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Grief and MAiD: Lessons Learned from Oregon



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As a growing number of countries adopt laws allowing assisted death and/or voluntary euthanasia, including Canada and the Medical Assistance in Dying Act, it is increasingly important to understand the grief experiences following these modes of death. Though research on this topic is minimal, some studies have provided insights that are applicable to understanding grief. Studies suggest that open conversations often precede an assisted death or voluntary euthanasia, which may lead family members to feel prepared for the death (Starks et al., 2007; Swarte et al., 2003). Additionally, legal frameworks providing clear protocols to follow help family members to feel well prepared for the death (Ganzini et al., 2009; Holmes et al., 2018; Srinivasan, 2018; Starks et al., 2007; Swarte et al., 2003). Some studies have found that disagreement with a loved one's decision for an assisted death or voluntary euthanasia may bring about more distress in the grieving process, compared to agreement with a loved one's decision (Gamondi, 2013; Holmes et al., 2018; Srinivasan, 2018; Starks et al., 2007). Not surprisingly, grief expression is negatively impacted by the sense of stigma and controversy surrounding these modes of death (Gamondi, 2013; Holmes et al., 2018; Srinivasan, 2018; Starks et al., 2007).

This article will summarize findings from the first in-depth exploratory qualitative study on assisted death and grief in Oregon, which can be used to inform the understanding of grief following a medically assisted death in Canada. However, before reviewing potential implications for understanding grief, it is important to have an understanding of the differences and similarities between Oregon's Death with Dignity Act and Canada's Medical Assistance in Dying Act.

In Oregon (and several other states in the U.S. where assisted death is legal), the assisted death process allows adults with a 6-month terminal diagnosis to "end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose" (Oregon Health Authority, n.d.). The person intending to end their life needs to have the ability to ingest the pills on their own, without the assistance of others. A physician or other healthcare professionals might be present, but it is not a requirement. Additionally, family members or friends might be present. Overall data from Oregon's Death with Dignity Act since the law was first implemented show that 34% of the people who requested a prescription died without ingesting the prescribed pills (Oregon Health Authority, n.d.). This can happen for several reasons. Those who have requested the prescription for an assisted death: 1) might die before receiving or deciding to take the prescribed pills 2) might no longer meet the requirements for taking the pills by the time the prescription is filled or by the time they feel ready to die (requirements include having an ability to ingest and swallow the pills on one's own and being cognitively competent), or 3) might change their mind and prefer to die without taking the pills.

In Canada, eligibility requirements for the Medical Assistance in Dying (MAiD) Act include having a "grievous and irremediable medical condition," which, in contrast to the United States, widens the scope of eligibility to include adults with a "serious illness, disease or disability," who are at a point where "your natural death is reasonably foreseeable," but without a "specific prognosis on how long you have left to live" (Government of Canada, 2020). The Medical Assistance in Dying law officially sanctions both self-administration and clinician administration of a lethal prescription, though in practice, and for various reasons, the majority of people who have used the law have received approval for clinician-administered medical assistance in dying, where a physician or, in some provinces, a nurse practitioner administers the lethal substance, thus is present for the death. In addition to the clinician who administers the prescription, other healthcare practitioners may also be present, as well as family members or friends.

The differences between the modes of death sanctioned by the law in Oregon and the law in Canada could have varying implications for griever. For example, griever in Oregon, compared to griever in Canada, may feel a sense of relief that their loved one potentially has more control over scheduling the date of death (for example, postponing or changing the day they ingest the prescription) because self-administration does not need to

involve coordination with a healthcare professional. On the other hand, grievors in Canada might feel more relief compared to grievors in Oregon because the responsibility of administering the prescription falls on a trained healthcare worker, rather than on the loved one. This is an area for future research. It is also important to note, however, that the similarities in the modes of death could result in similar impacts on grief. The modes of death made legal by the laws in Oregon and Canada overlap in the sense that both require the person seeking the law to make a request to end their life, both might precipitate conversations with loved ones and healthcare practitioners about the decision to end one's life, and both involve knowing the date that one will die, allowing both the person seeking to die and their family members to plan in unique ways for the death and grief process. Thus, findings from an in-depth exploratory qualitative study on assisted death in Oregon can be applied to better understand and support those grieving a medically-assisted death in Canada, and those in other countries where assisted death and/or voluntary euthanasia are legal.

The study, conducted in Oregon, included 22 participants who were grieving an assisted death. Results indicate that some aspects of an assisted death ease grief, while other aspects bring challenges. Four themes were selected following qualitative data analysis, including: 1) anticipating the death, 2) sense of control, 3) level of agreement, and 4) grief expression and stigma. Those interested in reading the full study can access it online in [Death Studies](#), or by contacting the author at esrinivasan@uwlax.edu. In the current article, a summary of the four themes will be presented. Below each theme, questions for exploration are included, derived from the data. Though the questions have not been tested, they speak to the grief reactions and situations that participants discussed and include questions that participants reported asking themselves in the grieving process. As such, the exploration questions can serve as helpful items for counselors to use with clients grieving a medically-assisted death. It should be noted that while these questions serve as a helpful starting point for exploring grief from a medically-assisted death, including neutral and positive reactions, the questions could also potentially bring up anxiety or challenging feelings, so counselors should proceed with the same protocol and precautions they would follow when discussing any topic that might provoke a range of feelings and reactions.

Anticipating the death

Anticipatory grief was often accompanied by anxiety, and included anticipating the scheduled date and time of the loved one's death. One participant described the feeling of being on an "emotional rollercoaster," as her loved one would schedule the death and then postpone the date. Participants described holding two opposing feelings of being grateful their loved one had the option for assisted death while also experiencing anxiety.

Along with anticipating the moment of death, participants could anticipate how they wanted to prepare for the death, including who to have present for the dying process and for immediate shared grieving, which provided a source of comfort. Knowing the scheduled day of death prompted open conversations, allowed family members to address unfinished business, and provided the unique opportunity for a specific moment to say goodbye preceding the assisted death process.

Grief exploration questions:

- In previous experiences with anticipating loss, what helped and did not help to cope with grief?
- Do you want to be present for your loved one's death? Why or why not?
- If you attend the death, who would you like to have present with you and why?
- Is there anything you'd like to say to your loved one before they die?
- Would you like to have a final goodbye with your loved one immediately before they use MAiD?
- Did your loved one change or postpone the scheduled date for MAiD? How did that make you feel? Did your loved one feel like they had the option to change or postpone the scheduled date for MAiD? How did that impact you?

Sense of control

Participants described experiencing a sense of control that came from knowing that their loved one could end current, or prevent possible future, unbearable physical suffering and emotional pain. This sense of control eased grief. Family members were also grateful that safeguards were in place for a legal and comfortable dying process, keeping loved ones from considering other alternatives, such as suicide completed in secrecy.

Grief exploration questions:

- How did you feel about the timing of the death?
- Did any aspects of MAiD help you to feel a sense of control? Did any aspects of MAiD contribute to feeling a lack of control?
- What helps you to feel a sense of control in the grieving process? What makes you feel a lack of control in the grieving process?
- Did you feel that overall the end of life options for your loved one were adequate? Why or why not?

Level of agreement

All participants had open conversations with their loved one about the decision for an assisted death. In most instances, participants agreed with their loved one's decision, which was later accompanied by a sense of ease in the grieving process. However, challenges arose for participants who felt conflict over the loved one's decision for an assisted death. Conflict included opposition to assisted death due to religious beliefs, opposition due to professional values, questioning if assisted death was the right decision, questioning the timing of using the law, wondering if the loved one should have been stopped, and feeling responsible for the loved one's death. In some instances, there were differing opinions within families over the loved one's decision, which brought discomfort in the grieving process. For one participant, professional opposition contributed to challenges in the grieving process. Specifically, the participant held conflicting beliefs about assisted death, supporting the option on a personal and community level, while also feeling that the option violated her professional training as a nurse, which emphasized using medication to alleviate pain and not to hasten death.

It will be important for those who have a loved one seeking MAiD to be aware that their level of agreement might not only impact their grieving process, but may also play a factor in decisions regarding preparing for the death itself. For example, the participant who felt professional conflict decided to not be present when her loved one ingested the prescription.

Disagreement with or conflict over the loved one's decision to die an assisted death can be significant in the grieving process and require different ways to work with grief. One participant who questioned the decision in general and wondered if she should have intervened found solace in recognizing that death was impending, as her loved one had a terminal illness. One participant felt a deep sense of guilt, stating that he felt like he had, in part, killed his loved one. At the same time, he was also a strong advocate of the assisted death law and discussed intellectually understanding his loved one's decision, while emotionally having a difficult time with the mode of death. One person who supported the law experienced distress from worrying that her religious community might be against assisted death. She worked with her grief by talking with her pastor, who brought reassurance that assisted death did not conflict with the beliefs supported by their church.

For some grieverers, coping with grief might include learning to hold ambiguity or conflicting feelings, such as having personal support for the law while also not fully feeling comfortable with their loved one using MAiD.

Grief exploration questions:

- Did you agree with your loved one's decision to use MAiD? Did other family members agree with the loved one's decision to use MAiD?
- What do you view as the cause of death? What do other family members view as the cause of death?

- What are your personal religious/spiritual beliefs around MAiD? Are you or were you part of an organized religion/spiritual community? Do your beliefs about MAiD align with your organized religious/spiritual community's beliefs about MAiD?
- Does your profession take a stance on MAiD and do your personal beliefs align with your professional beliefs?

Grief expression and stigma

Participants were very aware of stigma around assisted death, which made them self-select who they told about the mode of death. Although most participants had someone with whom they could openly grieve and express the mode of death, if needed, grief expression was also impeded by the awareness of stigma. For example, participants were aware of religious disapproval and broader political controversy over assisted death, making them hesitant to discuss their loved one's death. Participants described not wanting to be in a position of having to defend their loved one or to engage in heated debate. One person did not feel comfortable bringing up the mode of death in a support group. In another instance, a child was verbally attacked by neighbors who expressed religious disapproval over the loved one's assisted death. Participants also recalled their loved one receiving disapproval and sometimes harsh words from medical professionals when seeking to use the law. Feelings of anger about their loved one feeling unfairly judged and treated when seeking assisted death arose in participants' grieving processes.

Professionals offering grief support should be aware of potential stigma around MAiD. Mixed bereavement support groups offer the opportunity for shared support and for others to learn about MAiD, but the level of possible stigma surrounding MAiD could impact the comfort level of the person grieving a medically-assisted death. Professionals may want to consider offering a support group solely for those grieving a medically-assisted death, or individual counseling. Professionals should also be aware that MAiD will likely bring up grief unique to this mode of death.

Grief Exploration Questions:

- What rituals and outlets help you to cope with grief?
- Did you feel supported in your grief? Do you feel you can disclose the mode of death? What would help you feel comfortable in disclosing the mode of death and discussing grief?
- How does the broader culture feel about MAiD and how does this impact your grief process?
- Did you feel supported in the process of your loved one seeking MAiD?
- In previous experiences of coping with grief, what was helpful and not helpful?

- Did you explain MAiD to your children? Were your children present for their loved one's death? Why or why not? What are your resources for exploring grief with children and family?

Discussion

Though studies on grief and MAiD are minimal, there is overlap between findings presented in this study and findings from a Canadian study on grief following MAiD (Holmes et al, 2018). They include feeling comfort from being able to say goodbye, being able to prepare for the death, feeling a sense of control that the loved one could end potential suffering, experiencing anticipatory grief unique to knowing the scheduled date and time of the death, and feeling grateful for the safeguards involved, allowing for a peaceful death. It is clear that findings on grief from assisted death in Oregon can give insight into the grieving process from a medically-assisted death in Canada, though it remains imperative to explore how the aforementioned differences between the law in Oregon and the law in Canada might impact grief. It is essential to support those grieving a medically-assisted death. Continued research and efforts to understand and share grief experiences will allow griever to feel better supported.

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