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Grief and bereavement of family and friends around medical assistance in dying: scoping review

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ABSTRACT

Objectives The increase in the number of jurisdictions legalising medical assistance in dying (MAiD) has contributed to a growth in the number of family and friends who may face unique elements of grief and bereavement. The aim of this study was to review the literature of grief and bereavement of family and friends following MAiD, and to summarise findings for the development of community resources and programming.

Methods We performed a scoping review with workshop consultation of stakeholders. Six electronic databases and the grey literature were searched for qualitative, quantitative and review articles. Content-analytical techniques and multidisciplinary discussions led to the development of concepts and a conceptual framework.

Results Twenty-eight articles met the inclusion criteria. We identified five concepts that impact the grief and bereavement of family/friends: relationships between family/friends and the patient as well as healthcare providers; aspects of MAiD grief which can include secrecy and/or anticipatory grief; preparations which may include family/friends and should be centralised and harmonised; end of life as an opportunity for ceremony; and the aftereffects during which mental health outcomes are studied.

Conclusion This multidisciplinary scoping review incorporates stakeholder consultation to find that support is needed to address the complicated and changing emotions of family/friends before, during and after a MAiD death. Furthermore, additional societal normalisation of MAiD is necessary to reduce secrecy and stigma and improve the accessibility of resources for family/friends.

INTRODUCTION

Changes in legislation and cultural values have increased the prevalence of medical assistance in dying (MAiD).

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Past reviews have shown that grief and bereavement associated with medical assistance in dying (MAiD) are affected by secrecy and stigma.
- ⇒ Family/friends may require ongoing psychosocial support.

WHAT THIS STUDY ADDS

- ⇒ Grief and bereavement surrounding MAiD may start early and involve the concepts of: relationships, aspects of MAiD grief, preparations, end of life and aftereffects.
- ⇒ MAiD experiences create emotions that change over time and can be complicated by secrecy or fear of stigma.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ Bereavement resources are necessary before and after MAiD.
- ⇒ Research regarding MAiD bereavement should occur at multiple time points.

Currently, assisted death is recognised by 5 of 6 Australian states, 11 of 50 states of the USA, Canada, Luxembourg, Belgium, Netherlands, Switzerland, New Zealand, Colombia, Spain and Italy.^{1–4} The increasing prevalence suggests a corresponding increase in the number of bereaved individuals following MAiD.

The focus of MAiD is often on the patient, although family/friends are the ones who bereave, whether they were supporters or not of MAiD. Previous research suggests improved bereavement with MAiD due to the opportunity for closeness, saying goodbye, or copreparing for end of life (EOL).^{5–7} Nonetheless, with a limited number of jurisdictions permitting MAiD, factors such as social isolation, stigma or religious acceptance can impact the expression of grief and bereavement.^{8,9} These factors can change over time and the increasing legalisation of

MAiD reflects shifting attitudes towards EOL options. It is important to continuously study contributors and circumstances that affect the natural bereavement experience of family/friends during all stages of MAiD.

The psychosocial aftereffects of MAiD has been studied in previous reviews. Reviews focusing on caregiver or family experiences around assisted dying or hastened death recommend professional support for families during the MAiD process.^{7–10} Given the many challenges around MAiD, grief and bereavement are the focus of only a handful of studies. In the review of Andriessen *et al*,⁵ MAiD experiences are considered not to be worse compared with other types of death when assessing for grief, mental health and posttraumatic stress outcomes.⁵ The authors also introduce unique considerations following MAiD including coping with social stigma and confronting moral and relational conflicts within families. Although Andriessen *et al*⁵ provide a summary to explain the occurrence of psychosocial outcomes related to MAiD, no review has previously examined the factors contributing to grief and bereavement throughout the MAiD process. Furthermore, a unique contribution of this review is its engagement of key stakeholders to determine how to adapt findings from the literature for community resource development.

There are many people and processes involved in MAiD. Therefore, we will clarify the terminology to remove ambiguity within this article. Both euthanasia and physician-assisted suicide refer to a hastened death wherein a medical professional administers or prescribes a lethal drug to a patient; and MAiD encompasses both processes.^{3–11} The cause of death is often a severe or terminal disease whereas one mechanism to control the manner of death is MAiD. There are certain jurisdictions where a terminal disease is not a prerequisite to acquiring MAiD. Non-MAiD deaths will simply be referred to as death, whereas MAiD will be identified as a specific means of death when referring to active euthanasia or assisted dying. Although previous literature used ‘natural death,’ it is important to not conceptualise MAiD as unnatural to avoid pejorative connotations.

We identify the individual who considers and/or receives MAiD as the patient. We recognise that ‘patient’ is associated with biomedicalised processes, whereas critics of the biomedicalisation of death argue that death ought to be viewed through a social lens.¹² Given how MAiD is currently under the purview of medical professionals in all the jurisdictions listed above, ‘patient’ is currently an appropriate descriptor although it neglects the non-medical, psychosocial aspects of this identity.^{1–2, 13–15} Similarly, the individuals who provide professional assistance in the form of evaluation, administration and psychological support will be referred to as healthcare professionals (HCPs). HCPs can include physicians and nurse practitioners who provide MAiD, but also physicians, nurses, social

workers, psychologists, caregivers and institutions who provide additional logistical or supports before, during and after MAiD. The focus of this scoping review will be on the family/friends of the patient, who are most likely to be the bereaved. This term includes friends, family, neighbours, caregivers or anyone with a social or professional relationship with the patient who may grieve or bereave.¹⁶

Grief and bereavement are natural responses after experiencing loss. Currently, MAiD is still a relatively unfamiliar or novel EOL option in many jurisdictions, and its effect on grief and bereavement requires continued exploration. Our scoping review aimed first to summarise the current literature regarding the comprehensive grief and bereavement experiences of family/friends of a patient who received MAiD. Second, our review aimed to translate findings to help community organisations better develop resources or programming. Building on the concepts from our content-analyses of included articles, we intended to build a conceptual framework for the purposes of our second aim. The population includes people who supported individuals who had MAiD, the exposure is MAiD, and the outcomes are quantitative outcomes and qualitative themes related to grief and bereavement experiences.

METHODS

This scoping review search was informed by the framework developed by Arksey and O'Malley¹⁷ and expanded by Levac *et al*.¹⁸ Therefore, the authors (1) identified the research question; (2) identified relevant studies; (3) selected final studies for inclusion; (4) charted the data; (5) collated, summarised and reported the results and (6) consulted stakeholders to provide insights beyond the literature. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses¹⁹ extension for scoping reviews was used for steps (2) and (3).

The focus of the research question was developed by group consensus among members of the research committee, which included family of a patient who received MAiD. An additional purpose of question development was to guide bereavement programming and resource development for community organisations supporting MAiD, such as MAiDHouse. How can a summary of the literature regarding grief and bereavement of family/friends following MAiD help in the development of community programming and resources?

Search strategy

Published and grey literatures were searched and analysed. The included databases for published academic studies were: MEDLINE, EMBASE, AgeLine, CINAHL, PsycINFO and Scopus. Grey literatures were searched through: Google, Google Scholar, Health Systems Evidence and Grey Literature Report.

Searches were carried out between June and August 2021, and updated on 25 June 2022.

The key terms combined concepts of MAiD and bereavement. MAiD was searched using terms such as “medical assistance in dying,” “euthanasia,” “assisted suicide,” “physician aid in dying,” “right to die” and “assisted death.” The concept of bereavement was searched using terms such as “grief,” “grieving,” “bereave(ment)” and “mourn.” We conducted peer review of the search strategy with an academic health sciences librarian, who verified the search strategy (online supplemental appendix 1).

A targeted scan of organisational websites was conducted. The scan did not yield additional results that met eligibility criteria.

Eligibility criteria

Articles were screened for the following inclusion criteria: (1) legalised MAiD intervention as focus of study; (2) participants provided data regarding grief or bereavement experiences of family/friends following MAiD and (3) qualitative or quantitative outcomes related to experiences around MAiD. Publication types included reviews and empirical studies of qualitative or quantitative methodologies. Grey literature included books, editorials, conference proceedings or conference abstracts. Exclusions included: (1) Non-English articles; (2) focus not on family/friends; (3) results did not address grief or bereavement; (4) studied death was not legalised MAiD, and (5) non-academic publication media such as newspaper articles, book reviews or advertisements. There were no restrictions based on date of publication, setting of MAiD, timing of MAiD, context leading to MAiD (i.e., diagnosis) or administration method.

Screening and reviewing

Each author screened 20 articles to calibrate and refine the inclusion criteria and screening process. All titles and abstracts were double-screened; JB screened all and TH, MK, SRI, NH and AK each screened 20%. Full-text review was conducted in one phase. JB screened all full texts and TH, MK, SRI and AK screened 25% each. Discrepancies were flagged and resolved through group discussion. All articles were blind reviewed by two people: an experienced qualitative researcher, as well as a different member of our multidisciplinary team.

Data collection and coding

The full texts of the included articles were analysed using content-analytical^{20 21} techniques. Two authors, JB and HY, independently extracted data from included articles, and charted participant demographics and data. The data charting forms were developed on Google Drive after discussions among our research team. Codes were generated through a discursive process of analysis. After each researcher read all included

articles, thematic codes were generated using combination of deductive and inductive approaches. Deductive codes included stage of MAiD journey, response to MAiD, and relation to the patient. Specific topics presented in each study were then coded inductively as they emerged through the coding process. Quantitative data were also summarised narratively to allow for coding and relational comparisons. Exploratory analyses were conducted in NVivo²² by generating matrix queries, specifically by exploring emerging concepts at each stage of the MAiD journey. Quotes were collected to support emerging themes. Findings were regularly discussed with the multidisciplinary research team to inductively generate concepts. This was achieved by grouping similar codes and abstracting larger ideas.

Conceptual framework development and stakeholder consultation

The initial themes were presented at a virtual workshop organised by MAiDHouse (online supplemental appendix 2). This was attended by Canadian MAiD providers, researchers and family/friends who supported someone who had MAiD. Comments were incorporated into the development of final themes. The interdisciplinary research team chose to use visual imagery in the conceptual framework to convey MAiD concepts in response to workshop feedback. The dandelion was ultimately chosen as a representative image because it evolves through different phases and is open to different interpretations by readers.

RESULTS

Search results and included studies

The initial search was screened with an 8% discrepancy rate between reviewers. Details of screening and reasons for exclusion are found in figure 1. Ultimately, our review included 28 academic journal articles,

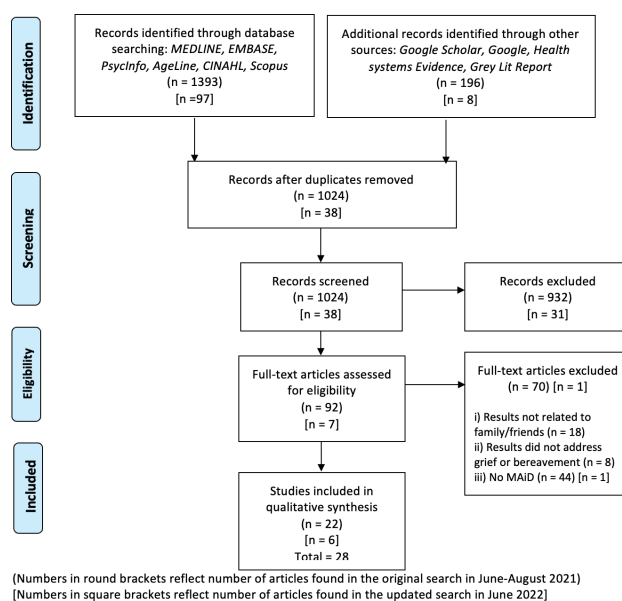


Figure 1 PRISMA flowchart for initial and updated searches.

Table 1 Overview of included review articles relating to grief and bereavement of family/friends

Author, year	Jurisdiction	Study type	Subjects/texts (time since MAiD)	Demographics	Type of MAiD	Main question	Main findings/concepts
Andriessen <i>et al</i> , 2020 ⁵	Multiple/not specified	Systematic Review	10 primary research articles	NS	Multiple	Assess grief and mental health of people bereaved by euthanasia	Bereaved individuals following euthanasia had similar to lower scores of disordered grief, mental health, and PTSD Secrecy and lack of social support increase grief
Gamondi <i>et al</i> , 2019 ¹⁰	Multiple/not specified	Systematic Review	19 primary research articles	NS	Multiple	Review family experiences of assisted dying	Themes that represent experiences: Context of the decision Grounding the decision Cognitive and emotional work Experiencing the final farewell Grief and bereavement
Goldberg <i>et al</i> , 2021 ⁴⁵	Multiple/not specified	NS	Qualitative and quantitative articles	NS	Multiple	Summarise experiences and perspectives of caregivers	Caregivers viewed MAiD more favourably than dying by natural causes It is unclear leads to better outcomes for caregivers, but psychosocial support is needed
Lowers <i>et al</i> , 2020 ⁷	Multiple/not specified	Narrative synthesis	34 end-of-life caregiving studies eleven hastened death caregiving studies	NS	Multiple	Explore experiences of family and friends providing care at home at end of life for hastened death	Caregivers actively work toward patient's goal of a peaceful death in hastened death studies HCPs play a major role in natural death and hastened death, and their understanding of legal abilities and personal willingness to provide practical support affect caregivers' satisfaction
Ontario HIV Treatment Network, 2017	Multiple/not specified	NS	NS	'mostly white... college educated'	Multiple	Identify impact of MAiD on family and friends	There are shared responsibilities between patients, family members and HCPs Opportunity to discuss death is important
Roest <i>et al</i> , 2019 ¹⁶	Netherlands	Systematic Review	14 primary research articles	NS	Multiple	Explore family member involvement in MAiD in the Netherlands	Four themes identified: Family-related reasons not to request MAiD Responsibilities during decision-making and performance of MAiD Grief after MAiD is complicated Physician-family relationship is important

HCPs, healthcare professionals; MAiD, medical assistance in dying; NS, not significant; PTSD, post-traumatic stress disorder.

including 6 published literature reviews and 22 empirical studies (tables 1 and 2). Most studies were published in Canada (n=15).^{6 23–36} Other jurisdictions included Switzerland (n=3),^{37–39} Netherlands (n=3),^{16 40 41} USA (n=2),^{42 43} Australia⁴⁴ or multiple jurisdictions or not specified (n=4).^{5 7 10 32 45} Of the 22 identified empirical studies, almost half employed exploratory qualitative methodology (n=13),^{23–26 28 30 31 33 34 36 37 43 44} with the remainder being either observational quantitative

studies (n=6)^{29 38–40 42 44} or mixed-methods studies (n=3).^{6 27 35} All 13 qualitative studies conducted interviews, the quantitative studies used validated questionnaires or specifically designed surveys, and the mixed-methods studies employed the above methods as well as focus groups and unstructured conversations. There were seven studies among the empirical studies that reported ethnicity of participants, and all were Caucasian.^{6 23–25 31 42 43} The empirical studies

Table 2 Overview of included empiric articles relating to grief and bereavement of family/friends

		9 bereaved family and friends				
Beuthin <i>et al</i> , 2021 ²³	Canada	Qualitative (semistructured interviews)	(average 15 months; range 4–36 months)	All caucasian, middle to older-aged women	Euthanasia	Explore bereavement experiences
Brown <i>et al</i> , 2020a(25)	Canada	Qualitative (semistructured interviews)	5 patients, 11 family members, 14 HCP	100% Caucasian; 77% female; ages >40	Euthanasia	Explore patient, family, HCP experiences with MAiD
Brown <i>et al</i> , 2020b(24)	Canada	Qualitative (semistructured interviews)	5 patients, 11 family members, 14 HCP	All Caucasian; 77% female; ages>40	Euthanasia	Explore perspectives on MAiD access and care delivery
Frolic <i>et al</i> , 2020 ²⁶	Canada	Qualitative (semi-structured interviews)	16 family members (“months after MAiD”)	56% female	Euthanasia	Understand Hamilton MAiD programme and MAiD legacy impact
Gamondi <i>et al</i> , 2015 ³⁷	Switzerland	Qualitative (semistructured interviews)	11 bereaved family members (median 24 months; range 12–72 months)	54% female	Assisted suicide	Explore family involvement in decision-making and subsequent bereavement
Ganzini <i>et al</i> , 2009 ⁴²	US	Quantitative (validated scales or questionnaires)	Family members of those who received MAiD (n=95) and those who did not (n=63) (range 4–36 months)	MAiD group: 100% Caucasian; 69% Female; Mean age 60.9 Comparator: 97% Caucasian; 79% Female; Mean age 60.1	Assisted suicide	Compare grief symptoms and mental health of family caregivers between those who received MAiD and not
Hales <i>et al</i> , 2019 ²⁷	Canada	Mixed-methods (focus groups, unstructured conversations, survey)	11 bereaved family members	NS	Euthanasia	Understand perspectives, identify improvement
Ho <i>et al</i> , 2020	Canada	Qualitative (semistructured interviews)	26 HCPs	88% female; 46% nurses, 27% physicians, 19% social workers, 8% spiritual health	Euthanasia	Explore HCPs challenges and resource recommendations

Continued

Table 2 Continued

Hashemi <i>et al</i> , 2021 ⁶	Canada	Mixed-methods (semistructured interviews, validated questionnaires)	13 caregivers of home MAID (average 18 months; range 10–28 months)	100% Caucasian; 69% female; mean age 60.1	Euthanasia	Explore quality of bereavement for home MAID	MAID was easier to accept, family/friends accepted and ready for death All participants had positive experience, and none suffered from complicated grief (IES-R mean=9.2 and BQG mean=2.1) Planned death day is odd, although often peaceful, with valued time to say goodbye
Holmes <i>et al</i> , 2018 ²⁸	Canada	Qualitative (semistructured interviews)	18 family or friends (before and after MAID)	NS	Euthanasia	Explore bereavement experiences	
Laperle <i>et al</i> , 2021 ³⁴	Canada	Qualitative (semistructured interviews)	Bereaved family members, 8 after euthanasia, 8 after natural death (range 6–48 months)	75% female; mean age 49.4	Euthanasia	Offer insights into the relational landscape of bereavement experienced in anticipated death Draft an interpretive model of grief	The bereaved are active agents who co-construct their experience with their social environment Bereaved family experience four landscapes: I feel open and visited I feel far away, along with the deceased I feel besieged I feel I am expanding and invested with a message
Laperle <i>et al</i> , 2022 ³⁵	Canada	Mixed-methods (semistructured interviews, questionnaires)	Bereaved, 25 after MAID, 36 after death with palliative care (average 11.8 months)	85% female; mean age 16	Euthanasia	Describe the grief experiences of individuals who have lost a loved one through MAID or natural death	No differences between groups in measures of prolonged grief disorder (Prolonged Grief-13) or psychopathological symptomatology of grief (Revised Grief Experience Inventory) Neither MAID or death with palliative care favour prolonged grief; although there may be less social stigma in Quebec, Canada
Oczkowski <i>et al</i> , 2021 ³⁰	Canada	Qualitative (semi-structured interviews)	20 HCPs	45% female	Euthanasia	Describe HCP perspectives, identify successes and suggestions	Need for centralised portal to cover technical and logistics Emotional support for patients and families before, during and after through SW, spiritual care
Philippkowskil <i>et al</i> , 2020	Australia	Quantitative (validated scales)	164 adults randomised to read one of four vignettes	79% female	Assisted suicide	Investigate the cause of death and age of the deceased on emotional responses to the bereaved, desire for social distance, and grief expectations	The age of death affected grief experiences The mode of death did not affect grief experiences (p=0.33)
Pronk <i>et al</i> , 2021 ⁴¹	Netherlands	Qualitative (semistructured interviews)	12 family/friends of individuals with mental illness who requested or received MAID	50% female	Euthanasia (lethal prescription or injection)	Examine experiences of relatives of patients that requested MAID due to mental illness	When patients with mental health request MAID, family/friends generally feel ambivalence. Family/friends more strongly want to be involved in decision-making and have their views heard by HCPs and the patient.
Schutt, 2011 ³¹	Canada	Qualitative (semistructured interviews)	seven bereaved family members	100% Caucasian; 57% female	Euthanasia	Explore insights from family members' experience of MAID	Procedural aspect of MAID augmented perception of biomedical process Should be presented with palliative philosophy
Smolej <i>et al</i> , 2022 ³⁶	Canada	Qualitative (semistructured interviews)	eleven caregivers of individuals who requested or received MAID	91% female; average age 54.5	Euthanasia	Explore the experiences and support needs of family caregivers who are or have provided care peri-MAID	

Continued

Table 2 Continued

Srinivasan, 2019 ⁴³	USA	Qualitative (interviews)	22 bereaved family members ('bereaved within 3 years')	100% Caucasian; 68% female; age range 61–80	Assisted suicide	Explore bereavement experiences	Themes identified with assisted death: General grief reactions Anticipatory grief Sense of control Level of agreement with assisted death Grief expression and stigma
Swarte <i>et al</i> , 2003 ⁴⁰	Netherlands	Quantitative (validated questionnaires)	Bereaved family and friends of terminally ill patients with cancer who received MAiD (n=189) and those who did not (n=316)	MAiD group: 54% female; mean age=48 Comparator: 58% female; mean age=49	Euthanasia (lethal prescription or injection)	Assess how euthanasia affects grief of family and friends	Bereaved family and friends of those who died by euthanasia had less traumatic grief symptoms (adjusted difference −5.29 (95% CI −8.44 to −2.15)), less current feeling of grief (adjusted difference 2.93 (0.85 to 5.01)), and less post-traumatic stress reactions (adjusted difference −2.79 (−5.33 to −0.25))
Trouton <i>et al</i> , 2020 ²⁹	Canada	Quantitative (survey)	18 physicians who provided MAiD	NS	Euthanasia	Explore physician practices for bereavement support to patients	Importance of bereavement support recognised (72.2%), but physicians do not have time or resources to provide support Bereavement following MAiD is unique due to unfamiliarity and potential for stigma
Wagner <i>et al</i> , 2011	Switzerland	Quantitative (validated questionnaires)	85 relatives or friends (mean 20 months)	56% female; mean age=60.15	Assisted suicide	Examine the effects of perceived social acknowledgement on symptoms of post-traumatic stress and complicated grief	General disapproval, rather than family disapproval or recognition, were correlated with PTSD ($r_s=0.50=0.56$) and complicated grief scores ($r_s=0.63-0.71$)
Wagner <i>et al</i> , 2012	Switzerland	Quantitative (validated questionnaires)	85 relatives or friends (mean 19 months)	56% female; mean age=60.15	Assisted suicide	Examine the impact of witnessing assisted suicide on mental health	Compared with general Swiss population, survey found slightly higher rates of PTSD (13%) and depression (16%) Rates of complicated grief were comparable (4.9%)
BGQ, Brief Grief Questionnaire; HCP, healthcare professional; IES-R, Impact of Event Scale - Revised; MAiD, medical assistance in dying; NS, not significant; PTSD, post-traumatic stress disorder; SW, social work.							

had study populations that most often consisted of family, friends or caregivers (n=17). There were five studies that included the perspectives of HCPs on a family/friend's bereavement, with two studies^{30 33} including only physicians, nurses, case workers and social workers, and another study²⁹ including only physicians. A few studies had specific research questions regarding a MAiD patient subpopulation or the setting of MAiD: Swarte *et al*⁴⁰ focused on MAiD within the context of patients with cancer; Hashemi *et al*⁶ studied MAiD cases which took place at home; and Pronk *et al*⁴¹ studied family/friends of patients with mental health in relation to MAiD. There were four studies^{34 35 40 42} that compared family/friend's bereavements of those who received MAiD and those who did not.

Identified concepts from scoping review

In our attempt to study grief and bereavement of family/friends in relation to MAiD, we identified five concepts from the coding: relationships, aspects of MAiD grief, preparations, EOL and the aftereffects. Within each concept, we present results specific to grief and bereavement as it relates to MAiD (online supplemental table S1).

Relationships

The interactions and the development of relationships over time can largely impact how family/friends experience grief. The defining relationship is often between family/friends and the patient,^{34 41} but interactions with HCPs can be impactful.

With the patient

There are many different relations between family/friends and the patient. Roest *et al*¹⁶ summarised several studies, noting that partners, children and siblings are the most common relations. However, this group can also contain neighbours, friends, nurses and more. Many aspects of these relationships can affect grief or bereavement. Specifically, having shared values and established common goal-setting facilitate acceptance of MAiD.^{7 37} Family/friends' involvement in MAiD is often based on personal values and perceptions of MAiD.^{7 45} Conflicting values can impact the level of moral dilemma felt during the process.^{10 41}

The patient's role through MAiD is relatively straightforward whereas family/friends can either be actively or passively involved in planning or attending MAiD, or be unaware until after the death. Specifically, family/friends can be described in two ways: those who are involved and those who are aware. In other words, being involved includes planning and/or attending the death; whereas being aware is recognition of MAiD without direct participation.³⁷ Interestingly, some patients will even ask for the consent of family/friends to be involved as they recognise MAiD may not be viewed favourably by everyone.¹⁶

The complicated web of players can be unique in each situation, creating multifaceted emotions and consequences. Pre-emptive support for those actively and passively involved in MAiD^{29 30 41} can better address specific grief and bereavement needs—before, during and after MAiD.

With healthcare providers

HCPs can ameliorate the quality of grief for friends/family. Despite the obligations towards the patient, family/friends have many interactions with the care team before and after the day of MAiD and investment into this relationship is important.^{24 25 34 46} In some jurisdictions, HCPs consider the future bereavement of the family when deciding to grant MAiD.⁴¹ In other jurisdictions, it is unclear who should initiate the discussions around MAiD. Family/friends may believe that the responsibility to learn about EOL options falls on them. This is further complicated by HCPs or family/friends who may have a preference not to participate in MAiD.^{25 27 33} These unclear roles or conflicting values create stress and anxiety that can lead to complicated bereavement.

It is repeatedly recommended that a centralised MAiD referral portal would help improve role delineation and enhance delivery of information. Confusion and inconsistency in EOL planning adds anxiety and increases complicated grief.^{7 27} Although physicians often deal with clinical symptom management of the individual receiving MAiD, a more diverse group of HCPs are needed to provide psychosocial support to family/friends.^{6 23 30} Bereavement support includes facilitation of communication around death, and counselling or physician referrals if necessary.⁶ One study highlighted that although physicians believe it is their professional or moral duty to provide bereavement support, they did not have the appropriate time or resources.²⁹ Therefore, many studies suggested that additional roles and responsibilities can be addressed by an interdisciplinary care team, which includes social workers, spiritual care providers, specialised nurses or even 'death doulas'.^{23 24 36}

Ultimately, when considering how HCPs can 'support the circle of support',²⁴ greater structure, funding and resources are needed. Currently, the full obligation and duration of the relationship between HCPs and family/friends is ambiguous and variable.¹⁶ Several studies suggested that support for family/friends should be provided before and after MAiD, with trust established over time.^{24 41 45}

Aspects of MAiD grief

MAiD has two distinctive features for family/friends which impact bereavement. Specific to MAiD, there are concerns around disclosure, producing anxiety related to secrecy and stigma. Additionally, with a confirmed date of death, anticipatory grief can manifest during contemplation of MAiD. These facets are commonly

referenced in our included studies, although not ubiquitous phenomena in all MAiD cases.

Disclosure and secrecy

The patient, with or without help from family/friends, may decide to keep MAiD a secret. This presents a distinctive feature of MAiD compared with other deaths.^{5 26 45} Concerns around disclosure include fear of societal stigma,⁴³ concern for relatives' reactions,⁶ or avoiding a possibly politically charged topic. Even following MAiD, the fear of being judged negatively impacts bereavement.^{33 37} For some, MAiD is perceived as a secret that acts as a heavy burden throughout the process.^{27 37} In an attempt to study disclosure of MAiD quantitatively, Wagner *et al*³⁸ reported general social disapproval as having the strongest correlation with post-traumatic stress disorder (PTSD) and complicated grief, whereas family disapproval can correlate with specific aspects of grief. In contrast, there is one study⁶ involving home MAiD deaths in Toronto, where the majority of family members considered themselves advocates of MAiD and were very public with their decisions. Philippkowski *et al*⁴⁴ used vignettes regarding the mode of death to understand the perspectives of Australian adults. They found mode of death had no interaction effect for emotional reactions, desire for social distance, or expectations of grief symptomatology. Ultimately, Gamondi *et al*¹⁰ encouraged development of open spaces to discuss death freely and extensively, even long before there would be a medical reason to discuss death.

Anticipatory grief

MAiD provides an opportunity to choose a set date and prepare and plan for EOL. Although anticipatory grief is not unique to MAiD, it is recognised as grief associated with the expectation of an upcoming death. The certainty of an ultimate date intensifies 'a parade of lasts' or a countdown.^{23 43 46} This can both be seen as a blessing to plan goodbyes or as a cause of apprehension. For some, recognising the EOL as the end of suffering can be comforting.^{28 34}

Bereavement support should start before MAiD, and requires a continued and interdisciplinary approach.^{25 27 46} It is common that family/friends may set aside their own feelings to focus on the patient's needs.⁷ Counsellors, resources and education to help recognise the need for support should be readily available and accessible from many locations and throughout the process. Physicians believe that bereavement of an assisted death is unique because of the newness and unfamiliarity of MAiD.^{29 36} Even when contemplating MAiD, grief of family/friends can start and evolve throughout the process.^{25 27 34 46}

Preparations

Coming to the decision to pursue MAiD is the first step of a long journey. The subsequent preparations,

which involve value-based evaluations and logistical arrangements, can be daunting.

Values and decision-making

The contemplation for MAiD can be contentious if there are conflicting values among patient, family/friends and HCPs. The source of conflict can be driven by ambivalence, religious beliefs, desire to have more time, or feeling responsible for a premature death.^{7 10 26 46} MAiD provides a timed death and a definitive end.¹⁶ These concepts seem contrary to societal or medical norms, thus creating conflict. However, belief in patient autonomy can supersede other values. Generally, there is less conflict from family/friends if MAiD seems to fit with longstanding values of the patient.^{16 28 36}

Grief can be proportional to the level of agreement with the decision to undergo MAiD.^{41 43} On the one hand, family/friends who agreed to participate in MAiD could sometimes feel guilt over being a facilitator of death.²³ Even some who were only passively involved felt culpable because they perceived that MAiD broke social rules.³⁷ On the other hand, family/friends who made a joint decision to pursue MAiD alongside the patient felt more accepting of the death.⁴¹ Overall, establishing mutual commitment to choice and dignity affected the outlook of family/friends. The confidence of the patient in their decision also influenced the degree of comfort felt by families.³¹ Even in early stages of precontemplation, family/friends can already start shouldering a heavy burden.^{7 43}

Schutt³¹ explored the framing of MAiD under either a biomedical or palliative lens. Biomedical decision-making focuses on the individual and the treatment. In contrast, palliative care is driven by relational ethics and involves the agency of family/friends and caregivers while focusing on comfort. They recommended having early conversations involving family/friends around EOL options to minimise suffering for patients and caregivers. This shared decision-making model is supported by many studies to improve the quality of grief and bereavement.^{5 6 10 41}

Logistics and arrangements

The logistics and information required to initiate the MAiD process can be a barrier, complicating how family/friends mentally process the death.^{30 36} Examples of barriers include having a rapidly progressing disease, undergoing psychiatric evaluation(s), and finding a practitioner who is able to write or administer the prescription. Lack of clarity regarding the process creates unnecessary complexity.^{7 27} Having committed to a decision regarding MAiD, each step can be an unpredictable hurdle to achieving an established goal.^{25 33 36 43} The timing and number of eligibility visits require sensitivity and consideration from HCPs. Brown *et al*²⁴ recommended opportunities for debrief if assessment outcomes are not what were anticipated.

Families/friends of patients who requested but did not receive MAiD had greater regrets regarding the death.⁴² The fear of the loss of capacity by the patient to proceed with MAiD can be emotionally devastating for all.^{16 24 27} Although the assessments seem to take a painstakingly long time, family/friends also struggle with processes that are too fast or shorten a lifespan prematurely.^{10 26 27 46} Oczkowski *et al*³⁰ advocated for harmonised referral systems and intake practices as well as systematised targets for time between MAiD assessments to align expectations. Setting expectations and establishing normalcy help foster healthy grieving.

The actual communal planning of death, such as deciding on a date and location, inviting attendees, and finding the appropriate HCPs can seem very strange.^{7 16 28 37 46} For many family/friends, the planning of a death day was unusual and described as 'an unpredictable care terrain, (resulting) in emotional uncertainty'.^{24 28 36} A confirmed date can help facilitate grieving if time is allowed to complete unfinished business, enact wishes, restore lost relationships or celebrate specific events.^{6 7 28 46} However, issues of lack of available space or human resources to perform MAiD can pose added challenges.²⁷ Purported institutional conscientious objections or unseemly locations negatively impact the experience.²⁵

It is a long path from contemplation to planning the final details of MAiD. Similar to other large life events, finding common ground for expectations can largely impact important memories.

End of life

Death is rarely seen as a 'good thing'. The death of an individual is seldom celebrated. MAiD allows a reinvention on how death is perceived. The common goal of patients, family/friends and HCPs has shifted towards providing a good death, which can then encourage healthy grieving and bereavement.

Location

An appropriate location is paramount for the comfort of the patient as well as creating appropriate memories of those attending MAiD. A location should allow for the comfort of the patient, minimising physical pain during transportation.^{25 28} Family/friends may not want to associate their home with death nor want to gather in a hospital. Another logistical barrier arises if institutions that provide residence for the patient prohibits MAiD due to faith-influenced policies or inadequate space for family/friends.²⁴ The location, time and people present must accommodate for the patient's accessibility, well-being, and privacy. This day is emotionally charged and heavily impacts the bereavement—it is the responsibility of HCPs to set expectations and deliver a good experience for the patient as well as their family/friends.^{27 35} Some participants of MAiD may have imagined what they believe MAiD would look like. Unexpected outcomes,

especially if manifested as patient discomfort, aggressive movements or uncertainty about MAiD effectiveness can easily be a source for mental trauma.³⁵

Ceremony

The death itself can be considered a meaningful ritual or ceremony,²³ with focus on the ability to spend time and say goodbye. In comparison with other experiences of death, family/friends believed MAiD was more peaceful and provided an opportunity for a well-controlled legacy or message.^{26 35} MAiD can seem abnormal with the knowledge that there will be a final goodbye. Nonetheless, MAiD can afford a greater sense of control for family/friends and patients, because there has been time to cognitively and emotionally prepare.⁴³ Furthermore, the knowledge that suffering has been minimised can be a cognitive comfort.^{6 26 28 31 46}

Aftereffects

Overall, many family/friends generally described a positive MAiD experience. Rarely, MAiD was described to be 'aggressive' or 'painful'.³⁵ When finding factors for the perceived positivity around MAiD, reasons include starting the healing process before death, avoiding a prolonged dying process, avoiding escalating care needs, mitigating pain and suffering, and facilitating acceptance through a set date.^{6 7 16 45 46}

Following most deaths, it is expected for family/friends to grieve. The experience and quality of grief can be impacted by the concepts outlined above. An optimised bereavement will minimise the mental and psychiatric distress of family/friends. The psychosocial distress following death has historically been called complex grief, recently called persistent complex bereaved disorder in the Diagnostic and Statistical Manual-5 (DSM-5), and just renamed in March 2022 to be prolonged grief disorder (PGD) in the updated DSM-5-TR.⁴⁷ Given the changing terminology and varying psychometric scales used to study this phenomenon, the included studies have inconsistently measured PGD, among other forms of distress.

Specific quantitative research on post-MAiD grief and bereavement of family/friends is limited, highlighting the continued invisibility of the patient's support system.⁴⁵ Among the included studies, only one³⁹ reported a higher prevalence of PTSD and depression in family/friends who were present at MAiD compared with the general Swiss population. This was measured through validated questionnaires completed by 85 participants, with no direct comparison group. In Switzerland, physicians generally prescribe a lethal dose of medication and patients often administer the medication at home with the help of non-profit organisations.³⁹

Several other quantitative studies did not find greater psychosocial differences following MAiD. Ganzini *et al*⁴² from Oregon directly compared

family members of those who had lethal prescription or ingestion (n=95) and family members of those who died from amyotrophic lateral sclerosis (n=63). They found no difference when measuring prolonged grief, depression symptoms, or use of mental health services. Similarly in Quebec, Laperle *et al*³⁵ evaluated 25 participants following MAiD compared with 35 participants following death with palliative care. There were no participants who met criteria for PGD. Hashemi *et al*⁶ reported no complicated grief on average for caregivers following a home-based MAiD death in Canada. Participants completed two questionnaires approximately 18 months following MAiD. In a large survey by Swarte *et al* conducted in the Netherlands,⁴⁰ bereaved family and friends of cancer patients who died by MAiD had fewer traumatic grief symptoms, and fewer PTSD reactions compared with those who experienced death due to cancer. This study compared 189 family/friends following euthanasia with a control group of 316 family/friends of matched control patients. Lastly, a systematic review⁵ on grief and mental health of family/friends found similar or lower measures of disordered grief, mental health, and PTSD when comparing people's bereavement following MAiD compared with other deaths.

Synthesis and conceptual framework

The concepts from our scoping review are highlighted and summarised with our conceptual framework, an image of a dandelion, carefully chosen to represent the ongoing multifaceted aspects of MAiD and the ever-evolving emotions related to grief and bereavement (figure 2).

The dandelion was chosen to represent MAiD-related grief as a natural flowering plant with a multitude of phases and interpretations. The dandelion reflects differing opinions and levels of acceptance of MAiD. The stages of budding, flowering and seeding parallel the preparations, EOL, and aftereffects found in our content analyses. The thorny leaves reflect the relationships and the many people (family/friends, HCPs) who support the process of death. The roots are hidden beneath the soil, similar to the distinct aspects affecting MAiD-related grief and bereavement. As a dandelion seeds, buds, grows, flowers, and disperses its seeds, the effects of MAiD-related grief metamorphose with time and can potentially have lasting impacts.

DISCUSSION

This scoping review was developed to explore how the experience of MAiD would impact grief and bereavement, as reported in qualitative, quantitative and review literature. Grief associated with all forms of

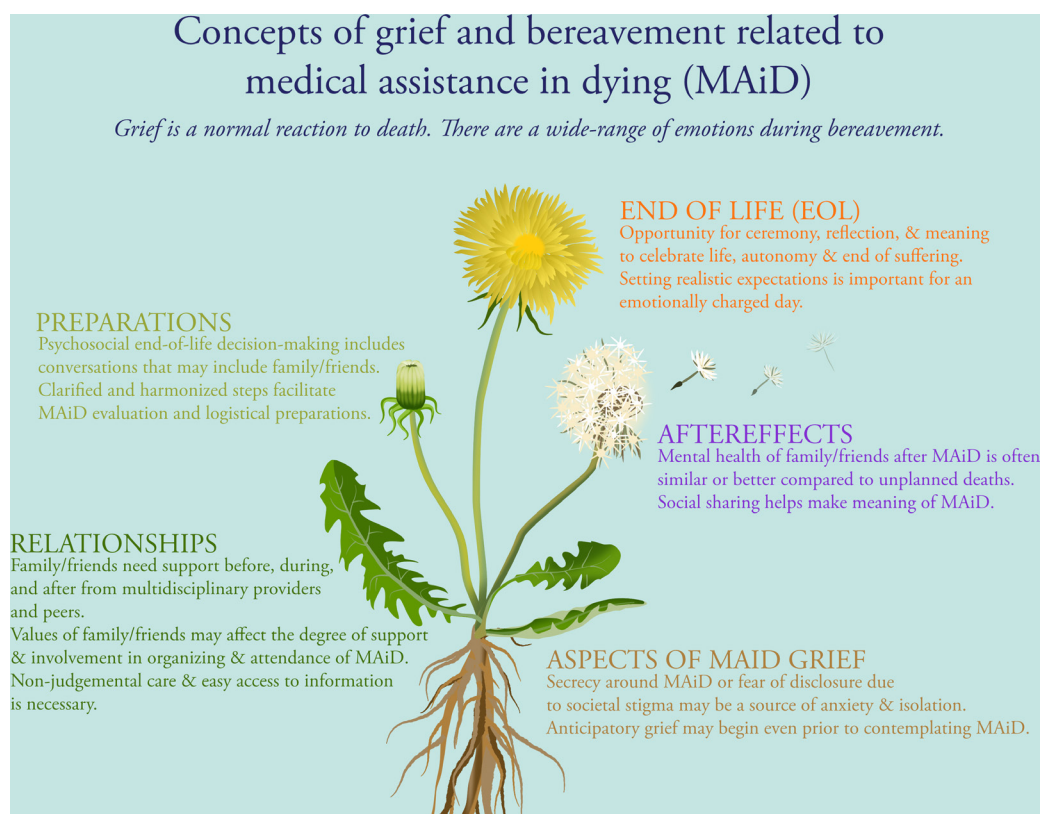


Figure 2 Conceptual framework for grief and bereavement of family/friends. The stages of budding, flowering and seeding parallel the preparation, end of life and aftereffects found in our content analyses. The leaves reflect the relationships and the roots represent the distinct aspects of MAiD grief.

death is normal, although some of the aspects of MAiD may impact how grief is experienced. Included articles with comparative populations demonstrate that MAiD created similar or slightly better experiences for family/friends.^{6 35 42} A secondary aim of this review is to help develop community bereavement programme and support resources. As such, the methods, theme development, and conceptual framework were guided by a research group and a Canadian virtual workshop including family/friends, the population of study.

Although there is an array of complex emotions and changes felt by family/friends throughout the MAiD journey, we have highlighted five concepts that impact how grief is experienced. First, the relationships between family/friends and the patient and the interactions between family/friends and HCPs can largely impact bereavement. These relationships can further be impacted by differences in values, causing unease or stress during EOL decision-making. Family/friends can be involved, actively helping to make decisions and attending the death, or just be aware without witnessing MAiD. Second, distinctive aspects of MAiD may be causes of future distress. Notably, anticipatory grief may occur before MAiD, and moreover, an aura of secrecy around MAiD can be complicated to navigate. Third, the preparations can become a foreign process that would benefit from establishing simplistic and standard timelines and expectations within each jurisdiction. Fourth, EOL with MAiD is a challenge but can be a rewarding opportunity for ceremony. Last, the aftereffects for family/friends are poorly studied with mixed results depending on jurisdiction regarding the prevalence of PGD and PTSD. Nonetheless, all studies with comparison groups reported the same or better grief experiences for family/friends following MAiD.

The death of one individual through MAiD involves many people.³⁴ Some HCPs and involved or aware family/friends may hold specific religious or cognitive views regarding MAiD.^{6 28 43} The manifestation of these views will impact the quality of interactions. Our results demonstrate that unified planning and early shared decision-making of involved family/friends can improve the quality of bereavement.^{7 31 37}

Previous literature has demonstrated that symptoms of grief can be tremendously different based on whether the deceased was a sibling, spouse, close friend or other relationship.⁴⁸ In their analysis of older people in Switzerland with 10-year follow-up, d'Epinay *et al*⁴⁹ reported severe increases in depressive symptoms after losing a close friend with shared values in comparison to a sibling, but also worsened functional status if an individual lost a child or spouse. Although this review did not include non-English studies, it is important to study diverse family and social structures of different cultures and how MAiD could impact grief or bereavement in those settings. Similarly, the jurisdiction may dictate whether family/friends experience euthanasia or assisted suicide, as well as the cultural

acceptance of MAiD. With regard to relationships with HCPs, research has already demonstrated the benefit of HCP support on positive grief reactions, although there are gaps in educating HCPs around MAiD-related grief.^{33 50 51} Despite being taught about death didactically, Sikstrom *et al*⁵¹ suggest the need for self-reflection and role-play exercises to reduce the anxiety of HCPs when discussing death and helping family/friends through complex emotions. HCPs can further help reduce confusion by setting expectations early and promoting clarified and harmonised procedures within a jurisdiction.^{6 7 30} The relative novelty of MAiD alongside the complex and evolving family/friends' roles (caregiver, MAiD planner, MAiD attendee or bereaved) add nuance when identifying and describing the experiences of grief.

Our review demonstrates that current barriers of MAiD disclosure include fears of social stigma, differing values and beliefs and the novelty of this EOL option.^{5 26 37 45} MAiD is often considered taboo, similar to other politicised biosocial medical issues, and can cause further isolation following the death of the patient. It is important to reduce stigma with early discussions exploring MAiD options in current EOL support programmes.^{29 30} It has previously been shown that emotional secrecy can negatively mediate physical and subjective well-being,^{52 53} whereas social sharing is beneficial to norm clarification and enhanced social cohesion.^{54 55} There can also be tremendous benefit from peer support when shared experiences can be verbalised. Having informal opportunities for sharing spontaneous feelings is critical for the expression of grief.^{41 46 56} The ongoing discussion around death, loss and grief throughout the MAiD process can be therapeutic to family/friends.

Anticipatory grief, also known as preloss grief, often occurs prior to death when there is advanced disease or a terminal diagnosis.⁵⁷ The knowledge of a final farewell can provide cognitive relief or distress.³⁵ In a study of dementia caregivers, factors that augment distressing anticipatory and complicated grief include ambiguity, frustration and guilt.⁵⁸ Although family counselling already exists to address impending loss, the unique features of an impending MAiD death should be considered in bereavement support as well.

Implications

This review identified distinctive relationships and aspects of MAiD, and enumerated contributors to grief during the preparations, EOL and aftereffects that shape the experience of family/friends.

Identified areas of research translation are presented in the conceptual framework for the purpose of programme and resource development for community organisations. Throughout MAiD, family/friends may be burdened with concerns about stigma resulting in secrecy or experiencing anticipatory grief before the day of MAiD. Guided discussions among all groups at

stages of contemplation, decision-making and preparations are beneficial. HCPs can normalise MAiD as a natural and accepted EOL option, supporting anticipatory grief and preloss. In places where non-profit organisations have guided family/friends through MAiD, it may be helpful to connect those grieving with similar experiences. Social sharing can also help set realistic expectations. Unification and harmonisation within jurisdictions of the MAiD evaluation and logistical steps can minimise HCP confusion and differences in practice.

In our review of the aftereffects, only three articles^{28 36 41} included perspectives of family/friends prior to MAiD. Given the possibility of anticipatory grief, it would be worthwhile to study the prevalence of PGD and other psychosocial measures prior to MAiD. Future research may consider multiple timepoints and documenting experiences iteratively, now that there is a standardised definition within the DSM-5-TR. With an increasing incidence of MAiD, comparisons can also be made within and between different jurisdictions for more nuanced understanding of risk factors.

Strengths and limitations

This study is strengthened by the comprehensive search through academic and grey literature and the inclusion of empiric and review studies. Furthermore, the screening, coding and development of the conceptual framework were completed by a multi-disciplinary group of researchers that included a family member following MAiD, a physician and MAiD provider, palliative-care researchers, social scientists and a lawyer. Theme development was further improved by a Canadian workshop during which comments from MAiD providers, researchers and family/friends were incorporated.

There are several limitations within this review. A scoping review is limited in its methodology and defined scope. First, this review had exclusion criteria for articles that were not in English. Therefore, there are experiences that may be expressed in other languages and cultures regarding grief and bereavement around MAiD that are not captured. Moreover, the included studies themselves had participants of similar ethnic and racial backgrounds. Second, this review suffers from the selection bias of all included studies, largely composed of qualitative semistructured interviews. Although we report that family/friends generally report a positive experience with MAiD,^{6 7 16 45 46} it is conceivable that those with negative experiences are less likely to participate in research. Third, it is described that anticipatory grief is a distinctive aspect of MAiD which may occur prior to death, yet only three studies included interviews with family/friends of patients who were considering (but had not yet undergone) MAiD. A comprehensive description of MAiD bereavement requires understanding experiences of family/friends at earlier stages. Lastly, although 28

articles are presented here, there are not enough articles with the same research question to compare grief and bereavement experiences between or among jurisdictions. It was outside the scope of this review, but a worthwhile area of further investigation in the future.

CONCLUSIONS

This scoping review provides a comprehensive description of qualitative, quantitative and summative literature to generate themes that capture the grief and bereavement experience surrounding MAiD. Concepts around relationships, distinctive aspects of MAiD, preparation, EOL and the aftereffects suggest a need for normalisation of MAiD, and its recognition as one mode of dying among others. Stakeholder feedback emphasised the importance of precise and inclusive language when discussing MAiD. Existing resources should be modified to include MAiD to reduce stigma. Although MAiD is relatively novel as an EOL option in certain jurisdictions, grief is a common occurrence. HCPs can support family/friends with bereavement throughout the MAiD process, which may contain anticipatory grief that starts long before the death. The circle of care should be expanded to address the complicated and changing emotions of family/friends before, during and after MAiD.

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