

Family caregivers bereaved by voluntary-assisted dying with a focus on motor neurone disease: the hidden patients

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Voluntary-assisted dying (VAD) refers to one form of hastened death, made by a person with decision-making capacity. In Australia, it encompasses self-administration of a lethal drug (elsewhere known as physician-assisted suicide) and practitioner administration (elsewhere known as euthanasia) to a person with a terminal illness.^{1–3} VAD is increasingly becoming legalized throughout the world such as New Zealand, 11 states of the United States, Canada, as well as several European jurisdictions. Such end-of-life laws have been passed in six Australian states with implementation presently at various stages across the country.^{2–4}

In a person-centred care system, the patient's needs and wishes are foremost with the treatment team, while opinions of family caregivers are often not as readily sought or considered.² Caregiver engagement in treatment decision-making may play a central role in how the caregiver responds to the course of the VAD and subsequently, this may affect bereavement outcomes.⁵ Therefore, it is important to understand the impact that this choice at end-of-life has on grief and bereavement in family caregivers.

Disenfranchised grief

For each patient, there are usually many significant others; family, friends and caregivers invested in a relationship with the patient who may also be involved in providing physical, practical care and emotional support during the illness.⁶ Research shows that family caregivers are at increased risk of mental health problems following the death, with some experiencing ongoing distress for years afterwards, which places them at higher risk of prolonged grief disorder (PGD).⁷

A lack of understanding or acceptance of VAD can stigmatize the bereaved, increasing their risk of social isolation, placing them at heightened risk of suicidal ideation or developing mental health conditions such as depression, anxiety or post-traumatic stress disorder.^{5,6} Stigma can disenfranchise grief, placing the bereaved at risk of PGD in future. Disenfranchised grief was first proposed by Doka⁸ to describe grief that is not socially recognized or supported, or where a bereaved person is not recognized as grieving a loss. While disenfranchisement can negatively impact grief following assisted dying, on the other hand, being actively involved in end-of-life planning, care and preparing for the loss can lead to improved bereavement outcomes.⁶

In a systematic review of literature on grief following euthanasia and assisted dying, Andriessen *et al.* located 10 articles over 25 years in three countries where physician-assisted dying was legal. The researchers found that there were no significant differences in prolonged grief or depression for those bereaved following assisted dying. The review's qualitative studies identified several untoward aspects such as moral conflicts, feelings of guilt and negotiating negative judgments about the death, while finding positive features such as '...having honored the deceased's will' and being given the opportunity to 'finish business' (p. 262).⁶

In exploring risk and protective factors for bereavement outcomes following assisted dying, Singer *et al.*³ identified risk factors such as ambivalence and having moral concerns about assisted dying, communication issues at end-of-life and having less time with the patient before death. Protective factors included being prepared for the death, planning the place of death, and having a

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sense of autonomy, the reduction of suffering for the patient and having the ability to support the patient's wishes. However, these factors were found to serve as both risk and protective factors in what the researchers termed a 'double-edged experience'.³

As in Australia, Canadian legislation for Medical Assistance in Dying (MAiD) does not allow a person to incorporate assisted dying in an advance health directive.⁵ Goldberg *et al.* suggest that some patients apply for MAiD sooner as an assurance against cognitive decline that would make them ineligible to access assisted dying. This has the potential to affect family caregivers who must face the death of their loved one sooner than expected, without enough time to prepare for the death.⁵

The case of motor neurone disease

In the first year of VAD implementation in Western Australia (July 2021–June 2022), a total of 190 VAD deaths were recorded.⁹ This represents 1.1% of deaths for the period and is consistent with medically assisted death rates in other countries, for example, 1.4% in Switzerland in 2016 and 2.1% in Belgium in 2018.⁶ While two-thirds of the VAD deaths in Western Australia were due to cancer, just over 14% were associated with neurological conditions, mainly motor neurone disease (MND) or amyotrophic lateral sclerosis (ALS).⁹ There are no direct comparisons of such data with the first Australian state, Victoria, to legalise VAD. The latest published half yearly Victorian report (July–December 2020) states that 77% of diagnoses were malignant, 23% were non-malignant and of these, 62% had a neurodegenerative disease.¹⁰

As nerve cells die, muscle wastage ensues and although progression is highly variable, most individuals with MND/ALS become increasingly disabled and die of respiratory failure 2–4 years after onset of symptoms.¹¹ It is therefore unsurprising that with such a prognosis, many patients with MND wish to hasten death by any means, not just VAD alone. People who are ineligible for VAD (i.e. not in the 12 months period) are still looking at alternative ways to hasten their death, rather than being caught in an unknown period of severe disability. A scoping review of the literature on desire for hastened death shows this wish is often due to various factors such as unbearable physical symptoms, psychological

distress, existential suffering or for social reasons such as not wishing to be a burden on family.¹¹ For many, the loss of communication and loss of physical abilities and autonomy that would make them dependent on others affected their desire for hastened death. The review also found that significant others and attitudes of healthcare professionals also have an impact on treatment decisions. Having a less rigid, adaptive coping style, as well as earlier connection to palliative care was associated with better psychological adjustment by the patient.¹¹

The Erdmann *et al.*¹¹ also showed that MND/ALS patients are more inclined to reject invasive treatments such as percutaneous endoscopic gastrostomy, but that culture influenced such healthcare options in various jurisdictions. Many jurisdictions also report a higher incidence of suicide in people with neurological disease, earlier in the illness trajectory while they have the capacity to act, even if not eligible for VAD.

In Oregon and Washington (United States), people with MND/ALS are second most likely to apply for assisted suicide after patients with cancer, while people with ALS commonly travel to Switzerland for assisted suicide. In the Netherlands, where assisted dying is also legal, around 20% of people with MND/ALS take up this option. The review concluded that people with MND/ALS may not be given enough clear information and counselling on treatment options and/or the discontinuation of treatment.¹¹

More recent evidence from a national population bereavement survey in Australia reported that MND/ALS family caregivers are one of the most challenged caregiver groups facing physical, psychological and social strain, before and during bereavement. They are more likely to be at a higher risk of PGD than the general bereaved population, with significant rates of depression and anxiety and high levels of unmet support needs.^{12–14}

In Western Australia, anecdotal evidence by counsellors working with family caregivers of people whose loved ones with MND/ALS have chosen VAD is that, initially at least, some family members tend to disenfranchise their own grief. These caregivers generally report not being ready for the death, feeling terribly sad and bereft, but also state repeatedly '*it's what s/he wanted*'. There is a feeling of disloyalty in wishing otherwise

because they had journeyed with their loved one's suffering and knew how much their loved one wanted it to end. There is also often concern about who they can confide in, which places many at risk of greater than usual social isolation during bereavement; another risk factor for PGD. The stark contrast between positive and negative aspects of bereavement following assisted deaths identified in research cited above^{3,6} would indicate that there are additional and conflicting issues to consider when providing counselling support to bereaved MND/ALS caregivers. The first author has had VAD counselling experience since the practice became legalized in Western Australia in July 2021.

Conclusion

As increasing jurisdictions legalizing assisted dying, and given the social implications for the bereaved, a lot more research is needed to investigate disenfranchised grief and the psychosocial repercussions for families following VAD deaths. While there is conflicting evidence whether VAD increases or reduces the suffering of family members during bereavement, there is a need for studies that compare bereavement outcomes for those bereaved by VAD to those bereaved by natural causes.³ Health professionals supporting the bereaved would benefit from clinical guidance in this emerging area of bereavement support, so that the potential for poor bereavement outcomes can be reduced. In particular, bereaved MND caregivers have been termed a neglected yet seriously ill population, akin to the hidden patients, which calls for better care provision and clinical practice.¹²

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Author contributions

Margaret Sealey: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Validation; Visualization; Writing – original draft; Writing – review & editing.

Samar Aoun: Conceptualization; Data curation; Formal analysis; Investigation; Methodology;

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Competing interests

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