients and families in decision-making and bereavement.

Introduction

Palliative care providers (PCPs) have helped patients and their families understand, explore, and access medical assistance in dying (MAiD) since its legalization in Canada in 2016. The Canadian Society of Palliative Care Physicians (2019) considers MAiD a distinct practice from palliative care. Patients, clinicians, and family members each play an important role in the assisted-dying decision-making process: families are intimately involved in assisted-dying decision-making processes, with physicians integrating the perspectives of family members alongside the patients' wishes (Dees et al. 2013; Roest et al. 2019). International empirical studies indicate that rather than a patient–physician decision-making dyad, a triad model comprising family–patient–clinician is closer to patients' assisted-dying decisional experience (Oczkowski et al. 2021; Roest et al. 2019; Snijdewind et al. 2014). In these decision-making triads, patients, clinicians, and family members work together to balance their preferences, needs, and values and work toward compromise (Snijdewind et al. 2014). Oczkowski et al. (2021) provide the following illustrative examples: “patients suffer longer to allow families to prepare for their death; families support their loved one's choice to die sooner; and clinicians bend policy to provide compassionate care to patients and families” (p.10). These findings align with decision-making in palliative care more broadly, as patients often engage in shared decision-making with clinicians and family members at the end of life (Kuosmanen et al. 2021). Palliative care decision-making can be influenced by the patient and their family's communication, pre-existing relationships, knowledge of one another's preferences, understanding of the care options available, and caregiver commitment or burden (Symmons et al. 2022).

Research exploring Canadian family members' experiences reveals that they provide emotional and practical support to patients going through the MAiD process, and many actively participate in planning and organizing the death (Beuthin et al. 2021;

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Frolic *et al.* 2020; Hales *et al.* 2019; Holmes *et al.* 2018; Oczkowski *et al.* 2021; Thangarasa *et al.* 2021). Families have diverse experiences with MAiD. Health-care systems with dedicated MAiD coordinators and assessment services can facilitate smoother logistical processes for patients and families (Frolic *et al.* 2020; Joolae *et al.* 2022). However, the availability of resources and services varies across all institutions that offer MAiD in Canada. Health-care settings with poor coordination support can exacerbate stress for family members (Oczkowski *et al.* 2021; Thangarasa *et al.* 2021).

Some family members take a more active role and others take a more passive or supportive role in decision-making (Gamondi *et al.* 2015; Thangarasa *et al.* 2021). Likewise, clinicians may take more active or passive roles in relation to MAiD based on their personal and professional values and experiences (Fujioka *et al.* 2018; Ward *et al.* 2021). Clinicians experience myriad emotions in relation to MAiD decision-making, including satisfaction from fulfilling patients' end-of-life wishes, to emotional stress, distress, and anxiety (Beuthin *et al.* 2021; Joolae *et al.* 2022; Ward *et al.* 2021). Patients, families, and clinicians often compromise to achieve the best possible death experience for the patient (Oczkowski *et al.* 2021). As patients often include not only their individualistic preferences but also the well-being of their family members in MAiD decision-making, patient-centered care may require clinicians to incorporate relational considerations into care planning decisions.

Several studies have explored patients' and families' experiences, including clinicians' involvement in the MAiD process (Beuthin *et al.* 2021; Frolic *et al.* 2020; Hales *et al.* 2019; Holmes *et al.* 2018; Oczkowski *et al.* 2021; Thangarasa *et al.* 2021); however, to our knowledge, this is the first study to explore these relationships from clinicians' perspectives. This article examines the roles that PCPs take on in MAiD decision-making triads. Investigating PCPs' roles in MAiD decision-making can enhance our understanding of their interactions with patients and family members and identify opportunities to improve these decision-making processes.

Methods

Study design

In this qualitative interpretive descriptive research (Sandelowski 2010; Thorne 2016), we used in-depth semi-structured interviews to explore PCPs' experiences engaging in end-of-life discussions with patients and their families around MAiD. We used purposeful sampling for recruitment. Purposeful sampling is a technique widely used in qualitative research for the identification and selection of information-rich cases for the most effective use of limited resources (Patton 2014). This involves identifying and selecting individuals or groups of individuals who are especially knowledgeable about or experienced with a phenomenon of interest (Cresswell and Plano Clark 2011). Participants were recruited through professional LISTSERVS, professional contacts, and clinical presentations. Clinicians who were interested in participating in the study were instructed to email the research team to complete eligibility screening and receive further information. Eligibility criteria included (1) being employed in a palliative or hospice care setting and (2) having worked with at least one patient who had inquired about or requested MAiD.

We recruited a group of PCPs with diverse experiences engaging in conversations about MAiD, including assessors, providers, conscientious objectors, and those with ambivalent opinions about MAiD. Interviews were scheduled for a time and location

convenient for participants. Thirty-four interviews took place in a private room in the participant's workplace, 8 occurred over the phone, 4 in a research office at the University of Toronto, and 2 asked to be interviewed in their homes. The interviews ranged from 30 to 97 minutes, lasting an average of 50 minutes. Participants were asked to share their experiences caring for patients and families who inquired about or requested MAiD. The interview guide included prompts for exploring the patients' relational context, how the family responded to the request, and their engagement in the MAiD process. All interviews were audio recorded, transcribed, and anonymized to protect participants' privacy and confidentiality. Interviewers compiled field notes containing information about context, nonverbal cues, and novel or interesting themes that arose during each interview. During data collection, we engaged in constant comparison through concurrent coding and field note analysis to determine when interviews no longer revealed novel themes (Thorne 2016). The research proposal was approved by the Research Ethics Boards at the University of British Columbia and the University of Toronto.

Participants

Three members of the research team (A.H., S.J., and K.S.) conducted 48 interviews with specialist PCPs working in acute and hospice care who had experience caring for patients who had inquired about or requested MAiD (Table 1). Those conducting the interviews had qualitative health research training and experience. The interviews were conducted in Vancouver (26) and Toronto (22) and took place between 2018 and 2020. We used purposeful sampling to recruit 22 physicians (MD), 15 nurses (RN), 7 social workers (SW), and 4 allied health professionals (AHP). Participants provided informed consent before their interviews and were assigned pseudonyms to protect their confidentiality and anonymity.

Data analysis

After reviewing each transcript and familiarizing ourselves with the data, we collaboratively developed a coding framework and discussed the application of these codes to the interview transcripts. We then used NVivo 12 software to facilitate data management and analysis. We analyzed the coded data using interpretive description (Sandelowski 2010; Thorne 2016) to attend to PCPs' experiences engaging in triadic decision-making with patients and families. Interpretive description is a useful methodology for understanding "complex experiential clinical phenomena" (Thorne 2016, p.29) in nursing and other applied health-care contexts. This approach allows for the analysis of participants' clinical experiences, their relationships with patients and family members, and the local medical and legal contexts surrounding MAiD. This analysis aims to produce useful clinical knowledge about the roles that PCPs enact in the context of MAiD decision-making.

Findings

Analysis using interpretive description revealed that PCPs take on 5 notable roles in their work with family members around MAiD. They provide emotional support and counseling, balance confidentiality between patients and families, educate family members, provide coordination support, and mediate family dynamics.

Table 1. Participant demographics

Characteristic	Qualitative study sample, n = 48
Gender, n (%)	
Male	9 (19)
Female	39 (81)
Age range, n (%)	
25–34	8 (17)
35–44	15 (31)
45–54	17 (35)
55–64	6 (13)
65–74	2 (4)
Role, n (%)	
Physician	22 (46)
Nurse	15 (31)
Social worker	7 (15)
Allied health professional	4 (8)
Type of institution, n (%)	
Faith-based	13 (29)
Secular	32 (71)
Location, n (%)	
Community	1 (2)
Hospice	7 (15)
Hospital palliative care	26 (54)
Multiple sites	14 (29)
Work experience in years, n (%)	
<1	2 (4)
1–5	12 (25)
5–10	14 (29)
>10	20 (42)
Participation in MAiD, n (%)	
Assessor	8 (16.6)
Provider	5 (10.4)
Neither	40 (83)

MAiD: medical assistance in dying.

PCPs provide emotional support and counseling

The most salient role described by participants was that of providing emotional support to families navigating the MAiD process. PCPs counsel families throughout the whole process, from the time that the topic of MAiD was first initiated to providing grief and bereavement support following MAiD provision.

You have to talk to them in more of a compassionate way... and sometimes it's just more about listening to what their concerns are and their experiences, because they're grieving... there's lots of just listening and supporting. (Heidi, RN, Toronto).

Participants reported that although patients are their primary focus, they also support family members and other clinicians who are impacted by MAiD.

If something doesn't work or the timing doesn't work, we make sure there's somebody there to support either the patient or the family or even staff. We've learned that a big thing is to always have somebody there supporting... our goal is to support the patient, and that's number one. And also to support the family because sometimes the family's on-board, sometimes they're not. So we're there for the family just as much as we are for the patient. (Nina, RN, Vancouver)

PCPs provide bereavement support to family members following the patient's death. There is a sense that MAiD deaths are different from natural deaths and possibly more challenging for family members to receive community support due to the stigma toward assisted dying.

The feedback we've heard is that families that if they were to go to a traditional support group offered by a hospice society, that there's different reactions from the community ... It doesn't feel like a similar kind of death, or there's a shame involved or a stigma attached to acknowledging that my family member died of a MAiD provision. So there is an online group that they can participate in ... And I will call the family in a few weeks to find out how they're doing. (Megan, SW, Vancouver)

PCPs balance confidentiality between patients and families

PCPs reported the need to balance confidentiality between patients and their families, especially when patients did not want their families to know that they were requesting MAiD. One participant describes his thoughts about a patient instructing him to conceal the cause of death from their family.

How do we balance confidentiality? How do we balance how this actually impacts the team, the family, and everybody else? It's not as simple as one person's decision. There's a lot of residual effect that are in place for that impact long after the patient dies. (Jack, AHP, Vancouver)

Jack does not provide a solution to this dilemma; however, participants suggested that PCPs can still provide grief and bereavement support to family members in cases such as this. PCPs also described situations where they provided support to family members without patients' knowledge.

I'm providing support to family members, who are supportive majority of the time. The family members have been supporting the patients that wants MAiD, which is good to see; they often remain strong with the patient, but then they come and talk to me, and they cry. (Sophia, SW, Vancouver)

By maintaining a confidential relationship with patients and their family members, PCPs show respect for patients and those in their circle of care. In cases where PCPs are asked not to share the patient's MAiD request with the family, they continue to provide bereavement support while maintaining the patients' confidentiality.

PCPs educate families

PCPs reported providing education to patients and families and helping patients make informed choices about their healthcare. Through these conversations, PCPs help set realistic expectations about MAiD.

Evelyn, a nurse in Toronto shared a difficult experience with a couple where a patient's wife objected to her husband's wish for

MAiD on religious grounds, necessitating professional education on the nature of the procedure to counter the incorrect and stigmatizing information about MAiD.

Her priest had told her that if they went through with this at the hospital, the doctor who helped ... should be charged with murder ... The priest told her that because it was suicide, that would be on the death certificate and his life insurance would be null and void. He scared her ... She was distraught ... Eventually, she came around because he would not give it up ... And so she came in and we talked about it. She actually wrote a letter apologizing to the doctor, because she had the same conversation with him that "you're a murderer," which was devastating to him ... it hit us emotionally very hard but I think it was a lot of emotion going into it ... I talked to her many times after, I called her routinely and make sure. (Evelyn, RN, Toronto).

Similarly, a SW explained the importance of educating patients and families about the MAiD process to ensure accurate understanding and dispel misconceptions.

My original role was mostly, if anyone brought it up, to provide [or] be a source of information. We give pamphlets that explain the process. I find that patients and families have visions of what the provision is like and sometimes it's straight out of the movies or what they've heard that the way criminals are killed when they have the death penalty. So they have envisioned really horrible deaths. (Megan, SW, Vancouver)

PCPs coordinate MAiD requests

While some hospitals and health systems had dedicated MAiD coordinators, in other institutions, PCPs took up this work in addition to their regular clinical duties. Participants organized procedural, administrative, and clinical tasks to fulfill patients' desired care pathways. Some participants working in conscientiously objecting institutions organized external assessors for clinical and eligibility assessments and facilitated transfers to a non-objecting institution, or home discharge, for the procedure. By taking on a coordinator role, PCPs relieved family members of the burden of organizing the MAiD, giving them more time to spend with the patient.

The system issues are so complicated. The first few cases that we did we weren't able to get the patient anywhere because none of the institutions had available beds, and in the end the patient died in the hospital, not through MAiD. And that began to create moral distress on my side ... because for me, this needs to be about allowing the patient to accomplish whatever goals they have. And I felt like I didn't live up to my end of the bargain, which was facilitating that wish, whatever it will be. (Stella, RN, Toronto).

Some participants thought that while their conscientiously objecting institution would not allow MAiD on site, it provided more coordination support than some non-objecting organizations. However, participants reported having to do more work to facilitate access and make the process smooth for patients and their families.

I'm sorry, I can't guarantee your assessment will happen on site. I will advocate for you and explain why we think there will be harm if we move you ... and we'll do everything we can." But the thing is, someone would be moved for the assessment and then come back here, and then they'd be moved again for another assessment, and then come back here. And then they'd be moved for the provision and they would not come back here. (Bella, RN, Vancouver)

PCPs mediate family dynamics

Participants reported helping patients and families navigate difficult relationships and tensions surrounding MAiD decisions. PCPs work to ensure there is clear communication between the patient and their family.

Henry, a palliative care physician and MAiD assessor and provider, conceptualizes his role as a referee, ensuring both the patient and the family have an opportunity to understand and appreciate each other's perspectives.

Sometimes there's discord in wishes between patients and families ... patients who had sort of said, no more chemo, I'm done, or no more antibiotics, or no more this or that, and their family's still, "Come on, Dad, one more!" ... a little bit longer, kind of thing. [My role is] to referee ... Sometimes to help the patient reinforce what they want to the family, sometimes to be a go-between. Other times, even acting in the reverse where you can see what's really important to the family and to make sure that the patient understands the impact that their decision is having, if they want to change their mind. (Henry, MD, Toronto).

A physician who identifies as a conscientious objector to MAiD described how MAiD requests can be an opportunity for clinicians to explore patients' family dynamics and identify and resolve challenging relationships with (estranged) family members at the end of life. She suggested that when patients' emotional needs and desire for connection and relationships are met, they may no longer want MAiD.

It has been surprising how [the MAiD request] is so enmeshed and entangled with other people. And how a lot is due to that relational piece, whether lack of it, or unfulfilled, or unresolved. And talking about some of those broader things, [like] are there ways we can resolve or reconcile, or bring light to these things that may help get you some closure? Usually – it's actually quite powerful for me to be able to see for those patients who – even just thinking about the driving factor(s) differently (Claire, MD, Toronto).

Discussion

The 48 PCPs interviewed described their roles working with patients and family members across all stages of the MAiD process. Our findings echo several Canadian studies, which suggested that, while patients are the final decision makers to request and consent to MAiD, family members play an important role throughout various stages of the decision-making process (Beuthin *et al.* 2021; Frolic *et al.* 2020; Hales *et al.* 2019; Holmes *et al.* 2018; Oczkowski *et al.* 2021; Thangarasa *et al.* 2021). Building on these studies, we conceptualize a triadic relationship between care providers, patients, and their families, each playing an important role in MAiD decision-making.

Previous Canadian studies find that family members prioritized the patient's decision to have MAiD over their personal opinions or reservations about the decision, underscoring the need to attend to familial well-being and dynamics in patients' end-of-life and MAiD journeys (Frolic *et al.* 2020; Holmes *et al.* 2018). Our findings highlight the intersecting interests and tension between patients and their families in MAiD decision-making. As some patients may pursue MAiD because they worry about burdening their families, to truly honor both patients and their families, PCPs must navigate the patient's broader decisional context and intersecting concerns, including whether the patient truly wanted MAiD if other options were available (Ho *et al.* 2021).

Our interviewees held variable views on MAiD, with some identifying as conscientious objectors and others acting as MAiD assessors and providers. Despite their personal views on MAiD's moral permissibility, all PCPs shared that when patients initiate a discussion about MAiD, they provide emotional support and counseling to both patients and families as appropriate. Navigating their intertwining roles in each stage of the MAiD process, participants held firm their professional obligations to understand patients' suffering and available options to ease their distress, clarify patients'

end-of-life care goals in their broader socio-relational context, and facilitate the most appropriate care pathway that respects patient autonomy, upholds their well-being, and supports family members. Participants described how some aspects of coordinating and facilitating MAiD requests led them to feel moral distress, for example, when they could not fulfill patients' end-of-life wishes, such as accessing desired socio-relational resources or MAiD.

In accordance with previous studies, participants stated that when patients chose to pursue MAiD, they provided substantial psychosocial support to families throughout the MAiD process and beyond the patient's death (Beuthin et al. 2021). Providing such support is important, as families that do not feel supported by PCPs or experience critical tones and colder approaches from PCPs may suffer further "hurtful roadblocks" in the emotionally charged process (Hales et al. 2019). This contrasts with another Canadian study where PCPs identified a significant emotional challenge with supporting the grief of family members who were present at the time of provision (Shaw et al. 2018). Given Shaw's study was performed in the first 6 months following the legalization of MAiD, it is possible that the challenge was partly associated with the lack of experience in the early days and that such difficulty eased after PCPs gained expertise in managing MAiD inquiries or cases. Nonetheless, since PCPs who conscientiously object to MAiD or fear psychological repercussions related to this process may experience their own distress as they support patients and families in navigating end-of-life care journey, more emotional and interprofessional support for PCPs as they continue to provide patient- and family-centered care in the evolving legal MAiD landscape may help to enhance respectful and compassionate triadic decision-making (Bouthillier and Opatrny 2019).

Echoing other studies, many participants reported providing a considerable amount of education to families surrounding the complex MAiD process (Hales et al. 2019). Participants requested that more robust and easily accessible educational resources (e.g. pamphlets, conversation guides, and training courses) should be developed to enhance PCPs' efficiency in their work, freeing up their valuable time to provide psychosocial support to families. As patients' MAiD inquiries, decisions, and deaths may create a myriad of emotions for families that change over time, the development of more effective tools and resources to enhance support for families throughout the MAiD pathway, particularly to address stigma, secrecy, and bereavement following MAiD provision, can enhance the triadic collaboration (Yan et al. 2022). Enhancing methods to identify which families would benefit from support before, during, and after MAiD provision may also help institutions allocate professional palliative care resources more equitably to support patient- and family-centered care.

Limitations and future research

Participants were self-selected to take part in this research study. As a result, there may be a selection bias toward clinicians who felt comfortable talking about their MAiD-related experiences in a research context. Our findings are rooted in the local contexts of 2 large Canadian cities and may not reflect the experiences of PCPs in more rural or remote areas of the country. Future research should explore the experiences of PCPs working in these geographical regions.

For this study, we interviewed PCPs, excluding those working in other specialties, including family medicine. Health-care providers practicing in other areas of medicine may have different patient populations and different experiences engaging in MAiD

decision-making triads. Further research with patients and families regarding their experience in the decisional triad may also determine stakeholder experience congruence. Future research should also investigate how PCPs' experiences with MAiD conversations and triadic decision-making evolve over time.

Future research may also examine this decision-making triad in the context of the new legislation changes (March 2021) for patients at risk of losing capacity who choose to sign advance directive for MAiD and those whose natural death is not reasonably foreseeable. Legislation changes scheduled to take effect in 2024 may expand eligibility further to include individuals with mental illness as their sole underlying medical condition (Government of Canada 2023). Research should continue to investigate clinicians' experiences with MAiD decision-making as legislative changes are enacted.

Conclusion

This is the first Canadian study, to our knowledge, to investigate PCPs' experiences engaging with patients and families in MAiD decision-making triads. This research finds that PCPs encompass multiple roles in working with patients and families to make decisions about MAiD, including providing emotional support and counseling, balancing confidentiality between patients and families, providing education, coordination support, and mediating family dynamics. As patients and families may require different forms of support throughout the MAiD process, PCPs can benefit from institutional and interprofessional resources to enhance their ability to support patients and families in decision-making and bereavement.

Competing interests. The authors declare none.

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