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3 **Canadian family members' experiences with guilt, judgment and secrecy during Medical**  
4 **Assistance in Dying (MAID): A qualitative interview study**  
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## Abstract

**Background:** Although research briefly mentions that family members experienced unexpected surprises during Medical Assistance in Dying (MAID), such as being judged or feeling guilty, these have not been examined in depth. The objective was to investigate three common MAID experiences of family members in Canada: guilt, judgment and secrecy.

**Methods:** A qualitative study with one-hour semi-structured interviews by telephone or video was conducted. Family members with MAID experience were recruited via local and national organizations. Transcript sentences were inductively coded for guilt, judgment and secrecy. Similar sentences were grouped together to create categories. All participants were invited to review the draft manuscript and their changes were integrated.

**Results:** Forty-five family members from 6 provinces who experienced MAID from 2016-20 participated. The person who had MAID was most often diagnosed with cancer, co-morbidities or neurologic disease. Most participants experienced guilt, judgment and/or secrecy. Over 35% experienced guilt and/or trauma from watching their family member die and being involved in planning their death. Nearly 50% experienced judgment from relatives, friends, religious people and/or healthcare professionals. Almost 70% kept MAID secret because they were not allowed to tell, for religious reasons and/or only told trusted people such as close friends.

**Interpretation:** The results suggest that family members could benefit from information addressing how to manage guilt, judgement and secrecy. Family members lack some valuable information about the MAID process, which led to some experiencing guilt and trauma. MAID programs and assessors/providers should provide family-specific information and support to help lessen the burden on family members and better prepare them for unexpected surprises they will likely encounter.

## Introduction

Medical assistance in dying (MAID) became legal in 2015 in Quebec<sup>1</sup>, 2016 in the rest of Canada and the eligibility criteria was amended in 2021.<sup>2</sup> With MAID, a person is administered or takes medications to intentionally end their life. Family members are often involved throughout a person's MAID journey, supporting them emotionally, spiritually, physically and logistically.<sup>3-8</sup> Family members have provided valuable information about their MAID experiences and feedback about the process.<sup>3,5,6,8,9,10</sup> Although helping plan MAID may help people better prepare for and accept someone's death<sup>7,11</sup>, family needs such as having non-clinical information about the process are not often addressed by the health system.<sup>4,6,9</sup> Moreover, the MAID process is complex<sup>12</sup> and can be confusing for patients and families.<sup>9,13</sup> Researchers have briefly mentioned that family members experienced unexpected surprises during MAID, such as being judged<sup>4,6,7,14</sup> or keeping MAID secret<sup>4,6,7,14,15,16,17</sup> but no research has examined these types of experiences in depth, even in jurisdictions where MAID has occurred for decades.

During the process, families and patients may encounter criticism and/or opposition from people who do not agree with MAID, including their own relatives, friends and healthcare providers.<sup>6</sup> Families and patients may feel unprepared for MAID because the literature and health systems mainly focus on clinical and procedural issues such as bereavement, quality improvement and timing.<sup>3,4,9,16</sup> Several studies have documented that family members involved in MAID may suffer from guilt and trauma, which can complicate bereavement.<sup>6,8,18,19,20</sup> Family members' prolonged guilt and trauma tend to be under-recognized by healthcare professionals and MAID programs because their involvement with the patient's relatives often ends at the person's death.<sup>6,8,9,18</sup> Although briefly mentioned in the literature, healthcare professionals may also not be aware that some family members keep MAID secret to avoid judgment or defending another person's decision. As family members may not have experienced MAID or death before, they may feel guilty, burdened or stressed about the role they had in planning and/or supporting someone's MAID death.<sup>3,6,7,9,16,21</sup> Keeping MAID secret may limit support and bereavement management options for family members since they do not feel comfortable or may not be permitted to discuss it.<sup>18</sup> Furthermore, although health professionals often communicate with families, they may inadvertently overlook family members' needs since the primary focus is on the person having MAID.<sup>6,8,22,23</sup> This study examines the experiences of family members who have gone through the MAID process in Canada. Our objective is to examine three unexpected and surprising yet quite common experiences that family members encountered during MAID: guilt, judgment and secrecy.

## Methods

Recruitment began with the Nurse Navigator from Nova Scotia (NS) Health MAID Access and Resource Team phoning family members of people who had died by MAID and asking if they would like to participate. Then, we recruited across Canada through English and French Facebook study advertisements posted and sent out by Dying with Dignity Canada and Bridge C-14. To recruit participants from provinces and territories with no interviews, we advertised through personal contacts, Bridge C-14, the Canadian Association of MAID Assessors and Providers, Dying with Dignity Canada's provincial coordinators, Linked-In and the Maritime Strategy for Patient-Oriented Research SUPPORT Unit. Recruiting and interviews occurred from December 2020 to December 2022.

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3 We conducted 1-hour semi-structured interviews in English and French by telephone,  
4 Zoom® or Microsoft Teams®. Interviews were conducted by the three authors. An interview  
5 guide was used (Supplemental File 1) with open-ended questions that asked about family  
6 members' experiences before, during and after MAID. All participants signed the consent form  
7 and this study was approved by the Nova Scotia Health Research Ethics Board (#1023965).  
8 When the interview started, participants were informed they did not have to answer questions  
9 with which they were uncomfortable and they were free to withdraw from the study without  
10 consequence. To establish rapport and help participants feel comfortable, the interview began  
11 with questions about the participant's demographics and the person who had MAID.  
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13 The 3 researchers recorded and transcribed interviews verbatim and analyzed them as  
14 they were completed. We read the first 20 interviews and, using the same analysis as our other  
15 publications,<sup>24-27</sup> inductively coded the sentences<sup>28</sup> which discussed unexpected and/or  
16 unpleasant surprises encountered during MAID. We grouped codes about unexpected surprises  
17 together and 3 prevalent categories surfaced: guilt, judgment and secrecy. For the next 25  
18 interviews, we coded all sentences discussing any of the 3 categories. Then, to help ensure  
19 anonymity, we grouped similar sentences within each of the 3 categories together to create  
20 themes. To enhance trustworthiness, we coded each others' interviews and met regularly to  
21 discuss coding. Data collection was stopped when data saturation was achieved (i.e., no new  
22 information about the 3 themes was identified).  
23

24 The researchers' are all white women. ETC has a PhD, was a patient and currently  
25 volunteers as a Patient Advisor on Nova Scotia Health committees. JL is an undergraduate  
26 student being paid as a research assistant. EL is a senior neurosurgery resident. None of the  
27 researchers knew the participants. As there was an assumption that questions would be important  
28 to family members, participants were asked if there was anything else they wanted to discuss. As  
29 we have not experienced MAID as a family member and to ensure our interpretation reflected  
30 their experiences, all participants were invited to critique the draft manuscript. We discussed and  
31 integrated the changes participants suggested.  
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## 35 Results

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38 Forty-five interviews with family members of people who had MAID in Canada were  
39 conducted (Table 1). All MAID deaths occurred between 2016 and 2021. People who had MAID  
40 had a variety of conditions/diseases, but cancer was most common (Table 2). Although we  
41 actively recruited from all provinces and territories, participants from 6 provinces volunteered to  
42 participate. Three prominent themes reflecting family members' experiences with MAID were  
43 identified: guilt, judgment and secrecy (Table 3).  
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46 \*\* Insert Table 1. Characteristics of participants about here \*\*  
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48 \*\* Insert Table 2. Characteristics of people who had MAID about here \*\*  
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50 \*\* Insert Table 3. Guilt, judgment and secrecy themes and quotes about here \*\*  
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53 **Guilt.** More than thirty-five percent of participants experienced guilt during MAID. Guilt  
54 occurred throughout the process and trauma occurred during and after the death as most  
55 participants had never seen someone die. Participants experiencing trauma said they were ill-  
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3 prepared for the sounds, movements and expressions as the person was dying; this continued to  
4 distress some of them for years. For instance, some had recurring flashbacks of the person's  
5 expression as they were dying while others could not forget the noises:  
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8 *"in the first few days afterwards I was quite haunted, just by the memory of being with her you  
9 know, right after she passed, with her body. ... I just remember not sleeping very well, and  
10 thinking like, wishing for just a little bit more time. Which I think is natural"* Participant 21  
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12 *"And so, when they were administering the medication, like it was described to me that this  
13 would be like really peaceful. But she started, kind of gurgling, like almost dry heaving, except it  
14 was not dry and that scared me a lot. But it was only seconds and then it was over. But then I  
15 said, 'Oh my God, she's gonna throw up, like we need to help her', and everyone was like 'Calm  
16 down, calm down.' ... It was pretty fast. ... I still keep wondering to this day, is, 'What was she  
17 thinking? She's choking, did she change her mind? Is that why she was choking?' That's what I  
18 keep thinking."* Participant 28  
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21 Although many participants were grateful that it was an option for their ill family member, 25%  
22 said they felt guilty for their (heavy) involvement in the MAID process. Some said their  
23 participation was traumatizing. For example, several participants felt guilty about their central  
24 role in helping organize MAID and/or suggesting the person having MAID set a date for the  
25 procedure:  
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28 *"And so I wondered when he had MAID was it really assisted suicide? ... And so I was like, 'Oh  
29 God, did I, did I help with that? Like did I, did I just give up?' ... I reckoned with that and the  
30 fact that ... we really had no choice if he wanted to have to go out on his own terms."*  
31 Participant 45  
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34 *"At one point, I almost felt like I was an accomplice to murder."* Participant 26  
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36 Some interviewees felt guilt for helping when a healthcare provider refused to assess or refer  
37 their family member for MAID:  
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40 *"It was just a hellish process for me. But I have, you know, the knowledge that I signed my mom  
41 up [for MAID]... Like the fucking doctor wouldn't do it... It's his job. He should have just done  
42 it. Yeah, so now I can never not have done it."* Participant 24  
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45 **Judgment.** Twenty-four participants experienced judgment before, during and after  
46 MAID. Notably, one-third of family members experienced judgment from their relatives/friends  
47 – most who did not want the person to have MAID:  
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49 *"his girlfriend, long term girlfriend, ... they'd been together for 25 years, she didn't want him to  
50 do it, you know. And I'm sure she had conversations with him trying to convince him otherwise."*  
51 Participant 5  
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53 *"the first [person] I told, was my oldest friend. And I knew what her reaction would be and it  
54 was not good."* Participant 42  
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4 One participant talked about their relationship with a sibling breaking down due to their parent  
5 having MAID:  
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8 *“it created a total rift with my sister and I, really for a year and a half to two years. And the only  
9 way to try to repair the relationship is to avoid any discussion of MAID and my mother. Not  
10 possible” Participant 23*  
11

12 Almost half of family members experienced a negative reaction from others (e.g., neighbors, co-  
13 workers, community members) who thought MAID was “not right”. Some participants said other  
14 people looked uncomfortable when they found out a relative had MAID or thought the person  
15 having MAID was not ill enough to die, such as:  
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18 *“one woman [neighbor] said to me, “Oh, what's wrong with him? There's nothing wrong with  
19 him.” Because they might see him out[side] doing some little thing, right. And as long as he  
20 could get up and move, he would go out and try to do stuff.” Participant 2*  
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23 Nearly half the judgments participants experienced were due to religious beliefs, such as a  
24 religious person saying they did not believe in MAID or cannot accept that the person went  
25 through with it. Some relatives and other acquaintances tried to convince people not to have  
26 MAID or openly expressed their religious objections to MAID, making the process  
27 uncomfortable for the family:  
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30 *“if it wasn't me and my sister and my daughter and my niece there supporting mom, like if it was  
31 anybody else in her family ... they would be imposing their [religious] views on her. ... that  
32 would have been a very uncomfortable ... challenging ... situation for my mom to be in”.*  
33 *Participant 6*  
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35 Many participants reported being judged by someone Catholic because their religion considers  
36 life, suffering and death sacred, such as:  
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39 *“His statement is ... ‘We believe that life is very special ... or sacred.’ You know, he worded it  
40 properly, but he wasn't in favour of [MAID].” Participant 12*  
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42 According to Catholic beliefs, people who die by MAID cannot have a funeral or burial.  
43 However, several participants said they have kept MAID secret as their family member wished  
44 to have a Catholic funeral and be buried in a Catholic cemetery. Some priests and deacons  
45 permitted a Catholic funeral or burial and were in the room when MAID occurred even though  
46 MAID contravened their faith. However, religious people also told three participants that the  
47 person who had MAID is going to hell:  
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50 *“He said, ‘Oh, I heard your wife died.’ And I said, ‘Yeah, she had an assisted death.’ And he just  
51 looked at me and said, ‘She's going to burn in hell fire forever.’” Participant 11*  
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54 One-fifth of participants reported that they or their family member were judged by healthcare  
55 professionals, such as palliative care, physicians and/or nurses. Some said that physicians had  
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declined to do the MAID paperwork, stalled the process or refused to talk with their family member about MAID. One coroner even classified a person's MAID as suicide, which was shocking to the participant:

*"this is about half an hour, 45 minutes after he died. The coroner and he's calling to tell me that he's got the information about my husband's death and he died by suicide. That's the exact word that he said to me. ... I was like in shock. I kind of was a little argumentative. But I didn't have the energy for it."* Participant 44

One participant said a healthcare professional tried to persuade their family member not to have MAID. Some people having MAID were residing in a religious organization that did not permit it, such as a hospice, and needed to be moved to another organization that permitted MAID when they were gravely ill. This made family members feel judged:

*"I believe she was provided with information by the social worker who worked at the Hospice, but ... the [religious] 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 ... by ambulance."* Participant 35

**Secrecy.** Many participants said they engaged in secrecy about MAID before, during and after the process. At the time of the interview, fifty percent of the family members said they had not divulged MAID to other people. For example, several participants did not know how to tell others that their family member had gone through MAID, others did not want to have to justify someone else's decision to have MAID or their (religious) relatives were uncomfortable with them telling anyone about it. In fact, twenty-three percent of the people who died by MAID asked their family member not to tell others about it:

*"It was his choice ... if he wanted everyone to know, he could have told them."* Participant 1

*"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."* Participant 7

Almost half of participants said during their interview with the authors, which occurred 6 months to over 4 years after the MAID death, that this was the first time they had talked about it. Many also experienced shame, in that:

*"I just felt like it was a big, bad, dirty secret."* Participant 6

*"It feels like this is like some kind of shameful secret. I know my brother was really, like embarrassed about it too."* Participant 28

Although a more rare experience, one participant's relatives forbid them from talking about the MAID procedure:

*"I wasn't allowed to talk about it. I was never allowed to talk about it again."* Participant 30

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3 Despite many participants keeping MAID secret, some selectively share it with a few trusted  
4 friends, relatives, co-workers, neighbors, etc. or someone else who was also going through  
5 MAID. Some interviewees initially kept MAID a secret because they did not know how to say it,  
6 did not want others to discourage MAID or the person having MAID wanted it to be secret. A  
7 quarter of participants only talked about MAID if someone specifically asked if their family  
8 member was doing/had done MAID. Their experiences are summed up as:

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11 *“It's happened quite a few times where I've been talking about her and someone asks a question*  
12 *'cause clearly they don't know [about MAID]. And I have that moment where I have to decide*  
13 *whether or not I want to tell the whole thing.” Participant 40*

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16 *“we certainly informed our children but only after the diagnosis was terminal ... We told them*  
17 *that that [MAID] was going to be a part of the process for her. And I guess her family as well -*  
18 *her immediate family. Yeah. So we really didn't discuss it. We informed, you know, the people*  
19 *that mattered.” Participant 4*

## 20 21 22 **Interpretation**

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24 **Main results.** This research captures crucial information that increases understanding  
25 about common family member experiences during MAID: guilt, judgment and secrecy. No  
26 matter how much research or advance preparation they did, many family members did not feel  
27 adequately prepared or supported during MAID. This, along with being involved in planning  
28 their family member’s death and watching them die, led to participants experiencing trauma and  
29 guilt. They were judged by relatives, friends, neighbors, religious people and/or healthcare  
30 professionals who did not agree with the MAID decision, which was outside of the family  
31 member’s control. The majority of interviewees kept MAID secret; some never told anyone  
32 about the MAID death while others selectively told trusted friends, relatives and supports. Most  
33 healthcare providers and MAID programs did not help families prepare for such unpleasant  
34 experiences. The negative and positive results reported were influenced significantly by family  
35 members’ data.

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39 **Explanation of findings.** Our study participants did not expect to manage guilt,  
40 judgment and secrecy. Experiencing these may further complicate grieving and  
41 bereavement.<sup>8,20,29</sup> Even if people prepare for someone’s death by helping plan it,<sup>3,5,6,7,8,10,29</sup> a  
42 third of our participants experienced guilt and/or trauma which could complicate  
43 bereavement.<sup>6,7,8,9,18,19,20</sup> The literature generally portrays MAID as a positive experience<sup>5,10</sup> but  
44 some participants found the dying and death process guilt-inducing and traumatic, especially if it  
45 was accelerated.

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47 Even though many family members plan and/or support someone’s active  
48 death,<sup>3,6,7,9,16,21,29</sup> the health system’s focus on the MAID patient, not family members’  
49 needs.<sup>6,8,22,23</sup> Studies mentioned family members experience guilt, burden, discomfort or blame  
50 for being involved in MAID<sup>5,6,15,19,29</sup> but most do not provide details. Our study captures the  
51 nuances of feeling guilty from participating in the process and trauma from witnessing someone  
52 dying and their death. For example, some participants did not know what to do with the body  
53 after MAID which was traumatic.<sup>14</sup> Family members’ guilt and trauma seem to be under-



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3 recognized by clinicians and MAID programs because their involvement with relatives often  
4 ends at the patient's death.<sup>6,7,8,9,18,19,20</sup>

5 Although researchers mentioned judgment, it does not discuss who was judging and why.  
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4,6,7,8,9,14,30,31 Many of our participants were unprepared for healthcare providers and religious people and hospices judging, criticizing or not participating in MAID<sup>23</sup> and did not know how to respond to judgment. For example, our participants had negative reactions from relatives, friends, health professionals, etc. because these people disagreed with MAID, did not want the person to have MAID or had religious objections. Most said being judged bothered them.

The majority of participants kept MAID secret in some form. We unearthed why families kept MAID secret<sup>4,6,7,14,15,16,17</sup> (e.g., the person who had MAID did not want others to know<sup>18</sup>, they divulged MAID selectively and religious reasons). Some selectively shared MAID, if it did not conflict with the wishes of who was having it.<sup>6,19,21,30</sup> Some family members did not tell MAID to relatives who opposed it which could have excluded them from the dying process.<sup>14</sup>

**Future directions.** Future researchers could study whether family members benefit from having access to information and details about managing guilt, judgment and secrecy. Researchers could also examine if there is a relationship between experiencing guilt, judgement and secrecy and grief-bereavement<sup>29</sup> difficulties. To ensure representativeness of family member experiences Future researchers should collect demographic data (e.g., race, education, income, religion, rural/urban, etc.) and recruit widely across Canada. MAID programs could create information packages about common unexpected surprises to increase family members' awareness.

**Limitations.** NS participants were recruited by the nurse navigator by telephone; thus, some may have felt obliged to participate. People without telephones may not have been contacted. As half of the participants were recruited using social media study advertisements with national organizations, participants had the privileges of internet access and time for an interview. We did not collect race for the first 20 interviewees; all but 1 of the other 25 participants were white. A simultaneous limitation and strength are the variety of family members but they are not from all provinces and territories. The study was originally designed by clinicians and researchers without input from family members. Our approach of asking questions and probing responses gave us richer, in-depth data, but meant that participants were not asked every question and were asked different probing questions.

**Conclusion.** This study provides detailed insights into unexpected MAID experiences of Canadian family members: feeling guilt and trauma, being judged and keeping MAID secret. MAID programs and healthcare providers could develop resources for and have conversations with families about managing these challenges. Our study can help MAID providers, programs and advocacy organizations enhance existing family information. Governments and health systems can use this research to identify gaps and improve family experiences.

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<b>Table 1: Characteristics of participants</b>	
<b>Age</b>	<b># participants (%)</b>
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%)
<b>Province</b>	
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%)
<b>Relationship to person who had MAID</b>	
Spouse/Partner or Ex-Spouse/Partner	17* (37.0%)
Child/Stepchild	27* (58.7%)
Sibling	1 (2.2%)
Niece / Nephew	1 (2.2%)
*One participant experienced MAID with 2 people	

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<b>Year had MAID</b>	<b># (%)*</b>
2016	1 (2.2%)
2017	3 (6.5%)
2018	6 (13.0%)
2019	6 (13.0%)
2020	30 (65.2%)
<b>Diagnosis</b>	
Aged	3 (6.5%)
Cancer	24 (52.1%)
Co-morbidities	8 (17.4%)
Neurologic disease**	8 (17.4%)
Other	3 (6.5%)
* One participant experienced MAID with 2 people, thus data in this table adds up to 46	
** Included ALS, Parkinson's, dementia and sensory neuropathy	

Theme (# Participants discussed, %), n=45	Sub-themes (# Participants discussed, %)	Exemplar quote
Guilt (16, 35.6%)	Felt guilt / shame about helping during MAID process (11, 24.4%)	"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." Participant 38*
	Loss of family member (in house) traumatic (4, 8.9%)	"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" Participant 16
	Trauma from seeing syringes / someone dead (9, 20.0%)	"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-that's what it takes, and the combination of drugs" Participant 45
Judgment – from relatives / friends (14, 31.1%)	Tried to convince person not to have MAID or against MAID (14, 31.1%)	"he just kept at me about it [MAID]. And then he said, like, 'I have to get it done. Whether I have to do it on my own, I'm going to get it done.' I said, 'You can't do without me, [husband].' He said, 'Yes, I can.' I said, 'I don't think so.' But it was me that was trying to stop the process until I seen how bad he wanted it and how bad he was feeling and like he was deteriorating." Participant 3
	MAID exacerbated family rift (2, 4.4%)	"my sister ... did not do anything. ... I followed up and found out ... the paperwork that was required and sent it along to my mom and my sister. ... nothing happened because my sister wouldn't print the paperwork and get my mom to sign it." Participant 24
Judgment – from others (e.g., neighbor, co-workers) (21, 46.7%)	People reacted negatively (20, 44.4%)	"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" Participant 25
	"Who gives a shit what they think" Participant 12 (3, 6.7%)	"I don't care what other people think about it. ... Doesn't concern me at all." Participant 26
	People don't understand unless they went through MAID (5, 11.1%)	"someone I didn't really know very well ... said to me, 'I couldn't do that to my dog, and you did it to your husband,'" and she walked away. ... I didn't do it!" Participant 29
Judgment – from religious people (22, 48.9%)	Catholics don't believe in MAID, no Catholic funeral/burial, going to hell (12, 26.7%)	"my mom was buried in Catholic cemetery next to her parents and we weren't sure if the Catholic Church could have refused that burial if we would have made that [MAID] public" Participant 37

	Believe life, death and suffering are sacred (4, 8.9%)	“they are very Catholic ... They think that you should just suffer for those last three 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” Participant 30
	Religious people are against MAID (14, 31.1%)	“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.” Participant 41
Judgment – Healthcare professionals (9, 20.0%)	Physician would not do paperwork, discuss or refer (6, 13.3%)	“I do recall her saying that there was some initial pushback from from her GP. And you know, she's a strong, like I said, person knew what she wanted, told him, how it was and and found her work-around” Participant 36
	Hospice did not permit MAID (2, 4.4%)	“the Hospice that she was in was the [religious organization] Hospice, so they would not permit her to have MAID there.” Participant 35
	Healthcare professional persuading person not to have MAID (1, 2.2%)	“the Hospice nurse was of Catholic origin and 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’ ... So, I wasn't too excited with that and stood guard.” Participant 33
	Coroner said died by suicide not MAID (1, 2.2%)	“That coroner phones me again. But he wants to go over the details of the death.. And just to remind me but it was suicide. ... I said, ‘No, he didn't die of suicide. He had pancreatic cancer.’ And then he gave me the rules of the five different deaths internationally. ... He gave me that little lecture and said it was suicide.” Participant 44
Secrecy (31, 68.9%)	Person having MAID didn't want people to know (11, 22.2%)	“[spouse] didn't want no one to know. ... she didn't even want her father to know, her brother to know. ... It was our two kids, her best friend, and my two 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 because he'd be down here.” Participant 8
	Participant (initially) did not tell others/post MAID on social media (28, 62.2%)	“once she was gone it was sort of... like 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.” Participant 21
	Don't want to justify MAID or people to ask questions (3, 6.7%)	“people who are not very close ... it's irrelevant to them. ... I really don't want them to ask questions about [MAID], snooping” Participant 22
	Religious reasons (5, 11.1%)	“She was buried with her parents and she's a Catholic. Non-practicing 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.” Participant 39



	(Shameful) secret, not allowed to say MAID (13, 28.9%)	“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” Participant 27
	Selective sharing (29, 64.4%)	“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.’” Participant 9

\*Information that Participant 38 added to clarify their quote is in square brackets.

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## Interview Guide

A qualitative study of families and informal supports' experiences with the medical assistance in dying (MAiD) process in Canada

*This is \_\_\_ investigator interviewing participant # \_\_\_. This is interview # \_\_\_ completed on \_\_\_ date.*

*I'd like to make it clear that you can withdraw from the interview at any time. You can also request not to answer a specific question at any time. If any names or personal details are mentioned, these will not be translated into the written records, rather an ID number will be assigned and your data will be anonymized.*

*Thank you for joining me today, I appreciate you taking the time. Do you have an hour to talk with me? If you see me looking off to the side sometimes, it's because I'm writing down notes.*

*In this study, we are interested in learning about your experiences with medical assistance in dying or what is often called MAiD.*

*It's ok if you are emotional, this is an emotional topic. I have my tissues ready too.*

Introduction:

1. Can I confirm that you have signed the consent form to permit audio recording of our interview? Check with Jocelyne about this.
2. Do you have any questions before we begin?
3. Do you understand the instructions?
4. Are you willing to proceed with this interview?

Background:

5. Would you be willing to share your age?
6. The person you know who had medical assistance in dying, MAiD, were they your spouse, child, parent?
7. In a few sentences, how would you describe this person?
8. What was their diagnosis?
9. How old were they at their diagnosis? How old were they at the time of their death?
10. How long had they been ill before their death?
11. When was their medically assisted death?
12. Was this your first experience with death?
13. Was this your first experience with MAiD?
14. What did you think about MAiD before \_\_\_ had MAiD?

*I'd now like to ask you about what happened before the person went through MAiD.*

Prompt

Can you tell me about what happened before they went through MAiD?

Before MAiD:

15. Did you and the person discuss MAiD before they began the process?
  - a. If so, do you recall when you first had that discussion?
  - b. If so, how long was it from the time of their diagnosis until they first considered MAiD?
16. Why do you think \_\_\_\_\_ decided to have MAiD?
17. What was your role when they were talking about MAiD?
18. Did you seek out information regarding MAiD? If so, where did you find it?
19. What did you think about the information you had about MAiD before the death?
20. When you found out \_\_\_\_\_ was going to have MAiD, did you seek out support? If so, what support? If not, why do you feel you did not need support?
23. How long was it from the time of their request for MAiD to when they died?
  - a. What did you think about that amount of time?
24. What do you think could be improved or different before MAiD?

*I'd now like to ask you about what happened as the person was going through MAiD.*

Prompt

Can you describe what happened on the day of MAiD?

Day of MAiD

24. Were you there in the room on the day of their MAiD death?
  - a. If yes, have you been present for other deaths? If so, how did MAiD compare to this?
  - b. If no, was this at yours or \_\_\_\_\_ request?
  - c. Who else was there on the day of MAiD?
  - d. What did you do in the hours before the death occurred?
25. Where did the death take place?
  - a. Ex: in hospital, in a nursing home, private home
26. Who administered the MAiD medications?
27. Was there anything about the procedure itself or the day of death that surprised you or you felt unprepared for?
28. What do you think could be improved or different on the day of MAiD?

*I'd now like to ask you about what happened after the person went through MAiD.*

Prompts

Can you tell me what you did immediately and in the months after the MAiD death?

Can you tell me about the support system you had before, during and after MAiD.

After MAiD:

29. What did you do after the MAiD procedure was finished?
30. Has the person's decision to have MAiD and being involved in the process changed how you think about MAiD?
  - a. If so, in which ways?
  - b. If not, why do you think that is?

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- 3 31. Were there times during the process that you felt alone, confused or under-supported? If
- 4 so, please tell me more about this.
- 5 32. In your experience, what could be done to improve the MAID process?
- 6 33. If someone else was interested in MAiD for themselves, what would you say to them?
- 7 34. If you fit the eligibility criteria, would you ever consider MAiD for yourself?
- 8 a. If so, why?
- 9 b. If not, why?
- 10 35. What kind of support did you have after the person's MAiD death?
- 11 36. Did you seek out support groups or counselling services?
- 12 a. If yes, can you tell me about who you reached out to?
- 13 b. If not, why did you not seek out these?
- 14 37. Do you think you needed different bereavement supports because \_\_\_\_ had MAID?
- 15 38. Did you tell others how this person died?
- 16 a. If yes, how did they react?
- 17 b. If no, why not?
- 18 39. Has anyone judged you because your \_\_\_\_ had MAID? Did you feel shamed or that you
- 19 had to keep MAID a secret?
- 20 40. What other support do you think people need if they are going through MAiD with
- 21 someone?
- 22 41. Was MAiD put in the person's obituary or information about their death?
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27 Closing Remarks:

- 28 42. Is there anything else that you want to talk about with your MAID experience that we did
- 29 not discuss?
- 30 43. Do you have any questions for me or about the research?
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