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Attitudes and expectations regarding bereavement support for patients, family members, and friends: Findings from a survey of MAID providers

Engaging in the full range of experience—living and dying, love and loss—is what we get to do. Being human doesn't happen despite suffering. It happens within it. —Lucy Kalanithi[1]

ABSTRACT

Background: Bereavement following medical assistance in dying (MAID) is not fully understood. Legislation does not require providers to offer bereavement support and our health care infrastructure does not facilitate a role for physicians in this. The clinician providing MAID is often not the primary care provider and frequently has no previous or ongoing contact with the patient or family, factors that may contribute to a gap in bereavement support. In the first 2 years after MAID became legal, assisted deaths on Vancouver Island accounted for 3.6% of all expected deaths, a rate higher than elsewhere in Canada, and Island Health assembled a list of physicians providing MAID. Given the availability of data on providers and the relative lack of research on bereavement support, a study was proposed to explore current physician practices and expectations for providing bereavement support for families of patients choosing assisted dying.

Methods: A quality improvement study was designed to determine if physicians providing MAID offer bereavement support, what beliefs and attitudes underpin the support physicians provide, and what physicians believe is expected of them regarding bereavement support. A survey was developed that included statements to be ranked on a Likert scale and open-ended questions that required narrative responses. On 5 September 2019, an email invitation to complete the survey was sent to 34 physicians on the MAID provider email list maintained by Island Health. After survey responses were collected, descriptive statistics were calculated and narrative responses were analyzed.

Results: Survey respondents included 18 physicians who had provided MAID services between June 2016 and June 2018 (15 prescribers and 3 assessors). The majority agreed that patients, family members, and friends need bereavement support in the days and weeks before and following an assisted death. While the importance of bereavement support was acknowledged by 13 respondents (72.2%), the same number indicated they have neither the time nor the resources to provide this kind of follow-up. For physicians providing some form of bereavement support, most referred people to resources (community programs, grief counseling, online information) or provided printed information. Notably, 12 respondents believed providing bereavement follow-up to be part of their professional and moral obligation to families. When asked if bereavement was different for an assisted death, 13 respondents said that in their experience

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it was. Reasons for this included the newness and unfamiliarity of MAID and the potential for stigma. Respondents also shared ideas about dedicating and/or designating nonphysicians to offer bereavement support, enhancing bereavement services delivered by other groups and organizations, and generating accessible supports from the health authority in the form of printed materials or default follow-up services.

Conclusions: According to survey respondents, bereavement following a medically assisted death is unique and bereavement support is needed. While most respondents consider providing bereavement support to be a moral and/or professional obligation, they also believe this responsibility should be shared between the family physician and MAID provider. In response to findings from this study, a guide for patients and families experiencing MAID is now available to support healthy grieving.

Background

Medical assistance in dying (MAID) became legal in Canada in June 2016.[2] Because MAID is a relatively new treatment option, it is unclear at this time what, if any, bereavement support is being made available to patients, their family members, and friends. While providing support to families following MAID is considered by some physicians to be integral to end-of-life care and morally important, our health care infrastructure does not facilitate a role for physicians in bereavement. There is no standard of care for attending to anticipatory grief or ensuring bereavement support for patients and families who experience MAID. Furthermore, a clinician providing MAID is often not the primary care provider and frequently has no previous or ongoing contact with the patient or family. Together, these factors may contribute to a gap in bereavement support.

Vancouver Island experience

In the first 2 years after MAID became legal, assisted deaths on Vancouver Island (population 765 000) accounted for 3.6% of all expected deaths, a rate higher than elsewhere in Canada.[3]

The MAID process and model employed on the island relies on considerable transparency and flexibility for all involved. The names of physicians providing this service can be accessed through the website of the health authority (Island Health) or other online or print sources, and patients can self-refer for an assisted death. The MAID process can be initiated with or without the involvement of the family physician. This is an important consideration because up to 30% of people on Vancouver Island do not have a family physician. The model allows any physician to provide MAID once required education is completed. This approach differs from other Canadian jurisdictions, where physicians providing MAID may be hired by a licensing body or government authority as part of a specialized team. In many areas, patients contact a central coordinating centre for referral to a clinician for formal assessment and/or provision of MAID.

There is no standard of care for attending to anticipatory grief or ensuring bereavement support for patients and families who experience MAID.

Island Health physicians involved in MAID are either paid on a fee-for-service basis or by salary in acute care facilities. Island Health maintains a list of physicians who have provided MAID and assists with communication among these physicians, allowing them to receive collegial support and informal contact with a large group of experienced practitioners. Island Health also has an extensive database of MAID assessments and death records.

Research to date

The majority of research addressing assisted dying focuses on the experiences and perspectives of the health care team.[4-7] There has been little study of family and friends' grief following a loved one's assisted death, or the nature of the bereavement care they receive. In Canada, the Ontario HIV Treatment Network conducted a literature review to investigate the impact of MAID on family and friends.[8] They reviewed studies in different countries, with varying legal requirements and approaches to assisted death, published from1994 to 2015. Researchers in the Netherlands examined decision making about euthanasia for family and friends and reported perceptions of a bonding experience for patients, families, and physicians; they described home visits from the physician to debrief the decision afterwards as beneficial, saying that such visits "help the survivors along in their grieving process."[9] A study from the United States compared grief responses following assisted death or suicide and found both similarities and differences.[10] Those grieving an assisted death had more understanding, searched less for motivation behind the death, and experienced a somewhat "eased grief," knowing that underlying illness made death an inevitability. Most viewed the cause of death as the terminal illness and not the assisted death. Those bereaved following an assisted death expressed uncertainty in discussing it with unfamiliar people as they wished to avoid aggressive debates and/or hurtful commentary, but also an appreciation of the legal safeguards supporting the practice, and a belief that their experience was quite different from those losing a loved one to suicide. In other studies, contextual factors were identified as mitigating or complicating bereavement after assisted death. The factors included social disapproval,[11] stigma[12,13] access to information,[12] involvement in decision making,[13] and whether assisted death was legal in the country.[14]

In Canada there has been limited examination of the bereavement support offered by MAID assessors or prescribers to family and friends at the time leading up to an assisted death or through the course of their grief. In one report of MAID providers conducting follow-up, there is no mention of bereavement support specifically: "Follow-up telephone calls to families several days after each medically assisted death have been very positive, with no regrets expressed by the family."[15]

Given the relative lack of research on bereavement support, a study was proposed to explore current physician practices and expectations for providing bereavement support for families of patients choosing assisted dying.

Methods

A quality improvement (QI) study was designed to determine the following:

- Do physicians providing MAID offer bereavement support, and if so, what does this practice look like?
- What beliefs and attitudes underpin the support physicians provide?
- What do physicians believe is expected of them regarding provision of bereavement support, if anything at all?

A survey was developed collaboratively by the project team, which included two physicians who have assessed, provided, and taught MAID on Vancouver Island, a bereavement clinician from Victoria Hospice, two members of Victoria Hospice and Island Health leadership teams, and a nurse researcher from the University of Victoria. The 20-item survey included 15 statements to be ranked on a Likert scale from strongly agree to strongly disagree and 5 open-ended questions.

For the purposes of the study, bereavement support was defined broadly as any action taken by the physician intended to inform/comfort the bereaved family/friend; this included direct physician action (e.g., phone call) or indirect action (e.g., referral to counselor or social worker, provision of information sheet).

Survey questions focused on the following areas of bereavement support:

- Current practices regarding bereavement support offered to friends and family following an assisted death.
- Beliefs about professional and moral responsibility regarding bereavement support.
- Comfort level with providing bereavement support.
- Perceived strengths, gaps, and challenges physicians face in this area.
- Recommended resources to improve bereavement care for family and friends.

On 5 September 2019 an email invitation containing a link to the survey was sent to 34 physicians on the MAID provider email list maintained by Island Health. Recipients were encouraged to forward the survey to colleagues who had completed MAID assessments. Recipients were also invited to participate in an in-person, 2-hour focus group. After only one recipient expressed interest in the focus group, study funds were redirected to the development of bereavement resources for physicians to provide to patients and families.

This QI study did not require approval by a human research ethics board[16] but was registered with Island Health's QI registry. To assess risk and enhance rigor we used the ARECCI screening tool[17] to establish a screening risk score of 3, which indicates minimal risk.

Quantitative data were collated and descriptive statistics were calculated using Excel. Narrative responses were summarized and grouped for content analysis of key messages.

TABLE. Responses of 18 Vancouver Island MAID providers (3 assessors and 15 prescribers) to selected statements about the need for bereavement support before and after an assisted death.

Statements	Agree % (n)	Neither agree nor disagree % (n)	Disagree % (n)
Before the assisted death, the patient, family members, and friends need bereavement information, support, and/or counseling.	72.2 (13)	16.7 (3)	11.1 (2)
At the time of death or in the hour or two immediately following, family members and friends who are present need bereavement information, support, and/or counseling.	33.3 (6)	50.0 (9)	16.7 (3)
In the days or weeks following an assisted death, family members and friends need bereavement information, support, and/or counseling.	66.7 (12)	22.2 (4)	11.1 (2)
I have the time and resources needed to address the bereavement needs of the friends and family members of the deceased following an assisted death.	16.7 (3)	11.1 (2)	72.2 (13)

Results

Of the 34 physicians who had provided MAID services between June 2016 and June 2018 on Vancouver Island, 18 completed the survey (15 prescribers and 3 assessors), for a response rate of 52.9%. The average number of years each respondent worked as a physician was 16 (range 4 to 38 years). All respondents were hospitalists or general practitioners with a special interest and practice in family medicine, geriatric medicine, or palliative care. Thirteen respondents (72.2%) indicated they were not the primary care provider or most responsible practitioner for the patients seeking MAID.

The majority of respondents agreed that patients, family members, and friends need bereavement support in the days and weeks before and following an assisted death **[Table]**. While the importance of bereavement support was acknowledged by 13 respondents (72.2%), the same number of respondents indicated they have neither the time nor the resources to provide family and friends with this kind of follow-up.

For physicians providing some form of bereavement support, most referred people to resources (community programs, grief counseling, online information) or provided printed information **[Figure 1]**.

Notably, 12 respondents believed providing bereavement follow-up to be part of their professional obligation (3), moral obligation (2), or professional and moral obligation (7) to families, while 6 respondents disagreed or were neutral regarding this obligation. Only 2 respondents felt family members expected bereavement support from them.

Fourteen respondents (77.7%) believed the responsibility for bereavement support lies with both the family physician and the clinician providing the assisted death **[Figure 2]**. Eleven respondents (61.1%) believed others are responsible for addressing these needs and identified spiritual care providers, counselors, and friends or family.

When asked if bereavement was different for an assisted death, 13 respondents (72.2%) said that in their experience it was. The narrative responses helped identify four themes underpinning this view:

- The newness and unfamiliarity of MAID: "The conscious decision is still new to all of us … this is a huge learning curve. We are all at various stages on this curve."
- The potential for stigma: "There is still some cognitive dissonance around MAID as an unnatural death, and families may need help to emotionally deal with this even when in intellectual agreement and support."
- The centrality of patient choice: "It involves a choice to end one's life which the family/friends must grapple with, perhaps sometimes considered a reflection on themselves thus leaving feelings of guilt, blame, inadequacy when in reality their support is a great gift."
- Less suffering, more peace: "MAID may actually be less traumatic. Depends on the family, but usually the family is more prepared and at peace."

Respondents who disagreed with the view that bereavement is different following MAID noted that "death is death," and said bereavement will depend on how accepting the family is of this choice.

Respondents offered suggestions for additional support such as a social work or counseling resources, an automatic offer of services, peer support resources, spiritual resources, and the same support as anyone who has lost a loved one in any way receives. For example, one respondent suggested that a specialized counselor or social worker "should automatically visit with the family before and after each provision and do follow-up calls. This person should be dedicated [to MAID] and not shared with the wards or any other service so they can take their time." Another respondent suggested that when "MAID assessments and procedures [occur] at hospice, contact is [already] made and families feel comfortable accessing it." In contrast to this, one respondent noted that although resources currently exist they are not always accessed by families, who either do not ask about them or do not pursue them.

Respondents who believe providing bereavement support is part of their scope of practice identified a variety of approaches, such as giving out a business card and inviting the family to make contact, identifying available resources for before and/or after the procedure, and making one or more follow-up phone calls. Respondents stated that their usual practice of addressing bereavement needs overall is shaped by:

- Having a close and ongoing care relationship with the family whereby they "can continue … conversations and check in over an extended period."
- Being familiar with death and confident in discussing the topic.
- Being able to make themselves available (although one respondent remarked that "no one has called after a MAID procedure day").

When asked about gaps in their practice of providing bereavement support, the most frequent concern was lack of time. Most physicians run full practices in addition to their MAID work and adding bereavement support before or after an assisted death would be problematic. In the words of one respondent:

> I usually do not have the time to follow up more than once and find most people's family physicians are too overtaxed

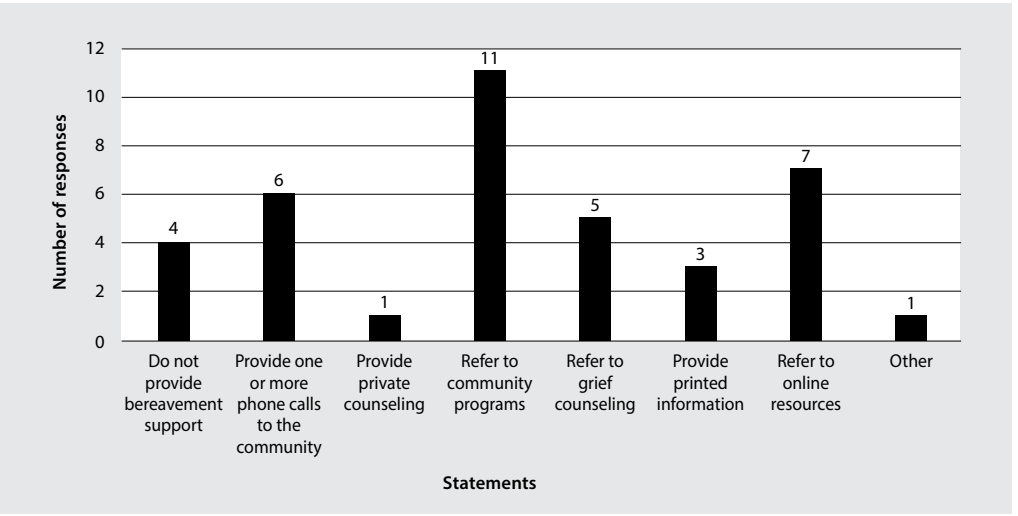

FIGURE 1. Responses of MAID providers agreeing with statements about their usual method of addressing bereavement needs after an assisted death. Note that respondents were permitted to select more than one response.

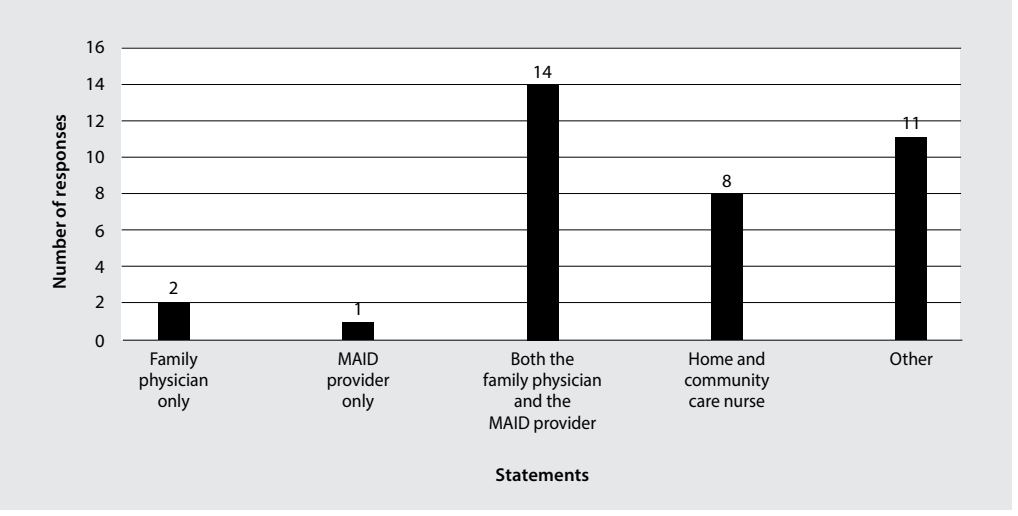

FIGURE 2. Responses of MAID providers agreeing with statements about who is responsible for addressing bereavement needs after an assisted death. Note that respondents were permitted to select more than one response.

to pick up the baton. I think we have to be conscious of the limitations of our obligations to a patient's family. I am in a care relationship with the person receiving MAID, not their family. While I feel there is a limited professional and moral responsibility to the family on the part of the physician, there is also the responsibility of the health authority to provide interdisciplinary resources to families. I cannot take all that on myself.

Respondents also shared ideas in their narrative responses about how current systems for bereavement support might be better organized by:

- Enhancing bereavement services delivered by other groups and organizations.
- Generating accessible supports from the health authority in the form of printed materials or default follow-up services.

Conclusions

The majority of survey respondents believe that bereavement following a medically assisted death is unique and that bereavement support is needed. Overall, the findings endorse the need for bereavement support, both before and following an assisted death. As earlier studies by Kimsma and van Leeuwen[9] and by Reid[15] have noted, in-person or phone contact with professionals following the death is helpful.

While most respondents consider providing bereavement support to be a moral and/or professional obligation, they also believe this responsibility should be shared by the family physician and MAID provider. Physicians on Vancouver Island who assess and provide assisted death do so in addition to their other professional duties and with deep dedication and commitment to patient-centred care. Assessing, planning and assisting a death are often time-intensive and require the juggling of multiple professional obligations and commitments. Further research is needed to better understand how physicians can share the responsibility of bereavement support before and after a MAID intervention. Clearer understanding is also needed of the perspectives of physicians who disagree or are neutral about the need to provide bereavement support. This has implications for medical education, training, and professional development. Discussions are vital regarding the limitations of obligations and where and how bereavement support should be provided.

In keeping with other studies that report stigma and social disapproval of MAID as valid concerns,[11-12] some survey respondents believe that stigma surrounds MAID. Families may need help to deal emotionally with this concern about "an unnatural death," despite their stated intellectual agreement with and support of MAID. At this early stage in the implementation of medical assistance in dying when stigma may apply, bereavement supports specifically designated for those anticipating or experiencing MAID are warranted.

Discussions are vital regarding the limitations of obligations and where and how bereavement support should be provided.

It may be that the current findings, especially those related to the uniqueness of bereavement following assisted death, reflect the newness of this option in Canada and the gradual unfolding of our collective cultural awareness and understanding, rather than evidence of a substantively different bereavement process. More research is needed to understand bereavement for families leading up to and following a planned and assisted death, and which services and professionals are best positioned to support them.

Study limitations

The survey was tested for face validity but not for reliability, and the findings may have errors associated with response bias or misinterpretation of questions. Also, while the physicians responding to the survey had expert knowledge and experience, the number of respondents was small. At the time of the study, nurse practitioners were not yet authorized to provide MAID on Vancouver Island and did not participate. Future studies will be able to include this group of providers.

Future considerations

Questions about bereavement support that still need to be considered include the following:

- Should bereavement support and/or counseling be seen as within the scope of practice for physicians providing MAID?
- What models exist where MAID providers and the primary care providers coordinate bereavement follow-up?
- What is the usual practice of family physicians regarding bereavement support outside of MAID?
- Does the contemplative time leading up to making a MAID request, or the time between the assessments and death, help to generate a sense of community for family and friends that is helpful to their bereavement?
- Does the need for bereavement support depend on the setting where the MAID death occurs (at home versus in a care facility where health professionals are more accustomed to death and dying)?
- Do we understand the role of palliative care services in pre-MAID bereavement, given that most patients choosing an assisted death have cancer and are in contact with palliative care teams? Are patients not receiving palliative care aware of bereavement support?
- Are the bereavement needs of those who request MAID but who are found ineligible or who lose capacity or who withdraw their request different from those who continue to experience MAID without interruption?
- How are the experiences leading up to and following MAID different from the experiences of a planned death that occurs after the withdrawal of life support measures in patients who have generally lost capacity and consciousness?

Bereavement guide

After hearing directly from MAID providers in the course of this study and hearing anecdotally about the experience of family members, we created a guide to support patients and families that any physician can use to support healthy grieving: www.islandhealth.ca/sites/default/files/2019-05/maid-bereavement-guide-patients-families.pdf. In addition, we are

currently drawing on findings from the survey described here for another study that focuses on family member bereavement experience following MAID. ■

Competing interests
None declared.

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