

Canadian family members' experiences with guilt, judgment and secrecy during medical assistance in dying: a qualitative descriptive study

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Abstract

Background: Although research briefly mentions that family members have encountered unexpected experiences during the medical assistance in dying (MAiD) process, from keeping MAiD a secret, to being judged and feeling guilty, the potential implications of these are less understood. This study's aim was to examine guilt, judgment and secrecy as part of the MAiD experiences of family members in Canada.

Methods: We conducted a qualitative descriptive study with 1-hour semistructured interviews by telephone or video from December 2020 to December 2021. Through local and national organizations, we recruited Canadian family members with MAiD experience. A subset analysis of unexpected experiences was conducted, which identified 3 categories: guilt, judgment and secrecy. Similar codes were grouped together within each category into themes. Participants were sent the draft manuscript and their suggestions were integrated.

Results: A total of 45 family members from 6 provinces who experienced MAiD from 2016 to 2021 participated. Many people who had MAiD were diagnosed with cancer, comorbidities or neurologic disease. Some participants unexpectedly found themselves managing guilt, judgment and/or secrecy, which may complicate their grieving and bereavement. Numerous participants experienced judgment from relatives, friends, religious people and/or health care professionals. Many kept MAiD secret because they were not allowed to tell or for religious reasons, and/or selectively told others.

Interpretation: Family members said they were ill-prepared to manage their experiences of guilt, judgment and secrecy during the MAiD process. MAiD programs and assessors/providers could provide family-specific information to help lessen these burdens and better prepare relatives for common, yet unexpected, experiences they may encounter.

Medical assistance in dying (MAiD) was decriminalized in 2015 in Quebec¹ and 2016 in Canada, and eligibility criteria were amended in 2021.² A person deemed eligible for MAiD intentionally ends their life when a physician or nurse practitioner (excepting in Quebec) administers lethal medications intravenously or by the person ingesting medications themselves.² Family members' valuable insights about their MAiD experiences have indicated their particular needs, such as anticipatory grieving, knowing when death will occur and witnessing death.³⁻¹⁰ Individuals often choose to discuss their MAiD decision with others, such as family members, who may be involved throughout and after the procedure. Relatives often provide emotional, spiritual, physical and logistical support to patients but are often undersupported by MAiD providers and programs with little time and resources.^{3,6-8,11-13} Although patients and families may prepare and conduct research about death and MAiD,^{12,14} their needs may go unheeded, as the process is complex, time-constrained and patient-focused.^{7,9,11,15,16} The MAiD

literature is mainly positive, although numerous researchers briefly mention unexpected experiences of family members, such as being judged, people voicing objections or keeping it secret.^{5,7,11,12,17-20} However, the details surrounding these experiences remain underexplored.

No matter how much they prepare, families may feel unprepared for MAiD, as most literature concentrates on clinical aspects and the person having MAiD, although this is

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changing.^{3,5,9,11,19,20} Losing someone by MAiD can have a long-lasting effect, and family members may require additional compassionate care.^{4,5} Families may encounter unwanted criticism and stigmatism from opposers (e.g., relatives, friends and professionals)^{5,7,13} or feel guilty, burdened, trauma or stress about planning or supporting MAiD, or keeping a MAiD death secret,^{3,7,9,12,19} which can complicate their bereavement and mental health.^{7,8,21–24} However, keeping it secret may also protect them from judgment and objections.^{5,25} Family members' prolonged guilt and trauma tend to be underrecognized by professionals and MAiD programs because their involvement with relatives often ends at death.^{7–9,21} Health care professionals may also not know that MAiD is kept secret^{7,11,12,17–19} and unintentionally overlook relatives' unique needs, which may undermine family-centric care.^{7,8,26,27} Support and bereavement options may be limited if relatives do not feel comfortable discussing MAiD, and what they need could differ depending on how involved they were in the process.²¹ While conducting the analysis, we identified that many interviewees discussed unexpected experiences. The research question is, how did Canadian family members who went through MAiD encounter unexpected experiences? As unexpected experiences may negatively affect family members' grief, bereavement and well-being,^{4,5} our aim was to examine a subset of these: guilt, judgment and secrecy.

Methods

A qualitative descriptive study was conducted, wherein researchers closely adhere to the data and describe a range of experiences using participants' own words and meanings^{3,7,10,18–20,22,28,29} from the interviews and during coding.^{28,30,31} Interviews had myriad information about family members' experiences, and the full analysis was used to develop patient and family guides for Nova Scotia Health and Dying with Dignity Canada. This paper focuses on the data subset of unexpected experiences, defined by responses to interview guide question 27 (Appendix 1, available at www.cmajopen.ca/content/11/4/E782/suppl/DC1) asking about surprises or what participants felt unprepared for. We also coded unexpected experiences discussed in responses to other questions. Additional data analyzed are beyond this paper's focus.

Sampling and recruitment

Recruitment used convenience and purposive sampling and occurred in steps from December 2020 to December 2021.³² It began with Nova Scotia Health's MAiD nurse navigator phoning and inviting family members of people who died through MAiD to participate, as the researchers did not have access to them. Dying with Dignity Canada and Bridge C-14 posted English and French study advertisements on Facebook and emailed these to members. To recruit from provinces and territories with no participants, we advertised through personal contacts, the Canadian Association of MAiD Assessors and Providers, Dying with Dignity Canada's provincial coordinators, LinkedIn and Maritime Strategy for Patient-Oriented Research SUPPORT Unit. Family members who

experienced a MAiD death in Canada were invited to email us, were screened for eligibility and signed the consent form, and then the interview was booked.

Data sources

MAiD literature about families' experiences^{6,7,9,17–19,22,27,33} informed the semistructured interview guide's open-ended questions. We improved questions as we learned while conducting interviews. The guide was pilot-tested with a family member who experienced MAiD to ensure questions were asked in lay language, and their data was included. No authors knew the other participants.

Experienced interviewer E.T.C. trained J.L. and E.L. and attended their first 3 interviews. After this, 1 researcher conducted a 1-hour semistructured interview per participant in English (J.L. conducted and translated one in French) by telephone, Zoom or Microsoft Teams. Participants were informed they did not have to answer questions that made them uncomfortable and could withdraw without consequence. To establish rapport and help participants feel comfortable, the interview began with questions about them and the person who received MAiD (e.g., ages, diagnosis and MAiD date). Authors made notes and, at the end, we asked for anything else important to them and how we could contact participants to critique the draft manuscript. Although we could refer to Bridge C-14, Dying with Dignity Canada or Nova Scotia Health MAiD program for support, no participants were referred to these supports.

All participants digitally signed the informed consent form. We digitally recorded and transcribed interviews verbatim. One participant requested their transcript and added 2 clarifying quotes, but no others did.

Data analysis

We thematically analyzed interviews in Microsoft Word.^{17,28–30} While analyzing transcripts as interviews occurred, we noted many participants discussed unexpected experiences. To test the coding process within the whole data set, we read the first 20 interviews and category card-coded all sentences^{31,32,34–36} that discussed unexpected experiences (Appendix 2, available at www.cmajopen.ca/content/11/4/E782/suppl/DC1). During this process, each sentence was divided into core subjects and descriptor words, and extraneous words were removed.³¹ We then grouped the 20 participants' common experiences into 3 categories (guilt, judgment and secrecy) and analyzed this data subset in the remaining interviews. To round out the 3 categories, we looked for codes that were new or contradicted, supported or clarified these.³² To help ensure anonymity, we grouped similar codes within each category together to create themes. We met to compare codes, categories and themes, and discussed differences, resolving disagreements through discussion.

Trustworthiness criteria^{37,38} are discussed in Appendix 3, available at www.cmajopen.ca/content/11/4/E782/suppl/E782. As MAiD occurred over 5 years and participants were heterogeneous, data saturation occurred when no new themes were identified in the subset analysis.³² It was necessary to interview

a larger number of participants to ensure data saturation for each of the 3 categories (guilt, judgment or secrecy), since many did not experience all 3 of these. We also did not want to turn away participants. Our disciplines as health care researchers, providers and students and identities as cisgendered, educated women shaped data interpretation, as we are neither involved in nor experienced with MAiD. Data were collected and analyzed from a position of middle-class heteronormativity and White privilege, and thus we may have overlooked experiences important to participants who do not have our privileges. To ensure our interpretation accurately reflected participants' experiences, they critiqued the draft manuscript. We discussed and integrated suggested changes (e.g., to correct spelling, and clarify that not all participants experienced each theme).

Ethics approval

This study was approved by the Nova Scotia Health Research Ethics Board (no. 1023965).

Results

Forty-five interviews with family members of people who had MAiD in Canada were conducted (Table 1). Most participants were the spouse/partner or child/stepchild of the person

who had MAiD. No participants declined to participate or dropped out. All MAiD deaths occurred from 2016 to 2021. Recipients of MAiD had numerous conditions and diseases, but cancer was the most common (Table 2). Although we recruited from all provinces and territories, participants were from 6 provinces. Participants' involvement in MAiD ranged from periodic contact, sometimes at a distance, to going through the entire process with a family member; thus, some were more involved than others. Overall, most family members had a mainly positive experience and were grateful their suffering relative had the option to choose MAiD. Many participants experienced an accelerated MAiD death as their family member was often very ill. Although most found MAiD assessors, providers and services supportive, the process was not always clear, they forgot information, and they would have liked print or online materials with details. As part of the grief and bereavement processes, most wished for more time with their family member and found letting go difficult. However, many participants also reported major and minor experiences with guilt, judgment and/or secrecy.

Family members' experiences

Family members reflected on their experiences of guilt, judgment and secrecy during the MAiD process. The following sections contain the themes identified in each of the 3 categories. The discussion within each theme follows the order of the quotations listed in Table 3, Table 4 and Table 5.

Guilt

Multiple participants experienced guilt and a few experienced trauma. Quotations are provided in Table 3.

Table 1: Characteristics of participants	
Characteristic	No. (%) n = 45
Age, yr	
20–29	1 (2.2)
30–39	3 (6.7)
40–49	7 (15.6)
50–59	13 (28.9)
60–69	13 (28.9)
70–79	7 (15.6)
80–89	1 (2.2)
Province	
Alberta	2 (4.4)
British Columbia	7 (15.6)
Manitoba	1 (2.2)
New Brunswick	1 (2.2)
Nova Scotia	24 (53.3)
Ontario	10 (22.2)
Relationship to person who had MAiD	
Spouse/partner or ex-spouse/partner	17* (37.0)
Child/stepchild	27* (58.7)
Sibling	1 (2.2)
Niece/nephew	1 (2.2)

Note: MAiD = medical assistance in dying.
*One participant experienced MAiD with 2 people.

Table 2: Characteristics of people who had medical assistance in dying	
Characteristic	No. (%)*
Year had MAiD	
2016	1 (2.2)
2017	3 (6.5)
2018	6 (13.0)
2019	6 (13.0)
2020	30 (65.2)
Diagnosis	
Aged	3 (6.5)
Cancer	24 (52.1)
Comorbidities	8 (17.4)
Neurologic disease†	8 (17.4)
Other	3 (6.5)

Note: MAiD = medical assistance in dying.
*One participant experienced MAiD with 2 people, and thus data in this table add up to 46.
†Included amyotrophic lateral sclerosis, Parkinson disease, dementia and sensory neuropathy.

Table 3: Selected quotations from participants about guilt

Major themes	Quotation
Felt guilt and trauma about their role in the MAiD process	<p>“It was just a hellish process for me but I have, you know, the knowledge that I signed my mom up [for MAiD] ... Like, the fucking doctor wouldn’t do it ... It’s his job, he should have just done it. Yeah, so now I can never not have done it.” (Interview 24)</p> <p>“At one point, I almost felt like I was an accomplice to murder.” (Interview 26)</p> <p>“I didn’t want her to die, but I didn’t want [her] to be afraid. ... And so I had a conversation with her. And I feel so guilty about this because I suggested, ‘Maybe [you’d] feel better if you just thought about, like, a date.’ ... And so I feel guilty because ... maybe she thought I thought she was a burden. ... I hope not. Oh God.” (Interview 38*)</p> <p>“I wondered when he had MAiD was it really assisted suicide? ... And so, I was like, ‘Oh God, did I, did I help with that? Like did I, did I just give up?’ ... I reckoned with that and the fact that ... we really had no choice if he wanted to have to go out on his own terms.” (Interview 45)</p>
Distress during and after the MAiD death	<p>“I’m going to use the word traumatic. You know, this is going to have a lasting effect on you. ... Yeah, seeing someone dead will traumatize you.” (Interview 16)</p> <p>“In the first few days afterwards I was quite haunted, just by the memory of being with her you know, right after she passed, with her body. ... I just remember not sleeping very well, and thinking like, wishing for just a little bit more time. Which I think is natural.” (Interview 21)</p> <p>“I was not prepared for the size of the needles and the number of needles ... to me, they look like needles one would use on a large animal like a veterinarian needle. But I guess that’s what it takes, and the combination of drugs.” (Interview 45)</p> <p>“When they were administering the medication, like, it was described to me that this would be, like, really peaceful. But she started, kind of gurgling, like, almost dry heaving, except it was not dry and that scared me a lot. But it was only seconds and then it was over. But then I said, ‘Oh my God, she’s gonna throw up, like, we need to help her.’ And everyone was like ‘Calm down, calm down.’ ... It was pretty fast. ... I still keep wondering to this day, is, ‘What was she thinking? She’s choking, did she change her mind? Is that why she was choking?’ That’s what I keep thinking.” (Interview 28)</p>

Note: MAiD = medical assistance in dying.
 *Information that Interviewee 38 added to clarify their quote is in square brackets.

Feelings of guilt about their role in the MAiD process

Several participants felt guilty about helping organize MAiD, such as getting involved when a health care provider refused to assess or refer their family member. Other participants felt they were “an accomplice to murder” (Interview 26). Choosing a date for MAiD could result in guilt: “‘Maybe [you’d] feel better if you just thought about, like, a date.’ ... And so I feel guilty” (Interview 38). One participant wondered if they had participated in assisted suicide and several felt guilty for giving up on their relative.

Distress during and after the MAiD death

Although many participants were grateful their family member was eligible for MAiD, some experienced distress during and after the death. One participant described that “seeing someone dead will traumatize you” (Interview 16). However, as it is now rare to witness death and see a body, trauma and feeling haunted may not have resulted from MAiD itself. Some were “not prepared for the size of the needles and the number” (Interview 45). Other participants said they were ill-prepared for the sounds, movements and expressions of their dying family member, which continued to distress them. The noises and involuntary body movements during the death could be difficult to forget, which led several participants to think their family member was changing their mind as the medications were being injected.

Judgment

Many participants reported being judged by relatives, religious people, health care professionals and organizations, and others before, during and after MAiD. Quotations are provided in Table 4.

From relatives

Numerous participants experienced judgment from relatives — most of these relatives did not want the person to have MAiD. A few even said they resisted MAiD until they realized how much their relative was suffering. Some suspected their relatives tried to convince their family member not to have MAiD. One sister judged their mother for having MAiD, which “created a total rift with my sister” for years after the death (Interview 23). Other siblings disagreed about MAiD, as one sister would not print or give MAiD paperwork for their mother while the other did.

From religious people

Much of the judgment experienced was owing to religious people not believing in MAiD or not accepting that someone had it. One participant protected their mom from religious family to avoid difficult situations. A religious person told a participant that the person who had MAiD was “going to burn in hell fire forever” (Interview 11). Numerous participants were judged by Catholics who believe life, suffering and death are sacred. Some Catholics openly expressed objections “‘cause in the church, you’re not allowed to kill yourself in

Table 4: Selected quotations from participants about judgment

Major themes	Quotation
From relatives	<p>“His girlfriend, long-term girlfriend, ... they’d been together for 25 years, she didn’t want him to do it, you know. And I’m sure she had conversations with him trying to convince him otherwise.” (Interview 5)</p> <p>“It [MAiD] created a total rift with my sister and I, really for a year and a half to 2 years. And the only way to try to repair the relationship is to avoid any discussion of MAiD and my mother. Not possible.” (Interview 23)</p> <p>“So, suddenly, like my mom was quite unwell and I talked to her and she asked again if she couldn’t have assisted dying. So that’s when I picked up the ball. Because I’m not a practising Catholic and I believe in and support MAiD. ... I ... found out the paperwork that was required and sent it along to my mom and my sister. And that’s when I discovered that my mom, she couldn’t use her technology anymore so, she wasn’t able to be able to print anything. And my sister was not invested in helping her. So, like, nothing happened because my sister wouldn’t print the paperwork and get my mom to sign it.” (Interview 24)</p>
From religious people	<p>“If it wasn’t me and my sister and my daughter and my niece there supporting Mom, like if it was anybody else in her family ... they would be imposing their [religious] views on her. ... that would have been a very uncomfortable ... challenging ... situation for my mom to be in.” (Interview 6)</p> <p>“He said, ‘Oh, I heard your wife died.’ And I said, ‘Yeah, she had an assisted death.’ And he just looked at me and said, ‘She’s going to burn in hell fire forever.’” (Interview 11)</p> <p>“They are very Catholic They think that you should just suffer for those last 3 days and be unconscious and go through all that and Like instead of doing it [MAiD]. ‘Cause in the church, you’re not allowed to kill yourself in any way.” (Interview 30)</p> <p>“It was like ‘I don’t believe in that [MAiD], you’re not gonna go to heaven.’ You know. ‘God brings you in, God takes you out.’ We got lots of those comments.” (Interview 41)</p>
From health care professionals/ organizations	<p>“One other frustrating aspect was the hospice nurse was of Catholic origin and she was very, she was trying to persuade Dad a lot about not receiving it. Like even the day before he died she was talking about, ‘Oh well, this isn’t my belief and blah blah blah blah.’ So, I wasn’t too excited with that and stood guard.” (Interview 33)</p> <p>“The hospice that she was in was the [religious organization] hospice, so they would not permit her to have MAiD there. She still had her own home so we were able to transport her back to her own home.” (Interview 35)</p> <p>“I do recall her saying that there was some initial pushback from her GP. And you know, she’s a strong, like I said, [she] knew what she wanted, told him how it was and found her workaround.” (Interview 36)</p>
From others (e.g., friend, coworker, neighbour)	<p>“One woman [neighbour] said to me, ‘Oh, what’s wrong with him? There’s nothing wrong with him.’ Because they might see him out[side] doing some little thing, right. And as long as he could get up and move, he would go out and try to do stuff.” (Interview 2)</p> <p>“Who gives a shit what they think.” (Interview 12)</p> <p>“Mostly very supportive, they understand. I’ve heard no condemnation. I think perhaps because the people that I know and that I relate with ... understand the process and they understand why it took place.” (Interview 15)</p> <p>“The only comment I ever had was someone I didn’t really know very well, but she had my husband for a doctor so, thought he was wonderful. She said to me, ‘I couldn’t do that to my dog, and you did it to your husband,’ and she walked away.” (Interview 29)</p> <p>“I told my friend as this was happening and they were entirely supportive. The first people I told, was my oldest friend when we were 8 years old, and I knew what her reaction would be and it was not good. ... but she said ... when the new legislation got approved ... ‘I just cannot fathom anybody doing that.’” (Interview 42)</p>
<p>Note: GP = general practitioner, MAiD = medical assistance in dying.</p>	

any way” (Interview 30) and they thought the person would not go to heaven. However, a few participants reported that a priest or deacon was present during death, even though MAiD contravened their faith.

From health care professionals/organizations

Participants were judged by health care professionals, such as palliative care providers, physicians or nurses. A few participants said a Catholic health care professional tried to persuade their relative not to have MAiD. Some gravely ill people were staying in a religious hospice or hospital that “would not permit her to have MAiD there” (Interview 35), and family members often helped arrange their move home or somewhere else to have it. Some physicians declined to do MAiD paperwork, refused to talk about MAiD or “there was some initial pushback from her [general practitioner]” (Interview 36), creating an access barrier.

From others

Multiple participants received negative reactions from friends, neighbours, coworkers, community members and so on, some who thought MAiD was not right. A neighbour judged the person having MAiD as not ill enough to die. Some participants did not care what others thought. For many, other people were “mostly very supportive” (Interview 15). But, several participants received comments such as “I couldn’t do that to my dog, and you did it to your husband” (Interview 29). Even some close friends reacted negatively when they learned about MAiD, while others did not.

Secrecy

Many participants engaged in secrecy before, during and after MAiD. During interviews, which occurred 6 months to more than 4 years after MAiD, numerous participants said it

Table 5: Selected quotations from participants about secrecy

Major themes	Quotation
Person having MAiD did not want others to know	<p>“It was his choice ... if he wanted everyone to know, he could have told them.” (Interview 1)</p> <p>“[spouse] didn’t want no one to know. ... she didn’t even want her father to know, her brother to know. ... It was our 2 kids, her best friend and my 2 neighbours, which had to sign a consent form, right. ... I had to go out and tell [spouse]’s father what had happened ... he knew that [spouse] was going to do it but [spouse] didn’t want him to know.” (Interview 8)</p> <p>“Nobody else really knew about it. I didn’t tell my children until everything was decided. It was like the day before. He didn’t want anybody to know. He wanted it to be his decision and he wanted that power. ... And he didn’t want the kids to know. And I said, ‘Well, you know, I don’t agree with that, but I will do it.’” (Interview 9)</p>
Not wanting to defend someone else’s MAiD decision	<p>“When it was over, I didn’t have the strength to tell the truth, to have to sit in discussion with a dozen people and justify [husband]’s decision.” (Interview 7)</p> <p>“People who are not very close ... it’s irrelevant to them. ... I really don’t want them to ask questions about [MAiD], snooping.” (Interview 22)</p> <p>“It absolutely felt like I was keeping this weird secret, partially for my own self-preservation and partly because I felt like it was a private decision. And legally you’re allowed to be absolutely private about it and I agree with that 100%, nobody deserves to know, you know, nobody’s entitled to information. ... it’s still awkward, it really is.” (Interview 27)</p>
MAiD is (not) a dirty secret	<p>“I just felt like it was a big, bad, dirty secret.” (Interview 6)</p> <p>“She didn’t shy away from it. She wanted people to know she’d used MAiD, she put that in her obituary. This-this was not a secret. And so I think by not making it a secret, even though people didn’t always understand, they can still be supportive.” (Interview 22)</p> <p>“It feels like this is, like, some kind of shameful secret. I know my brother was really, like, embarrassed about it too.” (Interview 28)</p>
Selectively sharing MAiD with others	<p>“We certainly informed our children but only after the diagnosis was terminal We told them that that [MAiD] was going to be a part of the process for her. And ... her immediate family. Yeah. So we really didn’t discuss it. We informed, you know, the people that mattered.” (Interview 4)</p> <p>“Once she was gone it was ... almost like a hierarchy of who this story belonged to. And I think until dad became more comfortable with talking about it, I didn’t talk about it as openly.” (Interview 21)</p> <p>“No one knows other than a core set of friends and family, how she chose to go ... I think in her generation there was still a stigma, which saddens me.” (Interview 25)</p> <p>“It’s happened quite a few times where I’ve been talking about her and someone asks a question ‘cause clearly they don’t know [about MAiD]. And I have that moment where I have to decide whether or not I want to tell the whole thing.” (Interview 40)</p>
Waiting to tell others about MAiD	<p>“She was buried with her parents and she’s a Catholic. Nonpractising, of course. Then we realized we could be refused. That is, we were told not to say it [MAiD] right away, to wait until later.” (Interview 39)</p>

Note: MAiD = medical assistance in dying.

was the first time they had talked about MAiD as they did not know how to tell others, or their (religious) relatives were uncomfortable with them telling anyone. Quotations are provided in Table 5.

Person having MAiD did not want others to know

Some MAiD recipients did not choose to tell others: “if he wanted everyone to know, he could have told them” (Interview 1). Others allowed participants to tell after their death. One participant “had to go out and tell [spouse]’s father what had happened” (Interview 8), while others kept it secret. One person who died by MAiD “didn’t want anybody to know” (Interview 9) until the day before the procedure.

Not wanting to defend someone else’s MAiD decision

Participants kept MAiD secret because they did not want to “justify [husband]’s decision” (Interview 7) or did not want people they did not know well “to ask questions ... snooping” (Interview 22). One participant kept MAiD secret “for my

own self-preservation and partly because I felt like it was a private decision” (Interview 27).

MAiD is (not) a dirty secret

Although this was not prevalent, some participants did refer to MAiD as a “big bad dirty secret” (Interview 6) or a “shameful secret” (Interview 28). However, others did not keep it secret and their obituary mentioned MAiD.

Selectively sharing MAiD with others

Although MAiD was secret, some participants chose to selectively share it with trusted friends, relatives, coworkers, neighbours or others going through it. A few families told immediate family “only after the diagnosis was terminal” (Interview 4), while others waited until family members became more comfortable telling others. However, owing to one participant’s fear of stigma, “no one knows other than a core set of friends and family” (Interview 25). Several needed to decide in the moment “whether or not I want to tell” (Interview 40).

Waiting to tell others about MAiD

A few participants held off divulging MAiD for religious reasons. They kept it secret until after their family member had a Catholic funeral and was buried in a Catholic cemetery, which the church prohibits for MAiD recipients.

Interpretation

This research captures important information to increase understanding about 3 unexpected yet common family member MAiD experiences: guilt, judgment and secrecy. Dying and MAiD are complex experiences, and individuals respond to death and loss differently. Many family members did not feel adequately prepared for MAiD or the aftereffects. This, along with being involved in planning death and watching someone die, led to some participants experiencing guilt and trauma. Some did not expect to be judged by relatives, friends, religious people and/or health care professionals who opposed MAiD. Many interviewees kept MAiD secret in some form; some never told anyone about MAiD while others selectively told trusted supporters. Most family members said they were unprepared for guilt, judgment and secrecy, perhaps because they lacked experience with death and MAiD.

The literature generally portrays MAiD positively,^{10,11} but studies briefly mention experiences of guilt, burden, discomfort or blame.^{4,6,7,18,22,34} Our study captures the nuances of guilt from participating and trauma from witnessing a relative's death, especially if it was accelerated. Although they helped plan a family member's death,^{3,7,8,10–12,33} some participants unexpectedly found themselves managing guilt, judgment and/or secrecy, which may further complicate their grieving and bereavement process.^{5,7–9,12,21,23,33} Health systems focus on the MAiD patient, not family members' needs.^{7,8,26,27} For example, some participants have found not knowing what to do with the body traumatic.¹⁷ Family members' guilt and trauma seem to be underrecognized by clinicians and MAiD programs, because professionals' involvement with relatives typically ends at death, and there are few resources for relatives.^{5,7–9,12,13,21–23}

Although researchers have mentioned judgment, they do not discuss who was judging and why.^{6–9,12,17,39,40} Many participants were unprepared for religious people, health care providers and hospices criticizing or not participating in MAiD²⁷ and felt unprepared to manage this. Most participants kept MAiD secret in some form^{6,7,12,17–20} because the person who had MAiD did not want others to know²¹ or for religious reasons. Some participants selectively shared MAiD, if telling did not conflict with the recipient's wishes.^{7,22,24,39} Other family members did not tell opposers about MAiD although many tried to include opposers in the dying process.¹⁷

Future research could examine whether family members benefit from having information or support for managing guilt, judgment and secrecy. They could continue unearthing the relation between guilt, trauma and complicated grief. Testing different educational and support initiatives to help relatives manage their experiences could be helpful (e.g., arts-based initiatives, counselling and support groups). To help

ensure broader representativeness of families' experiences, Canadian participants could be recruited and interviewed in multiple languages, and researchers could collect demographic data (e.g., gender, ethnicity, education, income, religion and rural or urban residence). MAiD programs could include information about guilt, judgment and secrecy in family resources and provide or refer relatives to MAiD-specific grief and bereavement supports (e.g., Bridge C-14 and counsellors).²³ As family members' level of involvement in the MAiD process may affect their experiences,^{3,26} we suggest that future researchers collect this information.

Limitations

As the nurse navigator phoned participants in Nova Scotia and invited them to participate, she may not have contacted families without telephones, and some may have felt obliged. To avert coercion, interviewers consented each participant and indicated they could withdraw from the study. Half of the participants were recruited using social media study advertisements with national organizations, which indicates they had privileges of Internet access and time. Participants were from 6 provinces and were not asked about their level of involvement in the process; thus, this may not represent all experiences. Ethnicity was not collected for the first 20 interviewees; 24 of the next 25 were White. Interviewing diverse participants may identify cultural and social differences about death and dying, which could enrich the data. This study was designed by clinicians and researchers; future studies and the interview guide should be co-designed and tested with multiple family members.

Conclusion

This study provides detailed insights into 3 unexpected yet common MAiD experiences of Canadian family members: feeling guilt and trauma, being judged and keeping MAiD secret. MAiD programs could develop or enhance resources for and have conversations with families about managing these challenges. Our study may also alert MAiD organizations about helpful information for families. Governments and health systems could use this research to identify gaps and improve family experiences with MAiD.

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