

## Research Article

# The Impact of Voluntary Assisted Dying on Grief and Bereavement for Family Members and Carers in the Australian State of Victoria: A Qualitative Study

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Prior to its introduction in Australia, many people opposed euthanasia—or voluntary assisted dying as it is known—because of its potentially detrimental impact on grief and bereavement outcomes for family members and carers. We examine the novel experiences of grief and bereavement of VAD for family members and carers who were going through, had gone through, or were contemplating VAD, juxtaposing the international literature on grief and bereavement. As such, 42 semistructured interviews with family members and carers were undertaken in the state of Victoria, which was the first jurisdiction to legislate in favour of VAD. Interviews explored many themes around end-of-life decision-making in order to ascertain the ways in which VAD helped or hindered grief and bereavement processes. A thematic analysis of the interview data was undertaken using QSR NVivo software. Four key themes were identified: values and meaning-making, expression of a continuing bond, anticipatory grief, and the burden of care associated with supporting loved ones going through VAD. These themes were juxtaposed with the key literature on grief and bereavement to demonstrate how VAD presents novel challenges for carers. We argue that while VAD deaths share similar characteristics to other deaths; in some respects, grief and bereavement outcomes for family members and carers are unique. For family members and carers helping a loved one go through VAD, they were able to derive a sense of meaning from fulfilling their wishes and striving for them to have a “good death”; they were able to maintain a bond with them through advocacy of VAD and unique rituals; and they were able to plan and prepare effectively by knowing the exact time of death. Family members and carers also noted that VAD presents some significant challenges for grief and bereavement, especially in terms of the impact of VAD on familial relationships and burdens associated with moral predicaments. Nonetheless, VAD was generally viewed positively by family members and carers, who expressed gratitude for mitigating their loved one’s suffering.

## 1. Introduction

Legislation allowing for euthanasia or voluntary assisted dying (VAD), as it is known in Australia, now exists in several jurisdictions across the globe (euthanasia is now lawful in all states of Australia. There are different versions of euthanasia legislation also legal in the Netherlands, Belgium, Luxembourg, Canada, Spain, Germany, Switzerland,

New Zealand, Colombia, and a few US states, including Oregon, Colorado, California, Washington, and the District of Columbia); as a result, the numbers of patients and families bereaved following this process are rapidly growing [1–9]. The impact of caring for a loved one going through VAD is relatively unknown. Given that caring for a dying person is reported to be one of the most significant and stressful experiences for a caregiver [10], it is important to

consider how grief experiences may be impacted by such a policy. This is particularly the case as bereavement has been linked to negative effects on physical and psychological health, and quality of life [11]. In addition, these negative outcomes can be further complicated by experiences within the health system, a lack of social support and various emotional, financial, and interpersonal factors that impact relationships with the deceased [12, 13]. This paper, therefore, explores how existing ways of understanding grief and bereavement may apply to the setting of VAD.

Some of the key concerns expressed about euthanasia focus on the emotional burden of end-of-life decision-making and the moral complexity for family members and carers [14–16]. Yet, studies that compare caregiver bereavement experiences with and without assisted dying report similar or improved bereavement experiences for family and friends following assisted dying [17]. For example, a study conducted in the Netherlands showed that bereaved caregivers of cancer patients who died by euthanasia had fewer symptoms of grief and posttraumatic stress than carers of patients who died of natural causes [18]. Similarly, in the United States context, Andriessen et al. [19] found that bereaved caregivers of a patient who accessed physician-assisted suicide had similar or lower levels of disordered grief and posttraumatic stress compared with those who died naturally. Andriessen et al. [19] showed that being involved in the decision-making process and ensuring that the person's wishes about their death were honoured and were associated with more positive experiences of grief and bereavement for caregivers. Conversely, other studies have suggested that grief can be challenging or complicated, especially in situations where the caregiver lacks social support and/or there is secrecy surrounding the death [19–21]. A recent scoping review [22] explored grief and bereavement of family and friends of patients who had received medical assistance in dying (Maid) across jurisdictions where assisted dying was legal. The authors identified that issues related to secrecy, stigma, and disclosure around assisted dying contributed to the bereavement experience in a manner unique to Maid, with the potential of complicating the grief experiences of caregivers. A second distinct aspect of caregiver's grief identified by Yan et al. [22] was anticipatory grief, specifically connected to knowing the date of death. Qualitative research conducted in Canada and Switzerland has shown that family caregivers can experience social isolation, social stigma, and moral dilemmas associated with their participation in respective models of VAD, and that these experiences can persist for months or even years after the person has died [4, 5, 23].

While the unique characteristics of caregiver's bereavement in the context of VAD have been explored internationally, there is very little knowledge regarding the experiences of bereavement for carers in Australia, resulting from the recency of the legislation. Given the divisiveness of legislation and initial fears around problematic grief and bereavement outcomes for families and carers, it is important to examine the impact of experiences of grief and bereavement for VAD on family members and carers. We examine family members and carers' experiences of grief and

bereavement, juxtaposing common themes emanating from interviews with the international literature on grief and bereavement to better understand the impacts of VAD. We explore how VAD has the potential to both help and hinder grief and bereavement outcomes for family members and carers. While it is beyond the scope of this particular study, this knowledge is critical in ensuring that appropriate resources, training, and services are developed to support grieving families.

## 2. Materials and Methods

This paper draws on data from qualitative interviews with caregivers who were providing care to persons who accessed VAD. This study forms part of a larger mixed-methods study exploring the end-of-life care experiences of patients, family members, and health professionals, and how these experiences were impacted by the Victorian VAD legislation.

In order to recruit participants, an advertisement was placed on social media asking for family members and carers of patients with a life-limiting illness who were going through, had gone through, or were contemplating VAD to write to the researchers. 41 semistructured interviews of approximately 60 minutes in duration were conducted by experienced researchers using an interview guide (see S1, *interview schedule*, in the supplementary materials).

As shown in Table 1, *participant demographics*, 42 participants were recruited (two were interviewed together as a dyad). Participants were mostly female (92.9%), a child (42.9%), or spouse (33.3%), and were caring for a loved one with an advanced cancer diagnosis (64.3%) or neurodegenerative disease (28.6%).

The interview schedule was flexible so that questions were used to prompt for more information and the methodological approach was iterative, allowing new topics to be raised by study participants and new patterns and emerging themes to be identified (see S1, *interview schedule*, in the supplementary materials). Interviews were conducted via videoconferencing technology (while videoconferencing has certain limitations, the interviews were conducted during the peak of the COVID-19 pandemic while there was a 263 lockdown in the state of Victoria and there was no option of conducting the interviews in-person) and were recorded and transcribed.

We employed a reflexive approach to thematic analysis, recognising that our interpretations reflect our position and active role in producing knowledge [24]. Using NVivo, three members of the research team coded interview transcripts iteratively, creating descriptive categories relating to family members and carers' experiences of grief and bereavement. We identified key themes in the data, drawing on the relevant literature to situate the emerging findings [25].

## 3. Results

Four themes were identified from the analysis. The first theme was about values and meaning-making, whereby family members were able to make sense of challenging decisions, by reflecting on their loved one's values and

TABLE 1: Participant demographics.

Participant ID #	Age	Sex	Relationship to dying patient	Dying patient's condition(s)
79	75	F	Wife	Lung cancer
83	60	F	Daughter	Dementia and heart failure
84	61	F	Daughter	Bowel cancer
85	60	F	Daughter	Ovarian cancer
86	60	F	Daughter	Neurodegenerative disease
89	34	F	Daughter	Breast cancer
93	61	F	Sister	Brain tumour
97	60	F	Partner	Brain tumour
103	78	F	Sister	Motor neuron disease
105	39	F	Daughter	Dementia
108	58	F	Wife	Pancreatic cancer
111	50	F	Daughter	Lung cancer and emphysema
116	59	F	Wife	Brain tumour
117	67	F	Wife	Oesophageal cancer
119	64	F	Wife	Lung cancer
124	57	F	Wife	Appendiceal cancer
125	73	F	Friend	Neurodegenerative disease
128	64	F	Sister	Motor neuron disease
129	59	F	Mother	Neurodegenerative disorder
131	70	F	Mother	Bowel cancer
132	60	F	Wife	Rare cancer
133	68	M	Son	Throat cancer
134	25	F	Daughter	Carcinoma
139	66	F	Daughter	Not provided
140	44	F	Daughter	Motor neuron disease
142	42	F	Daughter	Dementia
144	Not provided	F	Daughter	Brain cancer
148	56	F	Wife	Pancreatic cancer
149	32	F	Mother	Rare genetic condition
150	34	M	Father	Rare genetic condition
151	43	F	Wife	Motor neuron disease
155	58	F	Wife	Pancreatic cancer
156 interview dyad with 151	Not provided	F	Not provided	Motor neuron disease
160	33	F	Partner	Bowel cancer
163	46	F	Ex-partner	Skin cancer
167	64	F	Daughter	Not provided
168	37	F	Daughter	Pancreatic cancer
170	62	F	Wife	Pancreatic cancer
174	66	F	Wife	Lung cancer
178	57	F	Daughter	Pancreatic cancer
179	45	M	Son	Motor neuron disease
180	50	F	Daughter	Lung cancer

preferences. Honouring their personhood by ensuring their death was consistent with their life and was a big part of this process.

The second theme illustrates the ways in which carers expressed continuing bonds with their loved ones, and how they continued to connect with, remember, and honour their loved ones after their deaths. Anticipatory grief, the third theme, reveals the unique experiences in terms of knowing, preparing for, and creating rituals around loved one's VAD deaths at specific, pre-established times, in contrast to other deaths with terminal illnesses. The final theme, burden of care, highlights the challenges of care giving, specifically for those involved in assisting loved ones through the VAD application process and the lack of VAD-specific bereavement supports.

### 3.1. Values, Meaning-Making, and a "Good Death".

Participants recounted simultaneously: aspiring to uphold the wishes of their loved ones, their sense of personhood and obtaining relief and satisfaction at facilitating the feeling of some control at a stage of life when the outcome seemed to be predetermined. When asked about their experiences in supporting family members through the VAD process, many participants spoke about wanting to fulfil their loved ones' wishes. Carers explored the decision-making processes of their loved ones and tended to justify their family members' preferences for VAD by discussing the congruence of VAD with personal belief systems. The imperative to understand loved ones' decisions to end their lives in this way was strong with carers. In addition, this process of

understanding and aligning VAD with loved ones' values, convictions, and wishes provided comfort. Carers discussed political beliefs, personality traits, and lifestyles as constituting the primary basis for decisions, and they acknowledged that in many cases their loved ones had felt the need to advocate for themselves and their cause.

Advocacy in and of itself became a project through which carers and loved ones could often unite to ensure that the goals of their family members to die in the way of their choosing were achieved. This meant facilitating these wishes by helping them make the necessary usual treatment appointments, finding supportive doctors, navigating the bureaucracy in order to fulfil the eligibility criteria and, ultimately, being there when the VAD medication was consumed. For example,

In terms of that grief, I have no problems that she opted for it. So, I don't grieve for her wanting to die and being able to do it. I have no grief around that. In fact, I only have relief. And a relief that she was able to go like that, and relief particularly post-COVID that she's not still alive in aged care. In terms of grief, I think I have a lot of . . . There's a lot of stress and pain, I guess, if I think of how stressful the last year of her life was, for me personally as main carer and dealing with all of that. (P86)

Like imminent deaths in non-VAD settings, honouring loved ones' wishes for their places of death was a desire commonly expressed by carers and family members. This provided a sense of assurance for participants to know that the persons they were caring for were comfortable in the last moments of their lives as well as in environments that were familiar and in keeping with their identities. Participants often described hospital or aged care settings as undesirable, despite the availability of medical staff who could assist with care, their own unfamiliarity with VAD processes and postdeath procedural realities. It was important for participants to provide locations, environments, and often ambiances that meant something to their loved ones, which in turn gave them a sense of satisfaction. Other participants felt it was important to honour their loved ones' decisions as expressions of respect for their sense of autonomy, control, and dignity. For example,

But [it's given me] maybe some peace as well. . . it was obvious looking back how much pain she was in, not that she would've ever said that, but I know that the deterioration in her, she couldn't have gone on a lot longer the way she was. And then the toll on dad as well, emotionally, it was stressful for him. So I think on one hand, the uncertainty is stressful as well, isn't it? Not knowing, but I think the clarity mum had and we sort of supported her at that time. (P180)

Reflecting on her experience in caring for her father, a participant identified that this congruence between his strongly held values and opinions and decision-making to pursue VAD helped her family to feel comfortable with the process both before and after the death:

So, there's a pragmatism in amongst all that. So, Mum was comfortable with Dad's decision. Very sad, losing her husband of 67 years, but also, very comfortable in the knowledge that it was Dad's wishes. Yeah. So, I think that the family (felt) differently about it. But, they were accepting in the end, that it was Dad's life and it was Dad's wishes. (P8)

In positively framing their family members' experiences in terms of their values, participants implicitly—or explicitly—alluded to fears of worse alternatives: for example, that a loved one would experience a “bad death,” where physical or emotional pain when they were dying or lose control as death was imminent. For participants, these fears of a bad death meant not only their loved ones losing control and dignity, but also how this kind of death would impact their own experience. For some, this was linked to witnessing other deaths in the past which they had perceived as protracted, painful, or confronting, or just the idea of a “bad death.” For example,

[Thinking to myself] “I am so relieved that he's got this option. I had forgotten that he had this option and it's been terrifying me.” So that switched things for me dramatically knowing he wouldn't have to suffer if he chose not to. . . And (the patient in her care) said, “I will never do that. I will never do it to myself [die without dignity and control] and I will never do it to my family [put them in the position where they witness my decline].” So this was part of the gift he gave us. (P170)

Focusing on their loved ones' values allowed carers to reconcile decisions to explore VAD that perhaps may have sat uncomfortably with them. In many circumstances, carers saw VAD as the least bad option at times when fears of the unknown and a potentially bad death were present realities. Therefore, justifying this decision-making in terms of this project—to pursue their values—afforded carers a sense of peace and satisfaction.

*3.2. Expression of a Continuing Bond.* For many participants, the role of advocacy for the cause of VAD became a key means for continuing bonds with their loved ones following their deaths. Participants were frequently highly supportive of VAD legislation as an option for people with terminal illnesses and listed multiple factors which influenced these thoughts and feelings. This active support extended into the time after their loved ones had died and destigmatising the VAD process became an important goal, which is achieved via discussion within their communities or speaking to the media. Participants often talked about joining pro-euthanasia groups or continuing to advocate for the VAD cause, even following their loved ones' deaths. For example,

I'm really glad that I did it (speaking to the media), because as I said, my key aim in that whole process was to share it, to demystify it, and hopefully to destigmatise it. . . I felt so strongly that we have to have these conversations, we've got to get the information and the

knowledge and the understanding out into the community. (P84)

For participants, support and discussion of their own and their loved ones' experiences with VAD provided ways to continue their active roles and relationships, to support a cause they believed in and to remain engaged with the stories of their lives, even beyond their deaths. In addition, while most family members and carers were supportive of their loved one's decisions to pursue VAD, those who were more circumspect or ambivalent also felt the need to advocate for the cause. It would also seem that undertaking a task of spreading awareness and reducing stigma may also play a role in the effort to make meaning of, and to establish a narrative around, the story of their loved ones' lives, as suggested in the previous theme. This was particularly important for those who were more sceptical of VAD, as the practice of destigmatising VAD through advocacy helped reconcile their loved one's decision in their own minds.

I had my cries, don't you worry about it. It's a commitment that I made. Number one, to still live life as much as I can, because I feel not to is disrespecting those who don't have it anymore. And two is to be an advocate for people where I can. I haven't done that in a formal way yet, but I've got quite a lot of elderly people around me here, and friends with elderly parents. I'm trying to be advocates for them where I can, and yeah, because I think a lot of assumptions are made when people have conversations with them. (P116)

And

Her teaching. . . throughout life really pushed us to want to share her story. We had some reservations about whether or not she would want us to, because in the lead up to her dying, she didn't want anybody to know that, that was what she wanted to do. But that was purely because she didn't want to be judged, and she grew up an Irish Catholic and was very. . . she was a very religious person growing up. (P89)

For carers, sharing loved ones' stories gave them a sense of purpose. They frequently described their loved one's experiences and the personal and bureaucratic challenges they went through with a sense of pride, which helped their grief. The fact that their loved ones struggled and also succeeded gave them a sense of personal satisfaction that they had been able to achieve their goals to die in the way they wanted, and sharing those stories helped them relive those moments and victories and struggles along the way.

**3.3. Anticipatory Grief.** Another prominent theme was the unique form of anticipatory grief that was experienced by caregivers, that are associated with knowing the time, location, and precise cause of death before the death of a loved

one. Given that prognoses with terminal illnesses are generally no more than indicative, VAD created a novel sense of anticipatory grief for carers, sometimes prolonged, which elicited unique emotions. Family members involved in this study described ambivalent, ambiguous, confronting, "surreal," or "strange" feelings around knowing the precise time of death in a form of anticipatory grief unique to VAD. For example,

And

Like I suppose reality, gosh, it's going to happen tomorrow. I think I had to make it through when you think back, but I had to reassure myself that it would've been terrible to watch her deteriorate and perhaps be pumped full of morphine and be not very well in that terms. I know the sort of woman she was, she would want her dignity to be in control of things and have it the way she wants on her terms. But yeah, it was quite surreal actually knowing that it's going to happen at a certain date. (P168)

These statements suggest that feelings of a death being "surreal" may be enhanced in VAD settings owing to the nature of planning—and the carers' active roles—in the process with the persons who are dying. The rapid progress of a patient from conscious and engaging with those around them to that person being deceased in a manner of minutes or hours was often hard to grapple with for carers, who were left with complex feelings of shock, albeit without a surprise element.

It was evident that participants experienced a sense of preparedness and an opportunity for ritual and deeper connectedness with their dying loved ones, which appeared to be protective and helpful in bereavement. This also relates to the idea of meaning-making and the expression of continuing bonds with the deceased. Having family members access VAD medication seemed to allow many of the interviewed families and carers to fully engage in quality time with their loved ones and have important conversations about their lives together. Part of this meaning-making in grief appeared to be linked to gratitude for this quality time spent together as a family and the patients' active use of this time to support, explain, or convey wisdom to their relatives.

This idea about "being prepared" translated in various ways into what family members and carers described as processes of "farewelling," allowing both carers and loved ones to come to a mutual acceptance. For many, helping their loved one go through VAD enabled them to say goodbye, which was important for a sense of closure. For example,

We miss her, but there was very much such a good process of "farewelling," and coming to terms with it, and relief that it worked for her. . . (P167)

And,

She was such a wise sort of a person. I've got all those words in my head . . . And I think that having been able to have all those conversations and having been able to say

Health & Social Care in the Community 5 goodbye has actually been a real comfort to me. I think if something had to happen to mum and I just had to deal with the loss of her, and it came out of the blue, I feel like that would've just been devastating for me. (P178)

In this vein, some participants spoke about holding events so that their loved ones could say goodbye. As the previous participant discusses, these events were often bittersweet. It allowed for the important people in a person's life to come together to celebrate that life in a manner that was joyous; yet, simultaneously, also to say goodbye in anticipation, which was also devastatingly sad.

Interviewees spoke of goodbye rituals such as last meals with champagne, music, gathering loved ones, telling jokes, undertaking favourite activities together, creating the right ambience, or even just creating a sense of normality in a highly climatic time. These types of rituals, events, and processes allowed for more positive expressions of anticipatory grief which was something that could be shared because of the feelings expressed by both carers and patients going through VAD, although, in some instances, this was not possible. Depending on the nature of the relationships between family members, the ability to speak about VAD, death, and other intimate issues was more challenging and reflected long-standing, pre-existing histories between family members. Depending on the openness of expressions of feelings—or simply the desire to protect loved ones from pain—VAD sometimes created scenarios where both parties tried to tread carefully, avoiding the topic, as no one wanted to cause pain by provoking feelings of anticipatory grief. The sense of anticipatory grief was more challenging when it could not be shared openly.

Thus, anticipatory grief with VAD was complex, and the active participation of carers in VAD deaths complicated this and increased the burdens associated with caregiving as will be explored in the following sections.

*3.4. Burden of Care Associated with Supporting Loved Ones Going through VAD.* VAD presented situations that were burdensome in terms of both the process and presenting uncomfortable predicaments for family members and carers leading to complicated experiences of grief and bereavement. In particular, the moral dilemmas associated with facilitating a VAD death sometimes exacerbated other potentially detrimental bereavement outcomes. These situations sometimes engendered ambivalent feelings about loved ones' decisions and the unique roles involved in helping loved ones take substances to cause their death. Given the stigma of VAD, decision-making was at times secretive. In some cases, family members and carers who were privy to the secret were faced with the dilemma of knowing how and when their loved ones would die while lacking support systems or even being able to communicate the decisions to others. There were also other consequences associated with the deliberate nature of decisions underpinning VAD; for example, one participant

acknowledged the difficult feelings caused by not having the chance to say goodbye to her loved ones:

Participants also referred to conflicting thoughts and feelings about supporting their loved one's wishes while also experiencing uncertainties in their active roles in advocating and assisting them to access VAD. For example,

There was an intensity to this grief for this very different to others. I don't know if that's because of the role that I played. (P84)

And

I think he struggled with that for a little bit, you know? "I mixed the substance that killed her and held the cup" and all that sort of stuff. (P86)

The bureaucratic processes associated with accessing the VAD medication created a unique burden that further complicated bereavement and grief. This was particularly burdensome for those in rural and regional areas who needed to attend city facilities for VAD assessment appointments. As a participant describes:

I can remember crying every day in February . . . because I'd cared for her for so long, and then jumping over all these hurdles and getting her to Melbourne (for VAD assessments). (P86)

These data also revealed clear gaps in VAD-specific support services postdeath for carers and family members. Interviewees described coping strategies for navigating grief, including seeking support from other family members and friends, and reflecting on and enjoying activities that were valued by their deceased loved one. Some mentioned formal support services they had been offered or had considered, while many identified a need for more specialised assistance.

There were mixed feelings about the quality of grief counselling available and it was felt by participants that VAD-specific grief and bereavement services would be welcomed, given the uniqueness of the situation. The uniqueness of VAD was echoed by a number of respondents, who commented that they felt unsupported postdeath.

And then the other one for me is around support for the key contact... I was the key contact for dad, and our situation was unique... Everyone's situation is going to be unique... So this system, the scheme, needs to understand about how to support the supporter...how to support that person afterwards. We're given resources around bereavement, and so I rang...I've forgotten the actual name of it....And I was asking them what training they had undertaken around VAD? What was their understanding? And their response was, "Oh, well, we're all trained counsellors. We're all trained bereavement counsellors." That doesn't cut the mustard. That is not good enough, because the experience of VAD is so unique. You can't apply the same frameworks that you would apply in other palliative care situations. (P84)

In summary, while VAD created specific caregiving burdens for family members and carers of those going through the process, these burdens were not always well understood or supported by existing processes, potentially leading to further complications of grief and bereavement.

#### 4. Discussion

Families and carers involved in the VAD process encountered distinctive ways of experiencing grief and bereavement. The four themes we identified will be juxtaposed with the key literature on grief and bereavement to demonstrate how VAD presents novel challenges for carers.

*4.1. Values, Meaning-Making, and a “Good Death”.* Our research suggests that bereaved families and carers engage in processes of meaning-making following VAD by reflecting on their loved ones’ values, such as the desire for dignity and control or pragmatism. This places the dying person’s decisions in the larger narrative of their lives, providing comfort and protecting family members from distress or dissonance. The theory of meaning reconstruction proposed by Neimeyer et al. [26] has shown that “individuals who exhibit a normative grief reaction are successful at engaging in meaning-making and able to assimilate or accommodate to the loss, consequently forming or maintaining a thread of consistency as well as meaningful transition in their self-narrative” [26]. Bereavement after VAD can be seen as reducing the risk of complicated grief in comparison with other experiences of grief by maintaining the sense of personal control for both patient and family and enhancing positive meaning-making in the bereavement phase. This theory, commonly applied to general bereavement experiences is therefore also relevant in the context of VAD.

Fear of the alternative circumstances of death if VAD was not pursued also seemed to be part of family members’ meaning-making. The fear of lack of control and dignity for loved ones and the impact of witnessing a “bad death” (which they may have heard about or witnessed before with another family member) was often referred to. Such apprehension is consistent with multiple studies showing an association between higher caregiver burden and depressive symptoms in bereavement [27–29]. In addition, it is recognised that a lack of a sense of personal control in any given situation (such as caring for a loved one at the end of their life) can provoke anxiety [30], and the opposing situation (gaining control through knowing the trajectory and circumstances of a family member’s death) can provide comfort and stability. We have shown elsewhere [20] that facilitating a dignified, peaceful death for another person also corresponds with “caring well.” The perception of a loved one going through a “bad death” can lead to a sense that caring was not good enough, which is a problematic outcome for family members and carers, often leading to guilt.

In addition, dwelling on the illness, death, and processes around VAD itself often triggered negative emotions. Therefore, focusing on their loved ones’ values and their active pursuit of them, at a time when almost all control was lost for them in their last days, were said to have beneficial impacts on carers’ experiences of grief and bereavement. Demonstration of their loved one’s personal agency was helpful to carers to facilitate remembering them, the person they were, and the values they espoused, prior to their illness. Van der Geest and Satalkar [31] describe what they see as the “tragedy” of the “crumbling subject” who lose personal competence and become increasingly dependent. Therefore, sovereign decision-making is viewed so positively in the face of increasing fragility. This is why VAD was often contrasted with palliative care, which was seen as a more passive option for family members and carers, irrespective of their mostly positive views on palliative care.

*4.2. Expression of the Continuing Bond.* Families identified the benefit of telling their family members’ stories and linking these to their end-of-life choices. This relates directly to Klass et al.’s [32] “continuing bond” theory which describes the desire to continue to connect with someone who has died through rituals, actions, thoughts, and discussions and the comfort this can bring beyond death [32–34]. This research supports the existence of such bonds, with participants often discussing the importance of telling their loved ones’ stories and reminiscing about their strengths and lessons in life with others, thereby perpetuating their influence after their deaths [35]. Our study suggests that continuing bonds are perhaps even more important in the VAD context, with participants sharing their stories to keep their loved ones’ influence alive, especially in light of the stigma associated with VAD. Advocacy for VAD as a cause facilitated the bereavement process for many carers, helping them derive meaning and using storytelling as a cathartic experience.

Our study suggests that continuing bonds are perhaps even more important in the VAD context, with participants sharing their stories to keep their loved ones’ influence alive, especially in light of the stigma associated with VAD. Advocacy for VAD as a cause facilitated the bereavement process for many carers, helping them derive meaning and using storytelling as a cathartic experience. This is consistent with the literature on other stigmatised deaths, such as suicide, that show how bereaved family members and carers can be isolated by wider social reactions and processes [36]. Continuing bonds symbolise a therapeutic process to manage grief and keep the dead “alive.” In advocating for VAD and keeping their loved one’s cause alive, it serves in some ways to keep their loved one’s memory alive [36]. For family members and carers who tended to be more circumspect of VAD, this expression of the continuing bond through the practice of destigmatising it via advocacy also facilitated reconciling their loved one’s decision in their own minds.

Bereavement risk and complications were evident in our research where ambiguities in relationships had been present. While this is consistent with bereavement research and not unique to VAD, the role of family dynamics undoubtedly remains of importance [37]. As open dialogue and time to prepare are associated with enhanced coping [38, 39], discussion and interactions should be encouraged and where necessarily facilitated by health professionals.

**4.3. Anticipatory Grief.** It is evident from both this study and other international studies that the anticipatory grief experience in VAD is distinct from other similar deaths, for example, from terminal illness. While the term anticipatory grief has been used since the 1940s to describe the grief reactions experienced by families when imagining the deaths of loved ones and witnessing their deterioration, particularly in the case of terminal illnesses [40], it takes on new meaning with VAD as the precise time of death is often known.

Conversely, our findings confirm what has already been established in bereavement research that feelings of preparedness and open, supportive communication within families lead to better outcomes [38, 41]. There may be ways in which the predictable nature of death because of VAD can be drawn upon to provide this for families by contributing to another method of meaning reconstruction [26].

Family members and carers' thoughts and feelings ranged from appreciation and gratitude for being able to assist their loved ones in a way that felt meaningful and for the positive aspects of preparedness for death, mixed and strange feelings regarding their involvement and the lead-up to this time and a need for further support or a smoother process both during the VAD application process and afterwards in the course of bereavement.

**4.4. Burden of Care.** The administrative burden associated with VAD was often a big challenge for family members and carers. While this was extremely taxing for family members at the time, it did not frequently represent a complication for grief and bereavement, but rather a point of grievance that their loved one was subjected to such an onerous process.

Instead, grief was rendered more complex, and feelings of distress were connected with a family member's active participation in arrangements for VAD was the most emotional burdensome consequence of facilitating a family member through VAD. This is consistent with Gamondi et al.'s [5] work regarding the moral dilemmas facing families which represent a significant and unique burden of care that is unique to VAD for carers. Fears of being actively complicit in a VAD death were common concerns. Gamondi et al. [5] found that these moral dilemmas were alleviated if VAD was seen to be heavily endorsed by the dying family member and that the dilemmas were gradually resolved over time which we would hope and expect would be the outcome for our cohort also. Previous studies have

confirmed that the act of informal caregiving at the end of life can create existential dilemmas for caregivers [42]. In our study, the witnessing of VAD presented unique existential challenges for those involved, linked to the directness of the witnessing, the honesty of the conversations, the speed of the movement from mental capability and awareness to death.

## 5. Conclusion

Despite concerns about detrimental outcomes for grief and bereavement for VAD deaths, family members and carers' experiences share many similar characteristics to other deaths. Like with other deaths, carers were able to derive meaning by being able to further their loved ones' preferences about how they wished to die. Yet, unique to VAD, they could focus on specific aspects of their loved ones' values, allowing carers to reconcile decisions to explore VAD that perhaps may have sat uncomfortably with them. Family members and carers expressed a sense of gratitude for not having to witness their loved one suffer. In addition, through ritual and advocacy for VAD following their loved ones' deaths, they were able to continue a bond with them. Moreover, knowing the time of death allowed carers to help their loved ones prepare for their deaths. These experiences were generally helpful for grief and bereavement. However, more challenging were the burden of care associated with the administrative processes that were involved with VAD, the feelings of a moral dilemma with being actively involved in their loved one's death, potential relationship strain depending on the nature of pre-existing family dynamics, and the associated uncomfortable feelings of anticipatory grief.

When VAD was introduced in Victoria, little was known about the consequences for grief and bereavement outcomes for carers. In fact, many people opposed the VAD legislation's introduction because of its potentially detrimental impact on family members and carers. Yet, in our study, VAD was generally viewed as positive for their grief and bereavement by family members and carers who mostly focused on the benefits of helping their loved ones through the process of VAD. Nonetheless, VAD presents some challenges for grief and bereavement that we will not fully come to understand in the short term, especially in terms of the impact of VAD on familial relationships and the burdens associated with moral predicaments.

## Data Availability

The qualitative interview data used to support the findings of this study are restricted by the Monash University Human Research Ethics Committee (MUHREC) (Project ID number 26640) in order to protect participant privacy. Data are available from Dr Camille La Brooy, Camille.LaBrooy@monash.edu for researchers who meet the criteria for access to confidential data.



## Conflicts of Interest

The authors declare that there are no conflicts of interest.

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## Supplementary Materials

S1: interview schedule. (*Supplementary Materials*)

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