



Impact of medical assistance in dying on family and friends

Question

- What is the impact of medical assistance in dying on family and friends?

Key Take-Home Messages

- In jurisdictions where medical assistance in dying is legal, there are usually clear procedures to follow, and shared responsibilities between patients, family members, and healthcare providers (1).
- In several studies, the family and friends of patients who requested medical assistance in dying had less traumatic grief symptoms compared to family and friends of patients who died of natural causes (2-4). However, other studies have shown a higher prevalence of post-traumatic stress disorder (PTSD) and depression among family members or friends witnessing medical assistance in dying (5).
- Some studies found that the opportunity to discuss death freely and extensively in an open atmosphere with a loved one may make it easier to come to terms with an impending death (4, 6-8).
- Acknowledgement of the experiences of family members should be an essential component of all research investigating medical assistance in dying (1).

Studies included in this review use the terms “medical assistance in dying”, “euthanasia”, “assisted suicide”, “physician-assisted suicide”, “physician-assisted dying”, “physician-assisted death” or “aid-in-dying” to describe assisting another person in ending his/her own life. For the purpose of this review, we are using the term “medical assistance in dying” as this has been officially adopted in Canada.



References

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! The Issue and Why It's Important

Medical assistance in dying is only legal in a limited number of jurisdictions around the world:

- In the Netherlands, Belgium, Luxembourg, and Colombia medical assistance in dying is legally permitted, meaning that physicians are allowed to administer drugs to end a patient's life at his or her request (9).
- In Switzerland, physicians are allowed to prescribe or supply a lethal dose of barbiturates with the explicit intention of enabling a patient to end his or her own life (10). Medical assistance in dying in Switzerland is usually conducted through non-profit organizations (5).
- Residents of Oregon (U.S.) with a terminal illness have had the option to use aid in dying under the Oregon Death with Dignity Act since 1997 (3, 11). This law allows terminally ill Oregonians to make a request for physician-prescribed lethal dosages of medication for self-administration. In recent years, medical assistance in dying has become legal in some other states as well (California, Colorado, Montana, Vermont, Washington, and the District of Columbia) (9).

In June 2016, the Canadian government passed legislation allowing eligible Canadian adults to request medical assistance in dying from either a physician or nurse practitioner (12) in one of two ways:

- directly administering a substance (such as injection of a drug) that causes death; or
- providing or prescribing a drug that patients take themselves in order to bring about their own death (13).

In order to be eligible for medical assistance in dying in Canada, a person must be eligible for health services funded by the federal government, or a province or territory (this exempts visitors to Canada). The person must be at least 18 years old and mentally competent with a grievous and irremediable medical condition. The individual must make a voluntary request that is not the result of outside pressure or influence, and must give informed consent (13).

This review summarizes research findings that examine the emotional, psychological, and mental health impacts of medical assistance in dying on family and friends following this type of death.

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What We Found

The first study of the effects of medical assistance in dying on family members was conducted in 1990 in the Netherlands. This qualitative study found that family members viewed the “active” end of life process positively (2). Despite feelings of grief, many relatives were glad that further suffering had been avoided (2).

A later study, conducted in the Netherlands from 1992 to 1997, compared grief symptoms among family members and close friends of cancer patients who received medical assistance in dying (n=189) to grief symptoms among relatives of women who died unassisted deaths due to gynecological cancer (n=316) (4). The researchers found that family and friends of patients who requested medical assistance in dying had less traumatic grief symptoms, fewer current feelings of grief, and fewer post-traumatic stress symptoms compared to the family and friends of women who died naturally (4). The authors concluded that the bereaved family and friends of cancer patients who received medical assistance in dying coped better with respect to grief symptoms (4). According to the study authors, the better coping could be explained by: (a) the opportunity to say goodbye while patients were still fully aware; (b) family and friends being more prepared for the way of death and day of death; and (c) the ability to talk openly about death after the patient made the request for medical assistance in dying (4).

A small 2010 qualitative study from Oregon (n=22) found broad overlap between grief reactions (e.g., feeling sad, angry, or numb) and grief reconciliation behaviours (e.g., recalling the loved one, writing about feelings associated with the loss, or honouring the loved one with a celebration of life ceremony) following a medically assisted death compared to any type of death (3). Those who compared their grieving experience from medical assistance in dying to their grieving experience following other deaths felt that their grief was eased by knowing that their loved one had a sense of control over the dying process, and that the loved one had been able to avoid prolonged suffering (3). Medical assistance in dying also allowed for planning in terms of rituals, deciding who would be present at the death, and preparing how to say goodbye at the moment of death (3).

A larger quantitative study from Oregon, published in 2009, examined family members of patients who requested medical assistance in dying (n=95) and family members of patients who died of cancer or amyotrophic lateral sclerosis (n=63) (14). After a mean of 14 months post-death, 11% of family members in the medical assistance in dying group were depressed, 2% had prolonged grief, and 38% were receiving mental health care (14). Among those whose family member requested medical assistance in dying, whether or not the patient accessed a lethal prescription had no influence on subsequent depression, grief, or mental health service use. However, family members who received a lethal prescription

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were more likely to believe that their loved one's choices were honoured and less likely to have regrets about how the loved one died (14). A comparison to family members of patients who did not request medical assistance in dying showed few differences in terms of depression (14%), grief (0%), and mental health services use (41%) (14). Family members of those who requested medical assistance in dying felt more prepared and accepting of the death than family members in the other group (14). In summary, pursuit of medical assistance in dying did not have negative effects on surviving family members – possibly because of greater preparation and acceptance of death (14).

Two studies from the Netherlands (published in 2003 and 2013) found that talking about the request for medical assistance in dying prepared relatives for the imminent death and facilitated saying farewell (4, 7). At the same time, relatives reflected about unresolved feelings regarding the speed of the decision-making and the “unnatural” character of this kind of death (7). These data also show that, after medical assistance in dying has been chosen, there can be difficulty in choosing the date of the procedure and finalizing practical arrangements for saying farewell (7). Bidding farewell to someone who faces a known time of death is an unfamiliar emotional task and a careful balance has to be struck between the planned process and the natural desire to postpone the death. Some relatives saw timing the death as unnatural and preferred to keep out of this process (7).

One important theme that emerged from the 2013 study is aftercare and closure for relatives and friends – neither of which are provided (7). Interestingly, relatives were enthusiastic participants in the research interview that took place after medical assistance in dying, largely because it provided a chance for them to reflect on the process. Relatives mentioned difficulties accepting what seemed to be a rapid process of decision-making that led to a decision that was often difficult for them to comprehend. Many said that the step of planning a farewell disturbed them, given the usual taboos around talking about death and the convention of always hoping that death will be postponed (7).

A 2002 study conducted in the US interviewed

48 family members who had been involved with a patient pursuing medical assistance in dying (8). This study aimed to describe qualities of clinician-patient interactions about requests for medical assistance in dying that were valued by family members. Openness to discussions about medical assistance in dying was one of the three most important topics identified by participants (8). The other two most valuable qualities were clinical expertise in dealing with the dying process, and maintenance of a therapeutic clinician-patient relationship, even when a clinician and patient might disagree about medical assistance in dying (8).

A 2013 study from the Italian-speaking part of Switzerland found that all family members of those who received medical assistance in dying seemed generally unwilling to disclose either the type of death or their involvement in it (1). These relatives did not share the difficulties they faced; in many cases, the patients themselves asked them to keep the assisted suicide secret. These findings differ from the Dutch studies which found that medical assistance in dying brings openness in dialogue (4, 7). This difference could be due to the Swiss-Italian cultural background.

One cross-sectional study from the German-speaking part of Switzerland published in 2012 examined 85 family members or close friends who were present during medical assistance in dying (5). A higher prevalence of PTSD and depression was found in the study sample compared to the general Swiss population; however, the prevalence of complicated grief was comparable. Of the 85 participants (mean age 60), 13% met the criteria for full PTSD (5, 15), 7% met the criteria for subthreshold PTSD, and 5% met the criteria for complicated grief. The prevalence of depression was 16% and the prevalence of anxiety was 6% (5). This study did not include a control group who lost a loved one by natural death, so it is unclear if levels of PTSD, depression and anxiety would be similar in a matched control group (5).

Further research of the same sample found that inadequate social support and low levels of social acceptance of medical assistance in dying predicted PTSD severity and complicated grief (16). Perceived general disapproval of medically assisted death was an important factor predicting PTSD (16). Thus, non-disclosure of the manner

of death and strong views expressed by the community and society concerning the end-of-life decisions may lead to increased levels of PTSD and complicated grief among family members of those who chose medical assistance in dying (16).

Factors That May Impact Local Applicability

“Medical assistance in dying” is the term used in Canada. In various other jurisdictions in Europe and the US it is known as euthanasia, assisted suicide, physician-assisted suicide, physician-assisted dying, physician-assisted death or aid in dying. Although medical assistance in dying in a broader sense can be used synonymously with those terms, there are some important legal and procedural differences. All reviewed studies have been conducted in high income countries (Western Europe or the US), but cultural differences surrounding death may limit the application of findings in the local context. In addition, almost all study participants both in Europe and in the US were White, and persons in Oregon who chose medical assistance in dying were almost seven times more likely to be college educated; this difference in educational level was mirrored in their family members (14). This further may limit the generalizability to people of other races, ethnicity and socio-economic status.

What We Did

We searched Medline and PsycInfo using a combination of [text terms (Assisted suicide* or physician-assisted suicide* or assisted dying or physician-assisted dying or physician-assisted death or aid in dying or compassionate death or compassionate dying or end-of-life choice or medical assistance at the end of life or death with dignity or right to die or medical assistance in dying or euthanasia or medically assisted death*) or MeSH terms (euthanasia, Active or Euthanasia, Passive or Euthanasia or Euthanasia, Active, Voluntary)] and text terms (friend* or family or families or carer* or bereavement or grief). All searches were conducted on April 3, 2017 and results limited to English articles published from 2007 to present. Reference lists of identified articles were also searched. The search yielded

506 references from which ten studies were included. Sample sizes of studies ranged from 11 to 505.

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