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Bringing death to life

Rosanne Beuthin, Anne Bruce, Marney Thompson, A. E. (Betty) Andersen & Sarah  
Lundy

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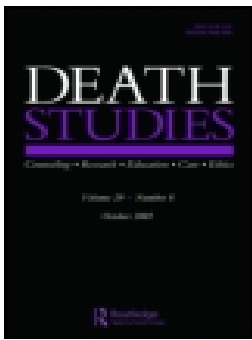
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## Experiences of grief-bereavement after a medically assisted death in Canada: Bringing death to life

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### ABSTRACT



Medical assistance in dying (MAiD) legislation was passed in Canada in 2016, yet the bereavement experience of family and friends is not well understood. Using interpretive description, we interviewed nine bereaved individuals. The time before the assisted death seems most impactful—an experience of *bringing death to life* shapes bereavement after death. We identified themes that inform this grieving: (1) certainty of date/time of death—intensifies a parade of lasts, initiates a countdown and affords time to say good-bye; (2) active family engagement as planners supports sense-making; and (3) enacting MAiD as ceremony slows time to “digest” loss.

Medical assistance in dying (MAiD) legislation was passed in Canada in June 2016, when amendments were made to the Criminal Code (Government of Canada, 2016). Within the Act, MAiD is defined as an umbrella term that includes a clinician-administered option and a self-administered option: “(a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death” (p. 7).

Although the legislation is relatively new in Canada, latest data to the end of 2019 shows that 13,946 Canadians have received a medically assisted death since enactment of the legislation (Health Canada, 2020). The same report indicates the prevalence of MAiD in Canada to be small, in that MAiD deaths as a proportion of overall death accounted for 2.0% of all deaths in Canada in 2019. In other countries that permit some form of assisted dying, the percentage of total deaths attributed to MAiD ranges from 0.3% (in U.S. states where patients must be at the end of life and only self-administration is permitted) to 4.6% (in the Netherlands and Luxembourg)

where eligibility is based on suffering rather than proximity to death and clinician-administered MAiD is permitted. The report also points to wide variability across Canadian provinces and territories, with the percentage of total MAiD deaths ranging from 0.3% in Newfoundland and Labrador to 3.3% in British Columbia. And for each person dying in this way, their family, friends, and loved ones experience the loss and grieve. It is suggested that on average, five people are bereaved for any death (Canadian Hospice Palliative Care Association, 2017).

Little is known about grief and bereavement that follows the assisted death of a loved one, within the Canadian context. While there is overlap in these terms, grief is understood as a multi-faceted *response to a loss* that impacts people emotionally, physically, cognitively, socially, and spiritually (Hall, 2014). Bereavement is *the state of having lost* someone due to death and the time period within which grief occurs. Neimeyer (2015) emphasized that “a central process of grieving [is] the attempt to reaffirm or reconstruct a world of meaning that has been challenged by loss” (p. 312). Current grief discourses reject the notion of linear stages of grief, favoring a more pluralistic approach to understanding grief (Machin, 2009).

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Much of the research addressing assisted death has focused on attitudes and perspectives of the professional care team (Beuthin et al., 2020; Bruce & Beuthin, 2019; Rousseau et al., 2017; Shaw et al., 2018; Spicer et al., 2017). There are a relatively small number of studies into families' experiences, and the findings have been mixed. Some studies report poor mental health outcomes of the bereaved as a consequence of assisted death, including depression, post-traumatic stress and prolonged or complicated grief (Starks et al., 2007; Wagner, Keller, et al., 2012; Wagner, Müller, et al., 2012). In contrast, other studies have found the opposite and others report that grief of family members was either no worse or easier than their grief following an unassisted death (Ganzini et al., 2009; Hashemi et al., *in press*; Swarte et al., 2003).

A number of studies examined pre-death factors that appeared to either ease or complicate bereavement after assisted death. A qualitative study in Oregon (Srinivasan, 2018) looked at the grief of 22 persons following an assisted death. Findings point to certain factors that eased grieving, such as preparing for death and feeling a sense of control. The author also found factors that may complicate grief, such as disagreement with a loved one's decision and perceived or real stigma. Other studies further highlight these complicating factors of social disapproval (Wagner, Müller, et al., 2012), family conflict (Kimsma & van Leeuwen, 2007), stigma (Fish, 2017; Gamondi et al., 2015), access to information (Fish, 2017), involvement in decision-making (Gamondi et al., 2013) and whether assisted death was legal in the country (Ferrand et al., 2012).

Since MAiD introduces a new type of death in Canada, it is important that health professionals gain insight into how bereavement is experienced. The purpose of this study was to explore the experience of bereaved people after the assisted death of a family member or friend.

## Study design and methodology

A qualitative design drawing on interpretive description (Thorne, 2016) was used. Interpretive description

aims to generate knowledge relevant for clinical contexts and is particularly useful when generating understanding and description of clinical phenomena.

## Participants

Nine participants volunteered representing family/friends who were bereaved following the medically assisted death of a loved one. The average time participants had been bereaved was 15 months (range of four months to three years, see Table 1).

## Recruitment

Bereaved participants were recruited through posters and advertisement in community papers and from a MAiD bereavement support group. Posters were also sent through a local hospice organization to people in the consent-to-contact bereavement database.

## Data collection

Participants were interviewed in person or by telephone (only two chose the latter). A registered clinical counselor with extensive experience in grief counseling conducted the in-depth, semi-structured interviews. Questions included: Tell me about your experience with the medically assisted death of your family member or close friend? How did you feel about their decision to pursue an assisted death? What was difficult in your bereavement? Most helpful? Anything surprising? (see Table 2). Interviews lasted approximately 60 min and were recorded and transcribed verbatim.

## Data analysis

Drawing on interpretive description (Thorne, 2016), concurrent data collection and analyses were employed. After each interview, the research team read, listened, and reflected individually on the data recording, transcript, and interviewer's post-interview reflective notes. Bi-weekly meetings were held to

**Table 1.** Participants.

Relationship to deceased	Time since MAiD death	Supportive of choice?	"Short story" title
Wife	3 years	Yes	In many ways I was spared the end of his life.
Friend	9 months	Yes	An empty place now.
Wife	5½ months	Yes	I think grief after MAiD is easier.
Wife	2½ years	Yes but	You're the one who has to deal with everything.
Friend	9½ months	Yes	Did not say procedure, said ceremony.
Daughter	4 months	Yes	Ritual is about marking what's happening now and about letting go.
Daughter	14 months	Yes but	A daughter's lingering questions.
Sister	14 months	Yes	The grieving process after is easier than the grieving before.
Wife	16 months	yes	I'd been warned it might be a little difficult.

**Table 2.** Interview guide.

Questions
Tell me about your experience with the medically assisted death of your family member or close friend. Prompt: How did you feel about your family/friend's decision to pursue an assisted death?
What was most difficult in your bereavement? What was most helpful? What surprised you?
How has this experience affected you?
How has this experience affected your grief?
Based on your bereavement experience, what would you share with family members or friends of someone who is considering a medically assisted death?
Knowing what you know now, what would you do differently? What would you keep the same?
What supports or resources did you find most helpful in your bereavement?
What supports or resources were missing for you in your bereavement?

discuss participants' stories and to iteratively revise or supplement interview questions as needed. To illuminate the experience shared by participants in ways that might simultaneously help readers imagine and connect with a participant's context and experience, we drew upon two additional interpretive analytical devices. First, we generated a "short story" from each interview, synthesizing core narratives and staying close to participants' words and phrasing. Our method had us piece together direct quotes that had impact based on our immersion in this subject matter (Wertz et al., 2011). We then chose to create a condensed composite story of two or three narratives that held similarities.

To further maintain a depth of immersion in the data, we drew on participants' words to generate "found poetry" (Patrick, 2016). These two narrative techniques offered our team a reflexive and creative means to embrace our methodology fully. According to Thorne (2016), "Knowing your data means dwelling in it repeatedly and purposefully and developing a relationship with it" (p. 167). Over time, preliminary themes were generated and continually refined to distinguish aspects of the data and raise the level of analysis from ideas to concepts through "interpretive rendering" (Charmaz, 2017). After analysis of all interviews, we noted that variation in stories had plateaued and felt confident that the data set was saturated. During analysis and manuscript preparation we sought input from a Patient Advisor about resonance with her own bereavement experience following MAiD.

### Ethics

Approval was received from the Human Research Ethics Boards of the Health Authority and University as per Tri-Council Policy Statement –2 Article 2.10 (Government of Canada, 2008).

### Findings

The time before the death seemed to be the most impactful. Participants focused heavily on stories

leading up to the assisted death when grief was ignited early, bringing the reality of pending death to life. We use the term *grief-bereavement* to capture this extended period of loss that includes pre-death stories, the assisted dying and moment of death, and stories of bereavement continuing to present time. Participants' responses were interwoven and inseparable throughout this period. Some scholars differentiate grief from bereavement (Hall, 2014; Neimeyer, 2015) where grief is understood as a response to loss, and bereavement is the state of having lost someone through death *and* the time period within which grief occurs. While others may use these terms interchangeably, our aim was to acknowledge both the distinction and merging of loss responses in participants' experiences; for this reason, we chose to hyphenate the term *grief-bereavement*.

Findings include a broader narrative of *bringing death to life* with three sub-themes that shape the grief-bereavement experience prior to MAiD and continuing afterwards. The narrative of bringing death to life is presented using a composite short story. This story (almost verbatim) also segues into three sub-themes: (1) the certainty of date and time of death—that acts to intensify a parade of lasts, initiates a countdown to death, and affords time to plan and say good-byes; (2) active engagement as facilitators and planners—that supports sense-making; and (3) enacting MAiD as a ceremony—that serves to slow time down in order to "digest" grief and loss.

### Short story: bringing death to life

Mom started gathering information about MAiD as soon as she was diagnosed. Though she wasn't sure it was what she would want, she wanted to be sure she knew as much as possible about all her available options. Her illness ended up advancing quickly, and she moved into hospice two months after her diagnosis. Two weeks later, while watching *Mary Poppins* with my seven-year-old son, mom turned to me and told me she'd been in touch with the MAiD doctor and had decided to go ahead with it. I think

she made the decision quickly because she knew she would soon no longer have capacity to consent. Knowing the time and date was jarring. It was really surreal knowing that “tomorrow at 09 am mom is going to die.” I think not knowing was better! It was so final, and knowing it was the ‘last’ car ride or the last ice cream—I just felt sad just knowing it was a parade of “lasts.” It feels like that knowing brings grief forward. During the ten-day countdown period there was also a lot to do, and we had to balance all of the planning and paperwork with completing our relationships with mom. I brought important experience and knowledge as a health professional that helped a lot with this process. It seemed like a large part of my role in mom’s MAiD experience was to teach others in our circle about MAiD, and about why mom wanted it. I also helped a lot with the ritual of the death and with ritual in the days leading up to it.

My sister and I didn’t want mom to choose MAiD. Our dad had died a natural death of the same cancer mom had, and I had been expecting to spend the same time in vigil with her at the end of her life as I had with dad. I was sad to learn that I’d miss out on that time, but I strongly believe that people should have the freedom to make this choice on their own. The morning of mom’s death felt like a normal morning. This was only possible because we’d had time to get prepared, and to have all the necessary conversations. It was a beautiful day, and mom chose to die outside in the garden. It was beautiful, wholesome, and perfect.

In these four months since mom died, I’ve been thankful for my body’s natural ability to get me through. Emotionally, I think this experience is like a roller coaster, where it goes up, sometimes stays flat, sometimes goes down, but never stays still in any one place. I don’t feel that my mom’s decision to have MAiD has impacted my grief negatively; if anything, it has made it easier because I know she was able to choose what was best for her. Even if we didn’t agree with her decision, prioritizing the quality of our relationship was the most important thing I could do. I think continuous support throughout the MAiD journey is so important. I’m going to be having a debrief soon with the MAiD doctor, I think it will help me to solidify my memories.

As illustrated in this short story, participants’ experiences of grief-bereavement invariably circled around the assisted death, beginning with the reasons why, when, and how the death occurred. Participants often described a sense of loss and grief that began with their discussions about assisted dying with their family member or friend. For some, the decision to pursue MAiD was made early on but it was not enacted immediately; instead, everything was set in place and ready (described by one participant as having MAiD “in our back pocket”). However, in this short story when the final decision happened, death sprang to life in a

“moment” when her mom turned to her and said she had “decided to go ahead with it.” Like other participants, this moment was seared into this participant’s memory and marked the initiation of what some called “the death countdown.” As one sister described it:

He was on the floor with his granddaughter playing with her. He was down to about 85-pounds ... he said everything hurt, all the bones, and I said, “Well it’s because you have no fat protecting all of your nerve endings.” He looked up at me from the floor with his beautiful blue eyes and he said “make the call.” And I know I’m going to get choked up saying it again because that was the hardest moment for me.

Yea, his daughter was there too and so I just said, “Oh, okay.” And he didn’t see me fall apart but I went out the back door on to the patio and had my sob, and so did she, for probably a minute only, and I said to her, “We got this. We can do this. We have to be strong, we can do this.” We both dried our eyes and went back in and I phoned the doctor’s office ... and from that moment on all of us felt a bit like zombies and we couldn’t think clearly.

Whether the assisted death occurred immediately following the requisite 10-day reflective period or after a longer interval, what stood out was participants’ perception of grief being brought forward and the challenges of this. As one sibling shared:

I really think that the grieving process after is easier than the grieving before. I didn’t think that would be the case but it really was. That week before was when – I almost feel like there should be somebody that comes to talk to you all, even if you are doing well, just to make sure that you’ve covered all those things that we covered. (Interviewer: So it was harder because...?). Just the waiting. And it’s just... – everybody was so sad and yeah, I mean that series of lasts is ... and I didn’t even think of how we would deal with that.

The intense grieving experienced prior to MAiD was often linked to knowing the date of death which was unprecedented for participants. The following three sub themes describe elements foregrounded with an assisted death that shaped participants’ grief and bereavement.

### ***Sub-theme 1: (living with) the certainty of date and time of death***

The certainty of having “an appointment” with a date and time for death was described as “weird,” “odd,” “strange” and “surreal.” Knowing in advance the moment of death intensified families’ experiences; everything felt amplified with a *parade of lasts* that

initiated what one person called a *countdown to death*. One daughter shared:

[What] I found hard, was not the actual day, but the two or so weeks prior where he had the interview with the doctor and dad saying ‘I really want to do this’ and then there was this date set. That was actually almost the hardest – knowing that my dad’s life was going to end here and I had this finite number of days and I couldn’t, well I felt like I couldn’t act like he was actually dying. I felt like I had to be strong for my dad and for my mom ... and I just found it, like I was almost going crazy.

For some participants, time seemed to momentarily stop when the final decision to “make the call” was spoken. This intentional ask was a turning point that many participants held close; a distinct moment crystallized in memory and storytelling (akin to a “will you marry me” moment).

Many participants described amplified experiences once the date was set, as if a clock started ticking and the reality of knowing, “four more days, three more days ...” was intensified. Stories of time being altered were central. One sister remembers:

It’s so bizarre, you know, can we book an appointment for Friday? And so the rest of that week was – oh this is the last time we’re going to do this, this is the last time we’re all going to go here, and this is the last time we’ll drive through the park. I said ‘this is just so odd and it must feel that way for you’. But just being able to talk about it with him was important.

In contrast, the fixed date also afforded time to say good-byes while their loved one was alert and present. Participants described abundantly their gratitude for this space to call family together; knowing specific dates meant family members could take leave from work and travel to be present.

Along with the certainty, participants also spoke of surprises. Many grappled with the suddenness of the death. Stories focused on how quickly the dying happened, within minutes, and described feeling unprepared. Said one wife: “I’d been warned that it was maybe a little difficult to be there, it’s so sudden, but it was shocking...” Another spouse participant expressed a similar sentiment: “you know, [it is] just really difficult to watch someone go from being there 100% present, to being gone 15 minutes later. It’s just abrupt and quick, and so maybe our human psyche is in shock because ... the finality of it all.”

Despite the certainty of knowing the date and time of death, many participants described feeling this time was both precious with many

benefits and disorienting with surprises and unanswered questions.

### ***Sub-theme 2: (engaging in) facilitator and planner role***

Participants also described how preparing for the assisted death felt like planning an event. From the time of diagnosis, through the decision making, scheduling, and final moment of the assisted death, family members were confronted with multiple losses and necessary tasks. They shared stories of being actively involved, informing and gathering family, making arrangements for homecare beds and walkers, scheduling visitors and friends, and completing unfinished business that seemed to support their sense-making throughout the process. This was perceived as both an honor and for some it was a burden. For example, some described the planning and organizing created a sense of doing something meaningful and productive during an emotionally difficult time. As one daughter stated:

It made it so much easier. When the decision comes things have to move quickly and if you’re aware of the things you can do before someone dies to make it easier after – there’s a lot to be done in that time! It’s very shocking and alarming to just go from one thing to the next from the time the decision without time to absorb.

Some participants also felt duty-bound to take on an organizer role that was perceived at times as burdensome. Said one wife: “That was his decision but it wasn’t mine. I’m the one that had to deal with everything. It was really difficult.” She later shared:

At the time nobody in hospice had ever [undergone] a MAiD procedure, so I had to go and talk to the head of hospice and make sure there wasn’t going to be any difficulty because I knew there were difficulties in other facilities with people—right as they’re dying having to be transported somewhere else ... so that was pretty stressful and demanding.

Balancing the emotional and relational needs as the clock was ticking down was challenging.

### ***Sub-theme 3: (enacting) ceremony to accompany procedure***

The third and final sub-theme presents stories of enacting MAiD as ceremony rather than a procedure alone; ceremony that served to help slow time down and digest what was happening. Knowing the exact time and death date moved some participants to

create formal and informal ceremonies at different phases: before, at the time of, and after the assisted death. The importance of creating ceremonies and enacting rituals was seen by many as a significant aspect of their grieving. As one participant who is a death doula and friend shared:

Nothing gets integrated in speed, we know that; and that's why I also trained to help families actually slow down after death. My gosh, don't rush this. Even if it's a couple of hours ...

We heard stories of formal and elaborate rituals rooted in culture and tradition, often led by religious or celebrant leaders. While MAiD was frequently referred to as “a procedure,” families/friends and the dying person created ways to individualize and humanize their experience. For some, this was expanded through intimate, informal acknowledging such as a touch, a kiss, a silent prayer, or shared everyday moments such as watching a favorite movie that took on extra significance. For others, their ceremonies were elaborate events that helped them to take time and legitimize grief in order to integrate their feelings, thoughts, and emotions. A poem generated by researchers from a participant's story of a home funeral following the assisted death reflects this experience.

We kept her body for two days  
wanting time to digest.  
People came—all her friends  
spent the day painting the prayer of St. Francis  
on her cardboard casket.  
Listening to music she loved  
doing nothing, just sitting with her  
because we'd imagined it together.  
Then, I put a blanket over her  
Face exposed—she looked radiant.  
Passing by our honor guard,  
standing and witnessing ...  
It was a remarkable two days  
so digestive.

All participants described the significance of ceremonial activities both big and small. One daughter explained why rituals and ceremonies helped her grieving.

I think it's one of the most important pieces of dealing with death, and especially with MAiD ... including ritual ... because it anchors you in

the present. It's so hard, it's just a blur, your hormones are going, your mind is racing, your heart is torn in pieces but to be able to have a ritual that just grounds you and reminds you of where you are right now and that the person who is dying is actually still living, they're actually living ... It's hard, you know when you look back after traumatic events or difficult events, it's hard to remember, things are so hazy, but when you use ritual it makes a few moments clear and you can really keep that in your heart. And it helps, ritual is about marking what's happening now and about letting go. I think it's one of the most important things for the process and then for softening grief afterwards.

However, ceremonial activities were not necessarily supported by all family members, and this added a layering to grief. One participant described how her husband insisted on sharing his death publically through the media as a way to memorialize and positively publicize assisted dying. She felt this robbed her of the privacy and quiet time she yearned for in their last days as husband and wife. So while ceremonies and rituals were powerful tools that helped to “soften grief” for some, they may have the opposite effect if unwelcomed.

## Discussion

Key findings from participants' stories include a broader narrative that MAiD experience was one of *bringing death to life*, a complex experience that shaped their grief-bereavement through three sub-thematic elements: (1) the certainty of date and time of death, (2) active participation by family/friends in planning and organizing, and (3) enacting MAiD as ceremony rather than procedure alone. We discuss each in turn.

Even though the focus of this study was bereavement following MAiD, the stories shared by bereaved participants highlight the significance of the pre-death period. As indicated by earlier studies, the time before and on the day of the MAiD is of “utmost importance” (Hales et al., 2019, p. 594). Our finding suggests having a scheduled death was highly emotional and a hallmark of the medically assisted death. Such certainty brought death to life in profound and meaningful ways. Each moment and activity took on heightened significance as the dying person and their families experienced a “parade of lasts,” alongside practical preparations for death.

Grief literature suggests that knowing someone is going to die affords people valuable time to prepare and adjust to the reality of loss. Preparedness is seen to include three aspects: emotional (identify and

express emotion), cognitive (understand death is impending) and behavioral (make funeral plans) (Breen et al., 2018). Low preparedness is associated with post-loss anxiety, depression, and complicated grief (Nielsen et al., 2016; Rando, 2000; Stroebe & Stroebe, 1993). Published reviews and recent studies of anticipatory grief/mourning suggest that people whose family member opts for assisted death have time to prepare themselves for the death and this brings greater acceptance of the death and more ease in bereavement (Ganzini et al., 2009; Srinivasan, 2019; Wright et al., 2008). Similarly, the bereaved participants in this study talked about the value of being able to say goodbye and make meaningful preparations in anticipation of the days leading up to and the day of MAiD. The act of “saying goodbye” surfaced in many nuanced ways, through special meals with family and friends, to a last drive down familiar roads, to witnessing the dying person’s last peaceful glance toward the sky.

The intensity of this pre-death period was fueled by numerous practical and relational demands unique to the fixed time and date of the assisted death. For some family members, this countdown initiated a busyness that helped make the assisted death a positive experience for everyone, while for others the list of “to dos” was burdensome. The intensity of the pre-death period is reported elsewhere, acknowledging the great adaptive efforts required by family caregivers (Coelho et al., 2018; Hales et al., 2019).

This intensity of the predeath period for family caregivers aligns with what is known about families’ experiences during assisted dying. In a Canadian qualitative study, Holmes et al. (2018) report bereaved family and friends provide emotional and practical support for MAiD and overall, describe the experience as strange, sad, and at times overwhelming. Despite these seemingly negative descriptors, they also reported positive overall experience of the MAiD. Similarly, Srinivasan (2019) conducted one of the first studies in the USA to focus solely on bereavement experiences following medically assisted death and described families’ heightened grief once the date was set. Similar to findings in this study, the anticipation of the death date brought both anxiety about the exact moment of death and appreciation of the time to openly communicate.

Our findings suggest that despite participants planning and organizing, there were surprises that were not (or could not) be anticipated. While some surprises such as the shock of how abrupt and quickly their loved one died can be addressed through

education, there may be potential sights (e.g., sudden gray coloring) and sounds (e.g., breath changes) that will necessarily be new to some people. Perhaps preparing families for potential experiences would be important. Similarly, a recent study (Hales et al., 2019), reported that families experienced anxiety associated with lack of clarity about the MAiD process, including details about the medications given, who would be involved, how much time they would have following the death, and what supports were available. Further research is needed into what kinds of information (and amount) grievers find helpful. For some, knowing too many details may enhance anxiety while for others, knowing more may offer a sense of control (Hebert et al., 2008).

The third theme addressed how enacting MAiD as ceremony served to slow time down in order to “digest” grief and loss. The literature is replete with descriptions of the role of ritual and ceremony in relation to non-assisted dying and grief over the centuries. Indeed, it could be argued there is a universal belief that ritual and ceremony are relational, emotional, and powerful ways to integrate loss for the bereft across cultures. Participation and engagement with ritual activities of ceremony are understood to support healthy adaptation and adjustment to the reality of the loss (Sas & Coman, 2016). A comprehensive history of ceremonial activities is described by Castle and Phillips (2003) who suggest that some aspects of post-funeral rituals facilitate adjustment to bereavement.

More recently, Reeves (2011) studied how death-related rituals facilitate acknowledgment and exploration of impending loss in a way that helps to prepare the dying person and their loved ones for separation. Sas and Coman (2016), drawing from earlier work by Van der Hart (1983), describe how rituals provide a safe space to legitimize emotion, validate the loss, and imbue a sense of control over the impending death and separation.

Our third finding of enacting MAiD as ceremony rather than procedure is supported by other studies (Buchbinder, 2018; Nelson-Becker & Sangster, 2019) and acknowledges the importance of ritual and ceremony in medically assisted deaths. We foreground an emergent relationship between ceremonies, experiential time, and assisted dying. That is, we note how ceremony served to slow time down and allowed participants to digest and integrate the loss that was occurring. In this study, the term ceremony is used broadly to refer to a multitude of actions that took place leading up to and during the time of death to acknowledge the moment. These pre- and post-death

activities, conceptualized as *enacting ceremony*, stood out as essential aspects of participants' journeys with assisted death. Similarly, Nelson-Becker and Sangster (2019) suggest ceremonial moments help people to infuse meaning in a time of suffering, to bring words to the unspeakable, and help one to be fully present to the significance of the experience that may seem surreal.

The importance of meaning making through interactions such as ritual and ceremony is well established (Maturana, 2011). Recently, Nelson-Becker and Sangster (2019) outlined the important functions of ritual as providing language to express thoughts and feelings, integration with others in a time of deep loss, a pathway to new life, a link with tradition, and emotional support. The potential benefit of ceremony during bereavement seems obvious when bereavement is understood as "the attempt to reaffirm or reconstruct a world of meaning that has been challenged by loss" (Neimeyer, 2015, p. 312). However, future research is needed to explore if, and how, supporting families to create rituals may enhance meaning making with assisted dying in diverse circumstances.

### Limitation and reflections

Participants in this study came from a single health authority where information regarding MAiD was widely available and public acceptance was high; a region with a responsive approach to assisted death. The participants represent a small and unique group of people with experience with MAiD. The bereaved participants were all Caucasian, middle to older-aged women. Many of the assisted deaths referred to within this study occurred during the early days of the legalization of assisted death in Canada and as such they (and their now-deceased loved ones) represent the earliest adopters and pioneers of this significant change to end of life care options in Canada. The determination and tenacity of this first group might have shaped their experience of grief-bereavement.

For this bereaved participant group, the time since the MAiD death ranged from four months to three years. It is important to note that grief at four months after the death may be felt and expressed quite differently than grief three years later.

Now that established mechanisms for the provision of MAiD are available, it will be important to understand what information and supports people need during the time before the assisted death occurs. Knowledge in this area of MAiD grief-bereavement would benefit greatly from studies with diverse

participant groups. Since both men and women almost equally choose MAiD in Canada (Health Canada, 2020), it is important to learn more about men's experiences with grief following an assisted death. What are the grief-bereavement experiences of indigenous, LGBTQ and religious communities following an assisted death? And finally, what are the needs of children and youth following an assisted death of a family member?

### Conclusion

Bereavement following MAiD is an emergent area of interest in Canada. Findings revealed how critical the time leading up to the assisted death is; a time that ignited grief early. This pre-death period was the most meaningful and impactful, *bringing death to life* in ways that brought grief forward, generated many practical tasks and activities for family members, and provided an opportunity to create formal and informal ceremonies that helped to make meaning and mark the significance of this time, and most importantly the value of the dying person's life.

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