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# Choreographing a good death: Carers' experiences and practices of enacting assisted dying

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## Abstract

The proliferation of assisted dying legislative reforms globally is a significant change in the social and medico-legal landscape of end-of-life care. Understanding the impacts of these legislative reforms on family members who care for a dying person is vital, yet under-theorised in research. In this article, drawing on semi-structured interviews with 42 carers for a person who has sought assisted dying in Australia, and extending ideas of ontological choreography we explore the new and complex choreographies enacted by carers in their endeavour to arrange a 'good death' for the dying person. We find that desires to fulfil the dying person's wishes are often accompanied by normative pressures, affective tensions and complexities in bereavement. Enacting assisted dying requires carers to perform a repertoire of highly-staged practices. Yet, institutional obstacles and normative cultural scripts of dying can constrain carer assisted dying practices. Understanding the nuances of carers' experiences and how they navigate this new end-of-life landscape, we

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argue, provides critical insights about how assisted dying legislation is producing new cultural touchpoints for caring at the end of life. Moreover, we show how emerging cultural scripts of assisted dying are impacting in the lives of these carers.

**KEYWORDS**

Australia, death and dying, end of life care, qualitative research, voluntary assisted dying

**INTRODUCTION**

In 2023, voluntary assisted dying (VAD) became lawful in all Australian states; joining other jurisdictions including the Netherlands, Belgium, Switzerland, Canada, and others in legalising assisted dying (Downie et al., 2022; Duckett, 2019; Mroz et al., 2021). This new health policy direction is a significant change in the social and medico-legal landscape of end-of-life care. Much of the discourse in support of assisted dying has centred on the importance of ‘good deaths’ with a particular focus on individual autonomous choice and respecting the wishes of the person about how they want to die, as well as the need to alleviate suffering (Duckett, 2020; Kirchhoffer & Lui, 2021). But good deaths are not assured by assisted dying legality. Although assisted dying opens up new options for people and their families at the end of life, it also introduces new challenges and complexities for social relations (Buchbinder, 2018; Elliott & Olver, 2008).

Assisted dying is inherently relational, woven into various familial and other interpersonal relationships (Buchbinder, 2021; Carrieri et al., 2020; Variath et al., 2020). As Buchbinder (2018) argues the legal and medical foundations of assisted dying require particular interdependencies: for care and support *between* patients and others (family, friends, health professionals, other carers). Yet the experiences of family members and other informal carers in the assisted dying process remains relatively under-theorised in research (Buchbinder, 2018; Roest et al., 2019; Variath et al., 2020). Moreover the experiences of family caregivers are only peripherally considered in many international clinical VAD guidelines (Gamondi, 2021; Gamondi et al., 2019). As such, understanding how assisted dying legislative reform affects family members and others who are supporting a person in the final weeks or months of life is vital.

In this article, drawing on qualitative interviews with family members, friends and other informal carers who have cared for someone who has sought to access assisted dying, we explore how assisted dying affects understandings and practices of caring (well) at the very end of life. Drawing on Charis Thompson’s (2005) concept of ontological choreography as a heuristic analytical device for exploring how assisted dying is relationally experienced and enacted, we consider how carers negotiate new realities and roles, attending to the new and complex work that is required of carers in arranging and enacting assisted dying. We illustrate how VAD changes caring relations and practices, illuminating points of tension and dis/connection that emerge in enacting assisted dying, and their consequences for carers.

## BACKGROUND

### Caring (well) in assisting dying

There is a wealth of literature on end-of-life care as both a rewarding but also physically and emotionally taxing experience, and carers can experience challenges such as family conflict, social isolation and disenfranchised grief (Pollock et al., 2023; Stajduhar, 2013; Stajduhar & Davies, 2005). Although these caring experiences are not exclusive to assisted dying, there are particular aspects that delineate the VAD caring experience from that of other kinds of dying, such as advanced knowledge of the time, place and manner of death, and the opportunities for planning and preparation that may be afforded to carers (Gamondi, 2021; Gamondi et al., 2013, 2019; Koksvik et al., 2022; Variath et al., 2020).

Caring for those seeking an assisted death is part of a broader moral construction of what it means to *care well* for those who are dying (Broom et al., 2016; Chattoo & Ahmad, 2008; Elliott & Olver, 2007, 2008). There are social expectations that shape care, and how carers feel that they *should* think and behave during the dying process (Broom, 2016; Broom & Kirby, 2013; Pollock et al., 2023; Variath et al., 2020). Given the recency of assisted dying legislative reform in Australia and a number of other countries, new cultural norms particular to assisted dying are likely to emerge that will mould the kinds of feelings and behaviours that are allowable or expected of carers.

Assisted dying offers the prospect of being able to curate final endings and memories that are potentially less painful (for the dying person and for their families). In this way, assisted dying can sometimes be seen as gift or act of care, rather than of self-interest and individual choice (Gandsman, 2018); a way for patients and carers to fulfil obligations to each other, and to affirm their social bonds (Seale, 1998). And yet, assisted dying may also contribute to a perception that one can control or tame the dying process, moulding it to a particular form or vision (Buchbinder, 2021; Seale, 1998). These ideas of control may create different pressures for carers who may feel moral responsibility over the process as they seek to fulfil the dying person's wishes (Gamondi, 2021). In Australia, VAD takes different forms (e.g. self- or physician-administered) and can take place across different settings (e.g. homes, hospitals, aged-care facilities) according to legislative differences. In the state of Victoria, where these interviews were conducted, assisted dying medication is often self-administered by the person at a time and place of their choosing. Family and friends may be present if the person wishes. But in circumstances of self-administration, a health professional is not required to be present. In these scenarios, family members are likely to play a more central, active role in organising and managing the death.

Additionally, knowing the time of death in advance has particular implications for carers, in terms of the emotional and material planning and preparation for the death, the duration of care and the form care takes (Variath et al., 2020). Carers have a precise focal point that activities preceding and accompanying death can be oriented around (Richards & Krawczyk, 2021). In turn, this is likely to change the rituals, aesthetics and meanings around dying, and impact the social bonds between the carer(s) and the dying person (Buchbinder, 2018; Richards & Krawczyk, 2021; Seale, 1998).

Although there is a growing body of research on the views and experiences of patients, families and clinicians about assisted dying (Brooks, 2019; Elmore et al., 2018; Gamondi et al., 2019; Kimsa & van Leeuwen, 2007; Koksvik et al., 2022; Nuhn et al., 2018; Sandham et al., 2022), there is relatively limited research attention on how family members and other

informal carers *enact* assisted dying care, including how assisted dying legislative reform changes caring roles, practices, expectations and affects. An exception is an ethnographic study conducted in the United States following the introduction of Vermont's medical aid-in-dying law (Buchbinder, 2018). Drawing on data from interviews with caregivers of terminally ill patients who had sought medical-aid in dying, Buchbinder (2018) found that assisted dying created new interdependencies between the dying person and the carers who supported them; thus, challenging dominant portrayals of assisted dying in public discourse (e.g. as a way to avoid dependency and exercise individual autonomous choice). Rather, Buchbinder (2018) argued, that assisted dying provided new opportunities for sociality and strengthening social bonds between the dying person and the carer as they co-produced and choreographed dying together (see also Buchbinder, 2021).

## Choreographing dying

The idea of choreography has been used in the social science literature to understand the undulations, movements, and performances of social life (see Goffman, 1959). Charis Thompson (formerly Cussins) (1996, 2005) developed the term 'ontological choreography' to refer to 'the dynamic coordination of the technical, scientific, kinship, gender, emotional, legal, political, and financial aspects' of assisted reproductive technology clinics (2005, p. 8). Drawing on ethnographic data from a Californian infertility clinic, Thompson (2005) used ontological choreography as a heuristic analytical device to capture the processes involved in navigating ambiguities and *making* parents through reproductive technologies; drawing attention to how use of reproductive technologies produces new subjectivities through 'complex choreography of nature, society, bodies, selves, and technologies' (p. 8). Thompson (2005) argued:

What might appear to be an undifferentiated hybrid mess is actually a deftly balanced coming together of things that are generally considered parts of different ontological orders (part of nature, part of the self, part of society).

(Thompson, p. 8)

The notion of ontological choreographies draws attention not only to how people and things like instruments, medications, bodies, and documents come together and are configured, but how this coming together of separate entities and processes involves highly intricate and staged coordination, and intensive work of different social actors. Through this carefully staged choreography, new realities of being a parent are constituted and embodied (Thompson, 2005; see also Williams, 2019).

There are synergies between use of reproductive technologies in enacting the beginning of life and VAD in enacting death. Like in Thompson's research, when the field of infertility medicine was undergoing rapid expansion and change, and regulatory frameworks were still being established, regulatory processes surrounding assisted dying in Australia are still in their infancy. Assisted dying can also be seen as choreographed, requiring the assemblage of events, bodies, medications, documents, and subjectivities, in space and time through close and intensive care work (Law, 2010). Assisted dying also requires help from a range of social actors (e.g. clinicians, carers); material devices (e.g. medication), and legal aspects (e.g. permits authorising access to VAD). It also introduces new actors (e.g. pharmacists responsible for dispensing medication, clinicians who have completed VAD training, members of health

departments who approve VAD applications, VAD board members responsible for monitoring and reporting).

In this article, we extend on Buchbinder's (2018) and Thompson's (2005) work, using ontological choreographies as an analytical tool to examine the experiences of carers supporting a person seeking to use VAD. Ontological choreographies allows us to attend to the practical and emotional work of carers in enacting assisted dying, and how assisted dying shapes family relations (and vice versa), producing new carer subjectivities and realities. In showing how different (multiple) realities of care emerge from enacting different choreographies of assisted dying, our aim is to provide new understandings of assisted dying, including the different ways assisted dying is created in Australia.

## METHOD

This qualitative study draws on data from semi-structured interviews with 42 family members or other carers who were supporting a person who had sought to access and/or had accessed VAD (see Table 1, *Participant Demographics*). The study is part of a broader mixed method longitudinal project involving a combination of quantitative measures and qualitative interviews with a diverse cohort of patients, carers and health professionals, and focus groups with non-participating health professionals and conscientious objectors. The overarching project aims were to assess the impact of VAD on patients, families, and health professionals in Victoria, Australia. Ethics approval was gained from the Monash University Human Research Ethics Committee [project ID 26640].

## Recruitment and data collection

Purposive sampling and community-based recruitment strategies were used to recruit carer participants with diverse perspectives and experiences of caring for dying individuals. An advertisement was placed on social media asking for family members and other carers who were supporting a loved one going through VAD to contact the research team to participate in an interview about their experiences. Participants were also directly recruited through health professionals, and patients who had participated in other aspects of the broader research project. Individuals who expressed their interest in the study were sent an information sheet with details about the study purpose and what their participation would involve. Participants were given opportunities to ask questions and discuss the information sheet with a family member or friend prior to making the decision to participate. Those who chose to participate in the study provided informed consent, signed electronically via the online survey website 'REDCap', prior to being interviewed. Participants also provided verbal consent to the interviews being recorded at the start of the interview.

An interview guide was developed by one author after a review of the literature. Interview questions explored: experiences of being involved in caring for a person going through VAD, the decision-making process, whether they supported the person's decision, the barriers and facilitators to caregiving in the context of assisted dying, relationships with family and health professionals involved in the person's care, and bereavement experiences. The interview guide was flexible and included prompts for more information, allowing for new topics to be introduced by the participants and explored during the interview. Interviews were conducted

TABLE 1 Participant demographics.

ID #	Age	Sex	Relationship to dying person	Dying person's condition(s)	Had the person died at time of the interview	Follow-up interview conducted
79	75	F	Wife	Lung cancer	No	No
83	60	F	Daughter	Heart failure, dementia	Yes	No
84	61	F	Daughter	Bowel cancer	Yes	No
85	60	F	Daughter	Ovarian cancer	Yes	No
86	60	F	Daughter	Neurodegenerative disease	Yes	No
89	34	F	Daughter	Breast cancer	Yes	No
93	61	F	Sister	Brain cancer	No	No
97	60	F	Partner	Brain cancer	Yes	No
103	78	F	Sister	Motor neurone disease	Yes	No
105	39	F	Daughter	Dementia	No	No
108	58	F	Wife	Pancreatic cancer	Yes	No
111	50	F	Daughter	Lung cancer	Yes	No
116	59	F	Wife	Brain cancer	Yes	No
117	67	F	Wife	Oesophageal cancer	Yes	No
119	64	F	Wife	Lung cancer	Yes	No
124	57	F	Wife	Appendiceal cancer	Yes	No
125	73	F	Friend	Neurodegenerative disease	Yes	No
128	64	F	Sister	Motor neurone disease	Yes	Yes
129	59	F	Mother	Neurodegenerative disease	Yes	No
131	70	F	Mother	Bowel cancer	Yes	No
132	60	F	Wife	Rare cancer	Yes	No
133	68	M	Son	Throat cancer	Yes	No
134	25	F	Daughter	Skin cancer	Yes	No
139	66	F	Daughter	Not provided	Yes	No
140	44	F	Daughter	Motor neurone disease	Yes	No
142	42	F	Daughter	Dementia	Yes	No
144	Not provided	F	Daughter	Brain cancer	Yes	No
148	56	F	Wife	Pancreatic cancer	No	Yes
149	32	F	Mother	Rare genetic condition	Yes	No
150	34	M	Father	Rare genetic condition	Yes	No
151	43	F	Wife	Motor neurone disease	Yes	No
155	58	F	Wife	Pancreatic cancer	Yes	No

TABLE 1 (Continued)

ID #	Age	Sex	Relationship to dying person	Dying person's condition(s)	Had the person died at time of the interview	Follow-up interview conducted
156 <sup>a</sup>	Not provided	F	Not provided	Motor neurone disease	Yes	No
160	33	F	Partner	Bowel cancer	No	No
163	46	F	Ex-partner	Skin cancer	Yes	No
167	64	F	Daughter	Not provided	Yes	No
168	37	F	Daughter	Pancreatic cancer	Yes	No
170	62	F	Wife	Pancreatic cancer	Yes	No
174	66	F	Wife	Lung cancer	Yes	No
178	57	F	Daughter	Pancreatic cancer	Yes	No
179	45	M	Son	Motor neurone disease	Yes	No
180	50	F	Daughter	Lung cancer	Yes	No

<sup>a</sup>Interviewed with Participant 151.

between June 2020 and February 2022, via Zoom. The interviews varied in duration, with an average duration of 1 h. Recognising the sensitive nature of the matters being discussed, care was taken by the interviewers to ensure that participants felt safe and supported and able to end the discussion should the need arise. Interviewers exercised care to avoid communicating their personal views in the course of the interviews, while still maintain a supportive and receptive demeanour.

Interviews were recorded, and later transcribed, de-identified, and checked for accuracy. Each participant was assigned a unique identification number to preserve their anonymity.

## Analytical approach

A reflexive approach to thematic analysis was employed, recognising that our interpretations reflect our position and active role in producing knowledge (Braun & Clarke, 2019). NVivo was used to organise and manage the data. Transcripts were read and coded iteratively by three members of the research team. Descriptive categories were created related to carers' experiences of assisted dying, including their involvement in assisted dying decision-making and enactment. Data were then examined for patterns related to the meanings that participants gave to their experiences. Key themes identified in the data were developed and compared across transcripts, and relevant literature was drawn on to further make sense of the emerging findings and refine the core themes (Green & Thorogood, 2005). In our analysis we paid close attention to how different features, including logics, emotions, roles, responsibilities, activities, interpersonal relationships, and spatialities, were brought together in organising assisted dying. We also looked for the different kinds of work, emotional and practical, that carers engaged in leading up to, during and following the dying process, noting moments of tension, vulnerability or resistance in the process.



## RESULTS

A total of 42 participants were interviewed. Most were women ( $n = 39$ ), while three men participated. Participants were the adult child ( $n = 18$ ), partner/spouse ( $n = 14$ ), parent ( $n = 4$ ), sibling ( $n = 3$ ), friend ( $n = 1$ ) or ex-partner ( $n = 1$ ) (see Table 1, *Participant Demographics*).

Through our analysis we identified three main themes. First, carer choreography required considerable emotional and material work for carers as they attempted to help produce a dying experience that accorded with the person's desires about how they wished to die. Second, carer experiences were characterised by ambivalence about their participatory role in the dying process, often accompanied by normative pressures and moral considerations surrounding what constituted 'good care'. Finally, despite attempts to curate good deaths, sometimes assisted dying did not unfold in the way that carers anticipated or intended, contributing to consequences such as loss of control, exclusion, and regret.

### Staging a good death

All participants expressed a strong desire to support the person they were caring for to be able to die according to their wishes. But to do this involved a repertoire of emotional and material practices and rituals, highly staged by the carer (with the dying person) through different choreographies (Buchbinder, 2018; Thompson, 2005). The following extract from a woman in her sixties caring for her husband at home captures her close involvement in practices leading up to and accompanying her husband's death. She described gathering family together and sharing a last meal and organising goodbye rituals. Her account below illustrates how she brings together different people and things (food, music, medication, furniture), coordinating of the different roles of the family members (preparing medication, making the person comfortable, telling jokes). It also shows her careful planning and curation of the space for death, considering both her husband's wishes (a nice view where he enjoyed spending time) as well as her own desires (a separate space for remembrance):

We joined in with eating with him because food gave him so much pleasure [...] I had thought a lot about the space we did it in. We've got a space down by the pool. And [husband] used to love going down there and playing music. It's a really nice, big space with a pool view. So, we decided we'd go down there to do this. I'm glad about that because if I want to be with him, I go down there. [...] His sisters were reading the book on how you do this and they were doing the timing with what tablet to take when. And the kids and I were just sitting on the bed together with him. He was joking around.

(Participant ID 119)

Her quote also revealed the importance of practices following death, including fulfilling his wishes about how he would like to be remembered, and caring for the body, including her unease that her husband was in an uncomfortable position:

He wanted us to have a Viking funeral in the swimming pool afterwards. [...] When he took the medication, I was acutely aware of what was happening. because I said, "Perhaps, sit you up against the back of the bed." When he died, he was in a very

awkward position and I was trying to move him into a more comfortable one. His sisters laid him down flat and they cared for him in that position.

(119)

Choreographing the death came with considerable moral and practical responsibilities. Several participants said that the dying person had requested their last day to unfold like ‘an ordinary day’, including some of the daily rituals that they associated with everyday family life, like drinking coffee, eating, or playing board games together. Creating a ‘normal day’ is illustrated below by a woman in her fifties, who cared for her mum at home:

It was sort of part of a normal morning, but we tried to. Went and got coffees for us and mum loves Scrabble, so we played a game of Scrabble. Didn't let her win [...] we had a lovely bottle of Bollinger bubbles and played Adele [...] by lunchtime she was sort of ready to take the medication. So [sister name] gave her the sedative. And she hopped into bed and we put a lovely doona cover over her and sat with her. [...] She had passed away and she was lying very comfortably in her bed. [...] It was very peaceful and lovely and we have lovely memories of that last day with her. It's still very raw and emotional, but far nicer for her on her terms and we're all together, and it was peaceful for her.

(180)

But maintaining ordinariness and normality (or at least the appearance of such) in extraordinary circumstances, demanded considerable work to be undertaken by the carer. A participant in her fifties supporting her mum talked about the pressure she felt to create the semblance of a normal day. Her account (below) illustrates the particular kinds of performativity demanded of carers, including the management or concealment of emotions like anxiety and distress to create a calm atmosphere. Notably, both mum and daughter appeared to be trying to minimise the others' suffering, using distraction, normalisation and performance:

I made her a cup of coffee and I said, “What about having something to eat?” I think she just was like, “Oh, okay. You can make me a toasted sandwich.” But, I think she was just trying to keep me occupied. And then [...] she just said, “I think we should just get started.” She wasn't crying and she was very calm and together. I think [brother and] I did a good job of trying to keep it together for her too, and not make it dramatic and not make her feel... I was very conscious because she'd said so much about, “I'm worried about you. I want you to promise me that you're going to be okay.” [...] So, she was very calm on the morning, and I think [brother] and I were as calm as we could be.

(178)

She went on to describe how assisted dying offered her mum the feeling of assurance of dying at home and saying final goodbyes. In this way, assisted dying can be a way of enacting care *for* another (Richards & Krawczyk, 2021):

I think she probably had a whole lot of things going on in the back of her mind about how she was feeling and what she was worried about happening. [...] I think she was monitoring her health very closely and she very much would've wanted to avoid

going into the hospital. And I think she also probably didn't want to just die and not say goodbye. I think there was probably part of that, that she thought in the end that I'm better to actually say, goodbye than for [participant name] to come here one day and for me to be gone.

(178)

Enacting assisted dying also called for rehearsal and sometimes improvisation. An example of this rehearsal is captured in an extract (below) from a carer in her thirties supporting her mum with her siblings and dad. She recounts repeatedly practising mixing and administering the medication in the days and hours leading up to the assisted death. Her quote captures her apprehensions surrounding whether things would unfold as planned, and the weight of ensuring that roles were performed correctly. There are also moral tensions evident in her account when she describes making her mum practice ingesting the substance as distressing, yet necessary:

... we were worried that she wouldn't be able to hold the medication, that she wouldn't be able to administer it herself. We didn't know if she'd be able to drink it through a straw [...] she'd started to have issues with swallowing and we were like, "Okay, she has to keep it down." [...] So there was so much anxiety around, "Come on, Mum, you have to do it." [...] We went through it about three or four times I think, because my sister and I, we had to be the ones to be mixing it, so we wanted to make sure that everything was right [...] They went off and dispensed it, brought it back, yeah, from that point my sister and I just kept going over it and over it in our heads ...

(89)

## Compromises and ambivalence

The intimate and active role that carers often played in organising assisting dying evoked complex and often mixed emotions, moral deliberations and sometimes compromises. Although carers expressed relief and gratitude around avoiding long drawn-out suffering and helping the person, they also expressed their unease and sometimes distress about playing a participatory role in the death. This discomfort is well illustrated in the following extract from a participant caring for her dad. She describes the 'torturous place' between holding on and letting go—of loss and 'helping her dad get to where he wanted to get to'. For her, making sense of her Dad's death meant resisting some of the cultural ways in which we think about the dying process, such as dying being a passive, gradual process of shutting-down and letting go.

It was pretty confronting [...] being with him and helping him get to where he wanted to get to. I'm glad I was able to help him, at the same time I don't know. Mixed emotions. I mean, I know it was the best thing, but he's my dad.

(111)

Another participant (below) caring for her dad, touched on the subtle interpersonal dynamics and moral tensions that emerged when family members were out of step with each other about whether assisted dying was 'the right thing to do'. In her interview, she described

feeling conflicted that her brother may not been on board with the decision, referencing his unease that VAD disrupted the natural dying process:

I think there was a part of him that was a bit like nature should take its course. I don't know. I still have a bit of an uneasy sort of unfinished feeling in relation to what [my brother] thought and what I thought. [...] It didn't seem like a conflicting kind of process to organize how we manage those last few days. But I'm a little bit conflicted about it in the aftermath in some ways.

(178)

The concerns raised by the participant's brother (above) that VAD had disrupted the natural course of dying provides insight into normative cultural representations of death and the role of medical technology in the dying process. Dying, according to Seymour (1999) is conceived as natural when medical technology or intervention delivers an outcome that the person expects, and that aligns with their broader understanding of death.

Moral tensions also arose when the dying person wanted to keep their request for VAD a secret from others or they wanted to exclude others from the death. This scenario was described by a participant with many siblings, but whose dad had chosen her as the sole person involved in his assisted death, thus excluding other family members from the event. In her extract (below) she reflected on her experience in bereavement, pondering whether her grief was tied to her involvement in the death:

... there was an intensity to this grief that was very different to others. I don't know if that's because of the role that I played.

(84)

She went on to describe how having a sole caring role limited her space to grieve:

I was so focused on being Dad's support, and the coordinator, and working through the logistics of it all, I didn't stop for that. [...] there was no space for me to be in grief. I had to be very, very present and very, very strong and calm for Dad.

(84)

Her participation in the death had enduring consequences, including the 'unrecoverable' breaking down of relationships with her siblings:

Dad wasn't in extreme physical pain. That created a lot of unease for people to understand why on Earth is dad accessing VAD? My sister was so angry, and she was pointing that anger at me because I was the one who was supporting dad and helping dad with his wishes.

(84)

In the aftermath, the disruption of family relationships exacerbated her grief and loneliness:

I was the one alone in amongst that, whereas other families would have had a shared responsibility in that space, whereas mine was very much a bit of a lonely journey.

(84)

Despite their efforts (front-stage) to manage assisted dying in a particular way (Goffman, 1959), some participants privately worried that the event would not unfold as hoped. In the following extract, a participant articulates her fear that the opportunity to say goodbye and be there with her mum in her final moments, may be taken away. Her excerpt illustrates the internal tussle of trying to manage feelings, prepare for a possible unexpected outcome, as well as struggling to find balance between exerting and letting go of control. This fear of losing control draws attention to the illusion of certainty that assisted dying provides, when in reality, enacting a death in a particular way is never assured:

I was worried when she initially got it [the medication] into our house that she might take it one day without telling me. And because she wouldn't have wanted to put us all through the goodbyes [...] I think all the way along you're never sure whether that's how it's going to unfold and you do wonder, but you push it away, thinking that might not happen, or something else could happen.

(178)

Participants' accounts also indicated that arranging assisted dying involved compromise and sometimes caused additional distress. On the one hand, supporting the dying person to access assisted dying was conceived by participants as act of care: borne from a desire to alleviate unnecessary suffering and respect the person's right to choose. Yet, the process itself could also cause suffering, particularly when the dying person's health was rapidly decline as is shown in the following quote:

... she was so compromised physically, which was just traumatic. Traumatic for me and [sister], and traumatic for her. She'd had nothing to eat. She was hunched over in her chair. It was dreadful. So, if there's only one thing that I have to say for this whole thing, it's that regional people having to travel long distances for appointments in compromised ill positions was the worst thing. [...] Her appointment in [major city] was at 1:30. The appointment was for 90 minutes. Then we had to get her back into the car and drive her back to [regional town]. So, that journey probably from 10:00 in the morning until 5:00 in the afternoon was awful.

(86)

Some participants' accounts suggest they experienced a moral quandary with how best to spend very finite time, and where to direct efforts. In a context where time was scarce, participants found it difficult to know if time and energy should be directed towards trying to access assisted dying or towards making final memories and sharing quality time together. The sense of time running out was a catalyst for urgent action and improvisation for some carers, who feared that the person would die alone or without assistance. In this way, time acted as a normative pressure for carers:

I'm trying to plan this and I've got Dad saying, "No, Wednesday." And I'm saying, "What if it doesn't happen Wednesday?" And he's just like, "No, Wednesday." And I was like, "Okay." I'm feeling the pressure here sort of. And I couldn't get an answer. So that's just the process. [...] the process of his illness, and the decline, and the

suffering, and all that we had to see, and look after, and put time into, and all of that sort of thing. And effort and emotional energy.

(140)

## Deviating from the script

Although most participants described scenes in which assisted dying created moments for closeness and peaceful farewells, this was not always the case. Among this cohort, there were examples of dying complicated by regret, exclusion or conflict. These scenarios generally played out when the reality of the experience of assisted dying deviated from the participant's expectations of the process (Buchbinder, 2021). Deviations occurred because the dying person was unable to access assisted dying such as when a person's application for VAD was denied or when the person became too unwell or died before the application process could be completed. In these situations, participants often expressed regret, disappointment or frustration of the missed opportunity to fulfil the person's hopes for assistance. The following participant describes her sense of powerlessness when the option of assisted dying (and the hope of dying 'peacefully' attached to it) was closed off:

[Mum] was just devastated because it's there for the taking. It's there. It's a real thing, and if you choose to use it, you should be able to without [...] She just said, "Oh, I'm..." it's too hard. In the end, you're just tired. You don't want to spend your last six months rustling around trying to organize things like we did. And dad, dad rang me up and he begged for me to find someone to help her. [...] They shouldn't have to be begging. [...] we couldn't really just grieve for her because we were that angry because she had to go through what she did. [...] We were with her when she passed, but it was... We were just so... I was filled with rage. The procedures that they were doing to her that she didn't want to have done, and she was going to die anyway, but they kept doing these things and stuffing tubes down her, but why? She could have just went peacefully, but they just kept on, "Oh, you've got to have this. You've got to have this. If you don't, you'll drown in your own..." whatever, I don't know how it works. [...] it's what she always wanted. It's what she always said. And when you're at the mercy, after everything that happened to her and she did everything right. Everything right. Saw every person she was supposed to, or followed all the rules and where does it get you?

(85)

In other cases, participants expressed sadness or disappointment that how they imagined assisted dying to look, did not come to be. For example, when the process felt rushed or did not occur in a manner that accorded with the patient's preferences, such as when choice of location or who was present at the death were constrained. The following participant described needing to move her dying mum from an aged care facility to the hospital to allow her to access VAD. Her quote illustrates, both the need to quickly adapt to new environments (and all the backstage work and rearrangement of roles that went along with this) (Goffman, 1959), but also the feeling of powerlessness when restrictions were placed on where VAD was permitted:

... having to move her [from her nursing home] to [the hospital] was just another hurdle to jump over. And at the time, there was all those hurdles, because getting to [major city], waiting, waiting. So, at the end, it would have been so much easier if she could have died where she was. [...] The whole day was pretty awful actually because we didn't know until 9:30 that a bed at [hospital] had become available. And then, my brother and I had to race in and get Mum sorted out. And she was still in bed and asleep and dopey. And I had to get her out and shower her. And it was all hurried, in a sense, her last day, which is maybe a good thing in a way because she didn't have time to think.

(86)

A small number of participants recounted the painful feeling of being excluded from the death, and not having the opportunity to say goodbye. This was deeply distressing for the following participant, whose ex-partner died without her knowledge. She also expressed a sense of responsibility and guilt that she was complicit in his decision to access VAD:

The most difficult was trying to understand why he did it without saying goodbye, without at least letting me phone him or visit. And then, the associated meaning of does that mean that I meant nothing to him. I wasn't enough. I felt like we were in an okay place. I didn't know what was going to transpire. I feel very responsible for him dying, for his death.

(163)

Another participant similarly recounted the feeling of exclusion, describing in vivid detail the distressing experience of watching from the sidelines as her husband does not experience the death that he had hoped for. In the scenario she describes, her role could be characterised as one of a reluctant spectator, observing a death scene that had become more spectacle than intimate private moment:

It was totally the opposite of what we imagined it to be. [...] It was a very negative experience for us. And in the end, I mean, all [partner name] wanted to do was to die, and even the dying process. The morning of the VAD was a whole circus. There were so many people around [...] I never got any private time with him before he died. There were nurses and people I've never seen, and people who hardly knew [name]. It's the first VAD I've ever been to, and the only time he'd die, and it was just shocking. I don't know if I'll ever get over it, really. And he was so angry at the end. [...] Anyway. I suppose I feel conflicted. I'm glad for his sake he's dead, but I'm thinking I just wish he didn't have to go through all that.

(117)

## DISCUSSION AND CONCLUSION

In this study, we contribute to sociological understandings of dying as a relational experience by illuminating the complex work of family members in supporting a person seeking an assisted death; and how assisted dying shifts carer roles and responsibilities (Borgstrom et al., 2019;

Broom, 2012; Broom et al., 2016; Exley, 2004; Gamondi et al., 2019; Gandsman, 2018; Thompson et al., 2016). Building on Buchbinder's (2018, 2021) anthropological research in the United States, a focus on choreographies contributes to understanding the multiple realities enacted in assisted dying in Australia. Assisted dying requires different social and material actors and settings to be rearranged, producing new choreographies of dying. Carers' accounts illustrate how the choreography of assisted dying care is contingent on the specificities of the person, their social contexts and the trajectory of the disease. The performances that unfold are particular to each circumstance, requiring different constellations of movements, actions, sequences, and emotions, to create different dying experiences. Here the carer plays a central role in helping bring about the dying person's vision about how and when they wish to die. Yet, what this looks like, and how it is arranged varies, and is contingent on disease, prognosis, individual preference, setting, familial dynamics, and timeframe.

In line with Buchbinder (2018, 2021) we find that enacting assisted dying depends on complex planning, preparation, performance, and resourcefulness from carers, requiring effort and often self-sacrifice (Thompson, 2005; Williams, 2019). Rather than a singular event decided and enacted by the dying person themselves, the care practices that lie behind it are far from straightforward. Harmonious goodbyes and peaceful, dignified deaths are not assured by access to VAD medication alone; they are carefully curated by carers through bringing together of various practices, processes and social relations. This partially improvised choreography resonates with what Strauss (1988) describes as articulation work. That is, the often invisible yet critical work involved in bringing together discrete elements, activities, actions and social relations to make a coherent whole. The carer must continuously adapt to accommodate for unanticipated contingencies associated with the disease and its prognosis and trajectory (see Glaser & Strauss, 1968; Mol et al., 2010; Strauss, 1988). The caring work performed by carers, while often undetectable, is essential in choreographing assisted dying well.

Our findings also draw attention to the challenges for carers associated both with the 'newness' of assisted dying in Australia and their shifting role in the dying process. The absence of specific cultural narratives regarding assisted dying for carers to draw from complicated experiences of care. Caregiving was often experienced by participants as uncharted territory to navigate, as they grappled with not knowing what to do, what to expect or how to feel. This led to the emergence of different cultural scripts of death and dying as well as the creation of new rituals and practices of care. In forming new cultural narratives, participants drew both from existing cultural narratives of death and from their past experiences (Seale, 1998). These findings also highlight emerging fracture points associated with assisted dying regulatory processes, where practices breakdown, or settings where assisted dying is prevented. If assisted dying choreography is to function well, it requires discipline and compliance from all actors. When actors do not play their part, fall out of step or resist each other (for example, due to conflicting logics of dying), the enactment of assisted dying is unlikely to unfold smoothly, leading to the potential for tension and disordered scenes.

Building on research on the moral aspects of caring for the dying (see Broom et al., 2016; Chattoo & Ahmad, 2008; Sand Anderson et al., 2020), these findings suggest that cultural ideals of assisted dying—as dignified, peaceful, without suffering—may have ramifications for carers; particularly if 'caring well' is equated with the carer successfully facilitating a dignified, peaceful death for another person. For participants whose experiences seemed to fit with these cultural ideals, there was comfort in feeling that a 'good death' was achieved. Conversely, these same ideals could negatively affect those whose experiences deviated from these cultural expectations. When good deaths did not occur, this could lead to a sense that caring was not 'good



enough'. Opportunities to manage dying (possibly reflective of broader cultural discomfort with uncertainty and desire to control or tame death), appeared to contribute to an illusion of being in control or of certainty about the dying process (Buchbinder, 2021; Pollock et al., 2023). An implication of this was that when death happened in an unexpected manner or time this could induce feelings of loss, grief or self-responsibility for some carers, tied with an outcome that was not aligned with normative visions of a 'good (assisted) death'. These examples where participants (and the dying person) had to manage their expectations around what outcome is possible, when the person died without agency or without dignity, illustrate the problem of polarising thinking around what culturally constitutes 'good' and 'bad' deaths (and good/bad care) (Seymour, 1999).

Deaths not going according to plan is a familiar theme in death and dying. People may not get to die at home even when they desire to do so, there may be suffering, and opportunities for farewells may be lost. While this is prepared for in the context of other kinds of dying, the accounts describing scenarios of assisted dying not going to plan articulated in this study, similar to previous research (see Buchbinder, 2021) points to an issue that is particular to VAD—the feeling of certainty and assurance. But, as Buchbinder (2021) notes, this too is an illusion (p. 157). As these findings show, not all carers are afforded opportunities to plan, prepare and arrange their deaths. While only a small number of participants narrated these kinds of experiences, they illustrate the need for perspectives beyond the ideal of individual autonomy in end of life decision-making (see also Buchbinder, 2018). It is, however, also important to acknowledge that as most participants self-selected to participate in the study after responding to social media advertising material that asked for people to respond who were supporting someone going through assisted dying, it is plausible that those who shared their experiences might reflect the extremes across a spectrum of experiences. That is, those with more positive and negative experiences. Additionally as participants were mostly women (which reflects the gendered experience of caregiving generally), these findings may not reflect the experiences of male caregivers; thus future research exploring men's experiences of assisted dying care is needed.

Finally, this analysis draws attention to new challenges and potential inequities that have emerged with VAD legislation, including the institutional obstacles that may constrain carers' (and patients') agency in choreographing assisted dying, such as living in rural and remote locations. We show how with the introduction of VAD and the entry of new actors into the frame (e.g. the medication, the VAD board, new regulations and policies), the distribution of power and responsibility shifts between actors and across settings. While some carers in this study described feeling more responsible as they were required to take on a leading role (sometimes unexpected) in the dying process, for others, in contrast, they experienced feelings of helplessness and exclusion. Their accounts suggest that their capacity for agency may have been constrained by other people, institutions or regulations.

A central figure in the choreography of assisted dying was the medication itself (and the permits and other legal aspects), which created new forms of compliance and control, raising new ethical issues, such as unequal decision-making and access, and surveillance. Yet perhaps what yielded most power in the field of assisted dying was the terminal disease. While people may endeavour to exercise autonomous choice about how they will die, and carers may seek to make this happen, the stronger agent is the disease itself, which will often determine what will eventuate (and when) despite how carefully carers wish to control and manage it. These findings have important implications for clinical practice, particularly regarding how to support carers of persons seeking VAD and in acknowledging the high expectations on carers to

facilitate agentic deaths for patients. An important consideration for future policy reform and the development of clinical guidelines is how emerging cultural narratives of assisted dying are impacting the lives of carers, and their experience of caring.

### AUTHOR CONTRIBUTIONS

**Sophie Lewis:** Conceptualization (lead); data curation (supporting); formal analysis (lead), funding acquisition (supporting); writing—original draft (lead); writing—review and editing (lead). **Camille La Brooy:** Conceptualization (supporting); data curation (lead); formal analysis (lead); writing—original draft (supporting); writing—review and editing (supporting). **Ian Kerridge:** Conceptualization (supporting); funding acquisition (lead); writing—original draft (supporting); writing—review and editing (supporting). **Alex Holmes:** Funding acquisition (supporting); writing—review and editing (supporting). **Ian Olver:** Conceptualization (supporting); funding acquisition (supporting); writing—original draft (supporting); writing—review and editing (supporting). **Peter Hudson:** Conceptualization (supporting), funding acquisition (supporting), writing—original draft (supporting); writing—review and editing (supporting). **Michael Dooley:** Conceptualization (supporting); funding acquisition (supporting); writing—original draft (supporting); writing—review and editing (supporting). **Paul Komesaroff:** Conceptualization (supporting); funding acquisition (lead); writing—original draft (supporting); writing—review and editing (supporting).

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The authors declare no conflicts of interest.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

### ETHICS STATEMENT

Ethics approval was granted from the Monash University Human Research Ethics Committee (MUHREC) [project ID 26640].

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