

Original Article

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Improving the Medical Assistance in Dying (MAID) process: A qualitative study of family caregiver perspectives

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Abstract

Objective. The road to legalization of Medical Assistance in Dying (MAID) across Canada has largely focused on legislative details such as eligibility and establishment of regulatory clinical practice standards. Details on how to implement high-quality, person-centered MAID programs at the institutional level are lacking. This study seeks to understand what improvement opportunities exist in the delivery of the MAID process from the family caregiver perspective.

Method. This multi-methods study design used structured surveys, focus groups, and unstructured e-mail/phone conversations to gather experiential feedback from family caregivers of patients who underwent MAID between July 2016 and June 2017 at a large academic hospital in Toronto, Canada. Data were combined and a qualitative, descriptive approach used to derive themes within family perspectives.

Result. Improvement themes identified through the narrative data (48% response rate) were grouped in two categories: operational and experiential aspects of MAID. Operational themes included: process clarity, scheduling challenges and the 10-day period of reflection. Experiential themes included clinician objection/judgment, patient and family privacy, and bereavement resources.

Significance of results. To our knowledge, this is the first time that family caregivers' perspectives on the quality of the MAID process have been explored. Although practice standards have been made available to ensure all legislated components of the MAID process are completed, detailed guidance for how to best implement patient and family centered MAID programs at the institutional level remain limited. This study provides guidance for ways in which we can enhance the quality of MAID from the perspective of family caregivers.

Introduction

In June 2016, following the decision of the Supreme Court of Canada to legalize assistance in dying, the Canadian government enacted Bill C-14, which amended the federal Criminal Code and permitted Medical Assistance in Dying (MAID) under certain conditions.

The road to legalization of MAID across Canada has largely focused on legislative details such as eligibility and establishment of regulatory clinical practice standards. As such, details on how to implement high-quality, person-centered MAID programs at the institutional level are lacking. With implementation left to the individual institutions or practitioners, there is a need to better understand opportunities for improvement that will minimize negative experiences for patients and family caregivers.

Prior international studies have examined patient perspectives regarding the choice to pursue MAID, understanding family caregiver role, or exploring clinician attitudes toward MAID (Ganzini et al., 2008; Lee et al., 2009; Nuhn et al., 2018; Smith et al., 2015; Shaw et al., 2018; Wiebe et al. 2018). Family member experience has also been evaluated (Dignitas, 2017; Gamondi et al., 2015, 2018; Harrop et al., 2016; Holmes et al., 2018; Swarte et al., 2003) and focused primarily on their journey toward MAID acceptance, the bereavement experience or their support need; however, few have studied this specifically to understand their views of potential quality gaps within the MAID process. Further, in Canada, there has been very little guidance on operationalizing a high-quality, patient- and family-centered MAID process at an institutional level. At the provincial level, to date, only Alberta has implemented a province-wide MAID program; therefore, it has largely fallen to individual institutions to design local MAID programs.

This study seeks to understand family caregiver perspectives of the MAID experience, as currently implemented at a large, urban academic health sciences center, and what improvement opportunities they might identify.

Methods

Study setting

This study took place at a large academic health sciences center in Ontario, Canada. Patients in either an inpatient or outpatient setting most commonly express a “desire to die statement,” which triggers an exploratory discussion with a member of their care team. Clinicians that are comfortable engaging in these exploratory discussions with patients seek to understand the patient’s needs and provide information on available end-of-life options. For clinicians who are uncomfortable discussing all possible end-of-life options, including MAID, a referral can be made to the institution’s ethicist who will facilitate a referral to a clinician that is willing and available to discuss with the patient. Thereafter, if the patient wishes to proceed with a written request, the College of Physicians and Surgeons of Ontario process map is followed, with the support of the institution’s ethicist.

Study design and participants

This was a multi-methods study including a structured survey, focus group, and/or an unstructured e-mail/phone conversation. A family member (or another key contact) of patients who underwent MAID at our hospital between July 2016 and June 2017 were invited to participate. Family members were identified from the organizations database of MAID cases, which were maintained and secured by the ethics center. The database includes key contact information for patients and family caregivers who participated in the process. Non-English speakers were excluded.

Participants could contribute via a structured survey, a focus group, and/or unstructured e-mail/phone conversation. Data collection was facilitated by the principal investigator, a quality improvement professional with no direct involvement in the MAID processes. Additional facilitators were made available during the focus group.

A letter of invitation was mailed to eligible family members outlining the purpose and voluntary nature the study. Follow-up phone calls or e-mails were conducted to capture nonrespondents. Unstructured feedback was gathered via e-mail/phone for those who did not wish to participate via other methods.

The structured MAID quality survey was designed based on a prior, validated survey regarding end-of-life care experiences at our organization (Sadler et al., 2014). This validated survey includes questions regarding patient and family-centered domains of care important at end of life, as identified in the literature (Teno et al., 2001) and provided an evidence-based foundation for our structured MAID survey. Additional questions regarding MAID-specific processes and experiences were drawn from the “Seventh report on quality control of Dignitas’ services in relation to accompanied suicide” (Dignitas, 2017). The final survey was 30 questions. Because both the quantitative and qualitative questions were derived from previously validated tools, we did not pilot test with our study population.

The focus group used Experience-Based Design methodologies (Bate & Robert, 2016) to capture the experiences of MAID family members (and patients) via an emotional mapping exercise

(Dewar et al., 2010). This methodology was selected because it is designed to plot participants’ positive and negative experiences in relation to a process/service and identifies where it must improve from the users’ point of view (Dewar et al., 2010). It involves mapping emotions and trigger points onto a process map to better understand the participant experience. The mapping exercise was followed by a semistructured debrief and general group discussion, which were recorded. Audio recordings were transcribed verbatim for analysis by an independent transcriptionist. Survey results, as well as e-mails and notes from telephone conversations, were transcribed for analysis.

This study was approved by the organization’s Research Ethics Board (REB #232-2017) and all participants provided consent to participate.

Data analysis

Narrative data from the three participant sources (focus group, survey, and unstructured e-mail/phone conversations) were pooled by the principal investigator to enhance comprehensiveness of the data for thematic analysis. A qualitative, descriptive approach was used to derive themes as they emerged from the narrative data (Sandelowski, 2000). Repetition and similarities/differences were used as theme-identification techniques (Pope et al., 2000; Ryan & Bernard, 2003).

Following thematic analysis, opportunities/themes were grouped into broader defined categories using a selective coding process. Because of the sensitive nature of the topic, the study team did not recontact participants to review the transcripts; however, if requested, they received a summary of any MAID process changes made.

Results

Of the 21 MAID deaths between July 2016 and June 2017, there were 27 eligible study participants (family/other). A detailed breakdown of invitations (and noninvitations) and responses is provided in Figure 1. Among 27 eligible participants, 23 were sent study invitations, and a total of 11 contributions representing unique patients were received (48% response rate) via the three methods for participation.

Narrative data were specifically analyzed with a view to understand family perspectives of the MAID process. As such, emerging themes take the form of opportunities for change or improvement, as opposed to general patient/family experience themes. Positive experiences or feedback were not included as themes emerging from the data (because they do not reflect opportunities for improvement). Table 2 outlines illustrative comments from study participants.

The improvement themes identified through participant feedback were grouped in two broad categories: operational and experiential aspects of the MAID process.

Operational improvement opportunities

Process clarity

Families reported that a lack of clarity regarding the MAID process led to unnecessary complexity and anxiety. In this most pervasive operational improvement theme, negative emotions were triggered during the initiation of the MAID request, where families expressed that they (or their loved ones) were unclear on how to make a request, how long it would take, and who

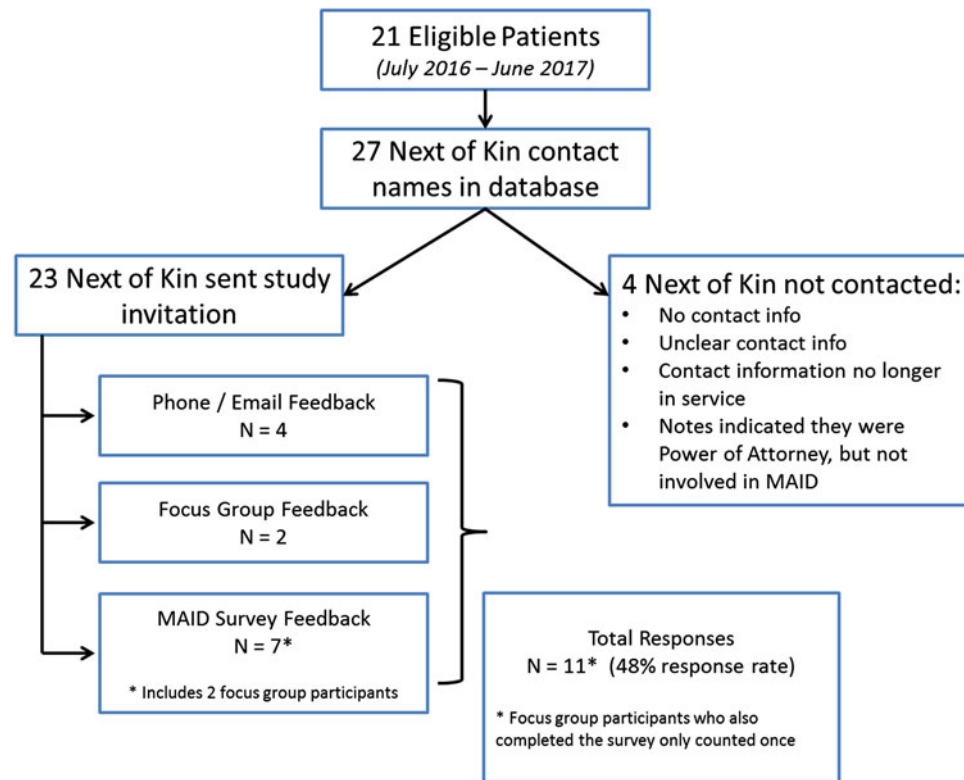


Fig. 1. Study response rates. MAID, Medical Assistance in Dying. NOK, Next of Kin.

they should approach. The latter was particularly relevant for inpatients that were unsure whether their current care providers would be involved and supportive.

There was a lack of clarity among respondents regarding who would be involved in the MAID process, including whether there was a “MAID team” to coordinate the process. Following the completion of MAID, the involvement of the coroner evoked a sense of “illegality” in the process for some families, and some found the involvement of organ and tissue donation professionals confusing and distressing.

Further aspects of process clarity pertained to MAID eligibility, as well as details regarding the medications that would be given, or how long families would have with their loved one following their death.

Scheduling challenges

Family members were distressed by challenges in the scheduling of MAID because of availability of space and human resources on their preferred date. Hospital occupancy and the availability of required clinicians often contributed to delays or rescheduling of the MAID procedure.

Ten-day period of reflection

The greatest source of negative emotion expressed by respondents was with respect to the mandatory 10-day period of reflection before the MAID procedure. Often described as “cruel,” families reported significant distress caused by this legal requirement, including anxiety about the potential loss of capacity of their loved one before the MAID procedure.

Table 1. Available characteristics of respondents*

Relationship of respondent to patient	Location of death
Spouse/partner (5/11)	Hospital inpatient unit (7/11)
Son/daughter (3/11)	Palliative care unit (3/11)
Brother/sister (2/11)	No response (1/11)
Friend (1/11)	

*Few participant characteristics are available because responses were anonymous and demographic details were not explicitly captured in the focus group.

Experiential improvement opportunities

Clinician objection/judgment

Study participants often described feeling a sense of judgment and/or objection from care providers with respect to their loved ones’ decision to pursue MAID. Respondents reported that frequent repetition of similar questions from clinicians and the often-critical tone of those conversations were often perceived as “hurtful roadblocks” in an emotionally charged process. Families of inpatients who underwent MAID reported a perceived change in approach from the patient’s care team following their expression of interest in MAID, with some providers being described as “cold” toward their loved one.

Patient and family privacy

The burden of keeping the decision to pursue MAID private added a layer of complexity to the experience, grief, and healing processes of many family members. Stress and anxiety around secrecy, while still engaging in logistical aspects of MAID

Table 2. Illustrative comments by theme

Category: Operational aspects	
Theme	Quotes
Process clarity	<p>It was my task to try and get in touch with the doctor [...] so, I e-mailed him. Nothing. E-mailed him again. Nothing. [...] So, I'm starting to get anxious because I don't know how long the process is going to take and I didn't realize that the doctor wasn't going to answer the e-mail. [...] So I called. I got an answer from an assistant. "No, you have to come in." So then we made the appointment to come in and so that was the first annoyance, confusion, difficulty, because no one tells you exactly how to start the process.</p> <p>The more they know the better off the situation is, so it's not so dark. At least there is a bit of light. The more information people have the better we are.</p> <p>At the very end there's this whole thing about whether the police need to get involved or not? [PI: That's right. The coroner]. And they need to do like a specific review also. That is like a funny thing to do too, to have to deal with at the end, right? [...] [...] because for both of us, the final experience was good but getting there for [us] was not very easy.</p> <p>The only detail I wish I had known was how quickly the anesthetic kicked in. I had the impression that [she] would drift off slowly over the course of a minute or two but in actual fact, she was out cold in about 5–10 seconds. From then on, the doctor clearly explained each dosage that was being given.</p>
Scheduling challenges	<p>Stressful not knowing if we would get a doctor or space for the day he wanted.</p> <p>[...] they set a date, but we had to wait the whole day until they called and said "not today, but tomorrow." That as awful for me and our three children!</p> <p>Most challenging was the change in date/time due to occupancy or bed availability. Our whole family was ready and together, and the delays (on/off/on/off) was very upsetting.</p>
10-day period of reflection	<p>Try not to wait too long for the actual date, until they are too sick!</p> <p>So [...] when you first make your request for MAID and the doctor says, "Yes, you are of sound mind and it makes sense for you," then I understand it. There should be a waiting period but [...] it's a bit cruel, right?</p> <p>The longest two weeks of my life.</p> <p>Disappointed in the 10-day waiting period. Patient almost lost capacity.</p>
Category: Experiential aspects	
Theme	Quote
Clinician judgment/objection	<p>[...] we came to the appointment and what was annoying at the appointment was [the doctor] sends, like, one of his interns first and they try and basically talk you out of it [...].</p> <p>I think the procedure was new for the nursing/support staff and some of them had a hard time with it. Many of them are very religious, which is fine, but staff need to respect wishes of patients and not dismiss a patient's beliefs. One nurse in particular was very cold to my mom. I believe the nurse asked not to be a part of my mom's care before her death, which I think, was for the best. So training staff not to be judgmental is important and continuing to allow them to opt out of care.</p> <p>Too much "are you sure" questioning.</p> <p>So the priest came and he basically said to [us], "I will not give you last rites because you pre-meditated this" and like, it was really rude and I honestly at that point wanted to hit him and kick him out of there.</p> <p>[...] once someone has made that decision [to pursue MAID] it's hurtful to put them through a process that's difficult or feels like you're putting road blocks up in front of them.</p>
Secrecy/privacy	<p>It was [his] decision to keep the decision to use MAID private except for immediate [family].</p> <p>I would hope that all patients would have access to a private room during such a difficult time. I am sure they would have arranged something but it would be nice to know that privacy for the family was assured.</p> <p>I know that it's been hard [...] because [they] will not admit to anyone how it happened, and I just kept saying [...] it's a private family matter.</p>
Bereavement support	<p>At the time? It's like – when do you access a bereavement group? Like, before or after? And how? It's really difficult after – during that week because there's the funeral.</p> <p>If you had a support group would we go? I don't know if we would. [...] I think for, I guess, chronically ill patients are their families, it's like the nurses who are coming in who should maybe take one of the main heads of the family [...] aside and say, "Listen. We know what you're going through. This is available." And then you can choose to take advantage of that ahead of time or not.</p> <p>It might help just knowing that there is, to talk to somebody who is, you know, outside of the family and you sort of lean on. Just to, you know, talk to them - but afterwards you just want to leave.</p> <p>Q: What stands out to you? Answer: driving my wife [there], knowing she wouldn't be coming home with me.</p> <p>You need someone to talk to after MAID, whether a support group or therapist out in the area we live. I know this was offered [...]. You need something in place closer to us.</p> <p>You should have at least a couple of hours with your loved one before MAID procedure. And someone to talk with after in our area(s), even if it was at our local hospital.</p> <p>I also wanted to let staff know that, in my case anyway, I grieved more before the procedure than after. So staff had to deal with me in a state they may not ordinarily see. But, knowing [she] experienced her death just the way she wanted to, shortened and minimized my grief.</p>

MAID, Medical Assistance in Dying.

and/or end-of-life care, were noted. Privacy was also raised with respect to location of MAID and patient identification within the hospital environment.

Bereavement resources

The final experiential improvement opportunity identified was in relation to nature and timing of the bereavement support

provided to MAID families. Some indicated that support before and on the day of MAID was of utmost importance, particularly for inpatients and those who felt they grieved more before the procedure, rather than after. Further comments highlighted challenges with proximity of bereavement supports to their home following MAID, because they felt it too difficult to return to the location of their loved ones' death (emotionally and logistically).

Discussion

To our knowledge, this is the first time that Canadian family caregivers' perspectives on the quality of the MAID process have been explored. Although family member experiences have been described elsewhere (Dignitas, 2017; Gamondi *et al.*, 2015, 2018; Harrop *et al.*, 2016; Holmes *et al.*, 2018), they have largely focused on understanding their unique role in navigating MAID with their loved one, the effect of MAID on family, and their bereavement and coping experiences. The findings of this study identify opportunities for improvement in the delivery of MAID in a hospital setting, as identified by those with lived experience.

Qualitative results of this study revealed opportunities for improvement related to both operational and experiential aspects of the MAID process across six themes. From an operational perspective, study participants struggled with lack of clarity surrounding the MAID process, the influence of hospital resources (beds and providers) on the timing and availability of MAID, and the highly challenging nature of the 10-day period of reflection. With respect to process clarity, although patients and families can be directed to general Canadian support literature (Bridge C-14, 2018; Dying with Dignity Canada, 2015), the logistics of navigating the MAID process varies by province, region, or city, and even by organization. National or provincial resources cannot provide the specific operational details families may need to understand the local implementation of MAID process. They must therefore be provided with organization or region-specific process maps that include specific information regarding how to initiate a MAID request, what to expect throughout the process, who will be involved, and what supports are available to them at each step. One such example of site-specific support is the "Death with Dignity" program in a Seattle cancer center, where a patient advocate is assigned to help navigate the steps involved in their assisted dying process (Loggers *et al.*, 2013).

Regarding the other operational improvement opportunities, given that the availability of MAID human and material resources and the mandatory 10-day period of reflection cannot easily be influenced, details regarding these potential roadblocks should be outlined along with alternative strategies and supportive resources available. Although a period of reflection is a common element of assisted death processes in every North American jurisdiction, with ranges of 48 hours to 15 days (Emanuel *et al.*, 2016), we found no readily available literature describing support for patients and families for this unique period.

Families also highlighted several improvement opportunities with respect to how they experience the MAID process. Influencers of their experience included clinicians' attitudes toward MAID, secrecy surrounding the MAID process, and how/when bereavement resources are made available to them.

The effect of clinician objection or judgment has not specifically been explored as part of the family caregiver or patient experience with MAID. The paucity of research in this area may be due to the variation in models across jurisdictions, where the setting (home vs. hospital) or method (patient vs. provider

administered) of the assisted death may require little to no interaction with objecting clinicians. For example, Gamondi *et al.* (2018) describe the perception that assisted suicide in Switzerland does not belong to the medical community, but rather belongs in the private or civil milieu, which may provide a level of autonomy that minimizes the effect that clinician objection or judgment can have on family caregiver experience. In the Canadian context, however, patients may be seeking MAID while admitted to a clinical institution where the providers or organization conscientiously object to MAID. The finding that clinician judgment regarding MAID requests can negatively influence patient and family caregiver experience may be of particular relevance in helping organizations determine the best model for the delivery of patient- and family-centered MAID within environments where conscientious objection is permitted.

The timing and location of bereavement support are relevant in the Canadian context, where access to MAID may be limited in specific regions, particularly rural or isolated areas, requiring MAID-seekers to travel further from home. This could potentially make access to post-MAID bereavement support more challenging. Further, bereavement support is made more complex for those burdened by the need for secrecy despite the simultaneous need to attend to multiple logistical steps in assisting their loved one in accessing MAID (Gamondi *et al.*, 2015). The challenge of the mandated 10-day wait period must also be considered when allocating predeath bereavement resources and developing support materials specific to the needs of MAID families.

Although there is great process variability across jurisdictions where assisted death has been legalized, many have adapted resources with broader applicability. There are many web-based resources to support families through all aspects of the assisted death process, developed by groups such as Dying with Dignity Canada, Bridge C-14 (Canada), or Death with Dignity (United States) that also include information for families related to grief and bereavement supports (Bridge C-14, 2018; Death with Dignity, 2018; Dying with Dignity Canada, 2015). However, most widely accessible online resources related to assisted death focus more on advocacy or creating awareness about assisted death policy and processes (Dignitas, 2018; Right to Die – Europe, 2018; Right to Die – Netherlands, 2018).

Given this diversity across jurisdictions (e.g., eligibility, setting, method, cultural specificities), patients and families experience of assisted death is at a very local level. As such, widely available resources must still be adapted to the local context to provide the degree of support necessary to positively influence their experience.

This study has several limitations. Study participants were from a single center, which may limit generalizability of our findings, particularly with respect to the nonhospital MAID experience; however, our institution provides approximately 7% of all hospital-based MAID in the province of Ontario. We therefore believe our sample strongly represents these family caregivers. Because non-English speakers were excluded, we are unable to determine whether language had any influence on the overall MAID experience. Results were aggregated, limiting the individual patient demographic data available; thus, we were unable to describe whether inpatients and outpatients who pursue MAID have differing experiences. Finally, narrative data were analyzed specifically from a quality improvement perspective and therefore did not focus on positive feedback during the theming exercise. Positive deviance is an important means of identifying high-quality practices that could be applied to other elements of the MAID experience (Bradley *et al.*, 2009).

The legalization of MAID in Canada has introduced a new pathway to patients at the end of life. Although practice standards

have been made available to clinicians to ensure all legislated components of the MAID process are completed, detailed guidance for how to best implement patient- and family-centered MAID programs at the local organizational level are immature. This study provides guidance on improving the operational processes surrounding hospital-based MAID by identifying specific quality gaps in the experience of MAID patients and their family caregivers.

Family caregivers play a critical role in supporting patients to obtain MAID (Gamondi et al., 2018) and, as such, their perspectives must be taken into account when creating guidelines or resources that support the formal legislated process (Gamondi et al., 2015). Future research in this area should focus on quality improvement interventions aimed at supporting families through the emotional challenges of the mandatory 10-day period of reflection, and the evaluation of strategies to minimize barriers to MAID such as timely and predictable access to providers and support resources.

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