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RESEARCH ARTICLE

'This is perfect, thank you': Research poetry on gratitude for voluntary assisted dying in Victoria, Australia

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Abstract

Objective: To undertake the first scholarly examination in Australia of how those involved in seeking voluntary assisted dying (VAD) discuss the concept of gratitude for this new end-of-life choice. The article shares findings through research poetry, an arts-based form of research where poems are developed from data (here, interview transcripts).

Methods: Twenty-eight semi-structured qualitative interviews were conducted with 33 participants (32 family caregivers; one patient). Participants were asked about their VAD experience, with caregivers also asked about the experience of their family member. Data were thematically analysed, focusing on expressions of gratitude for VAD. Miller's five-step process was adopted to create the research poetry.

Results: Gratitude for VAD was a significant concept for participants. We identified three gratitude themes relating to what people were grateful for, who people were grateful to and other feelings mixed in with their gratitude, such as ambivalence. We created six poems to illuminate these findings and give voice to the gratitude expressed by patients and family caregivers about VAD.

Conclusions: Gratitude for VAD was emphasised by participants as an important part of their experience and something that can help family caregivers cope after a VAD death. Expressions of gratitude can support health professionals providing VAD and create support for law reform in other jurisdictions. Research poetry reflecting this gratitude can contribute to reducing the stigma attached to VAD and enhance awareness of this relatively new end-of-life choice. More research is needed into the emotional experience of those involved in seeking and receiving VAD in Australia.

KEYWORDS

assisted suicide, euthanasia active voluntary, gratitude, research poetry, voluntary assisted dying

1 | INTRODUCTION

This is the first Australian study, and one of the few internationally, that examined how patients and family caregivers express gratitude for voluntary assisted dying (VAD). The article reports findings through research poetry, an arts-based form of research where poems are developed from data,[1,2] here, participants' direct words from qualitative interviews. Research poetry is slowly gaining traction in ageing research,[1–4] prompted by its capacity to amplify the voice of participants and generate emotional engagement with research findings.[1,2]

Voluntary assisted dying is when a person seeks to take, or have administered to them, medication that will cause them to die.[5] Voluntary assisted dying has been lawful for decades in places such as the Netherlands, Belgium, Switzerland and the US state of Oregon, but ongoing reform has seen legalisation in various forms in 17 countries, including Canada, Austria, Spain, Germany, New Zealand and Australia.[5] Law reform to allow VAD has been challenging historically,[6] but the trend for more jurisdictions to permit the practice is likely to continue.[7] The path to reform in Australia has been particularly notable[8,9] with VAD laws passing in all six Australian states[10] and the Australian Capital Territory[11] since 2017. The remaining territory, the Northern Territory, is also considering reform.[12]

Underpinning reform has been a desire from patients and the wider community (particularly older people) for additional choice at the end of life.[10] Yet, there is limited research in Australia on the experience and perceptions of patients seeking VAD and their families. Existing literature generally focuses on barriers and facilitators to access.[13–16] That research found that supportive doctors and state VAD services (e.g. VAD care navigators) are vital to facilitate access to VAD, while complex eligibility assessment processes, regulatory barriers and objections by institutions and individual doctors impair access. There is also research on how patients and family caregivers can act as 'regulators' to guide system behaviour.[17–19]

There is a small body of empirical research with patients and families internationally, which mentions, but does not focus on, gratitude for VAD. This includes gratitude for having a VAD law,[20] having greater control and the option to choose VAD when unbearably suffering,[20–23] being supported to achieve a peaceful death[23,24] and being able to say final goodbyes.[20,21,24]

In Australia, only one article reports on gratitude and VAD, but only briefly and in the wider context of family grief (e.g. 'meaning-making in grief' was enabled by VAD being a planned death and appreciation for avoidance of suffering).[25] There is, however, evidence from grey literature, including reports of VAD oversight bodies, that patients and family caregivers express gratitude.[26–28] Further, one arts-based knowledge translation project documented personal stories of those seeking VAD and their families,[29] including reports of gratitude for VAD.[30]

This article draws on semi-structured interviews, primarily with family caregivers of people seeking VAD in Victoria (the first Australian state to legalise VAD), and reports on gratitude expressed about this new end-of-life choice. The article presents a thematic analysis of the data as well as research poetry for each theme.

Policy impact

Gratitude for voluntary assisted dying (VAD) can help families after a death and support health professionals providing VAD. It can also foster support for law reform in jurisdictions where VAD is not yet lawful. Research poetry representing this gratitude can help address the stigma attached to VAD and the low public awareness of this choice.

2 | METHODS

2.1 | Eligibility

This research was part of an international study examining VAD regulation in Australia, Canada and Belgium.[31,32] The data reported here are from semi-structured, qualitative interviews. Participants were eligible if they were (a) patients seeking VAD in Victoria, whether or not they were approved for VAD; or (b) family caregivers who had supported or were supporting a patient through VAD and could report on their perceptions of the patient's experience (and their own).

2.2 | Recruitment and sampling

Participants were recruited through Twitter/X posts and advertising on the project website. Patient interest groups *Go Gentle Australia* and *Dying with Dignity Victoria* also shared study details via social media, newsletters and emails. Convenience sampling was used initially. Purposive sampling was also employed to seek demographic and experiential diversity, including diversity in patient age, gender, illness, location (metropolitan/regional), timing of seeking access and patient experience of VAD (self-administration, practitioner administration, sought VAD but did not use it or was not found eligible). Reports from the Victorian VAD Review Board assisted in determining these diversity domains.[33] Purposive sampling was primarily achieved through direct emails from the above-mentioned patient interest groups to potentially matching participants. Recruitment ceased when the dataset had sufficient 'information power' to meet the wider study aims.[34,35]

2.3 | Data collection

Data were collected via semi-structured, qualitative interviews between August 2021 and October 2022. BPW (health law and regulation professor) and RJ (lawyer and PhD student) conducted all interviews together, with one as a designated lead.

Twenty-eight interviews were conducted with 33 participants (32 family caregivers; one patient) (Table 1). Interviews related to 28 patient experiences are shown in Table 2. The article generally reported on the perspectives of older persons with 23 of 28 patient experiences and 18 of 33 interview participants being 60 years or older (Tables 1 and 2). Interviews ranged from 56 to 130 minutes (mean 90).

TABLE 1 Characteristics of interview participants (*n* = 33).

Characteristic	Number
Age (years), mean 56.6, SD 15.1	
20–29	1
30–39	4
40–49	7
50–59	3
60–69	13
70–79	4
80–89	1
Gender	
Women	26
Men	7
Relationship to person seeking voluntary assisted dying[a]	
Child (including stepchild, child-in-law)	17
Spouse (including de facto partner)	10
Parent	3
Sibling	2
Close friend	1
Self	1

[a] One participant spoke about two patients, so is included in two categories; hence, percentages in this latter section of the table are calculated using the number of relationships (34). To further clarify the relationship between interviewees and patients, five of the interviews each involved two family caregivers being interviewed together about their family member's experience of voluntary assisted dying (e.g. a son and daughter-in-law speaking about their parent's experience). Two interviews were conducted with different family members separately about the same patient experience.

BPW and RJ debriefed after each interview and maintained a reflexive journal. All participants provided free and informed consent prior to the interview. All family caregiver interviews were conducted after the patient had died, so additional patient consent was not sought.

Interviews were conducted via Zoom, except for two by telephone and one in-person. All interviews were digitally audio-recorded and transcribed verbatim (to standard conversational level) by a professional company subject to a confidentiality agreement. Participants could amend or add to their transcript (member checking).[36]

The interview guide stepped participants through the process of seeking VAD (Appendix S1). Family caregivers were asked to not only focus on the patient's experience but also report their own experiences. Interview prompts included the experience of getting and using the medication, as well as feelings and motivations.

2.4 | Thematic analysis

Transcripts and any additional information provided by participants during member checking were thematically analysed line by line. Codes for the wider study were developed inductively and deductively, drawing on iterative discussion of initial themes.[37] An example of a deductive code relevant for this article from the literature was 'VAD motives' (i.e. why did a person seek VAD) while 'gratitude' was an inductive code identified early in analysis that was prominent in the data. BPW and RJ both coded 17 interviews (double coding) and BPW then coded the remainder. Codes were discussed and iteratively refined throughout data collection, analysis and in research team discussions. Analysis was aided by NVivo (release 1.6.1 QSR International).

Next, for the purposes of this paper, a more granular thematic analysis was undertaken of the subset of coded data about gratitude. This included the specific 'gratitude' code as well as other codes relating to feelings or motivations, decisions to take the VAD medication and the 'thing that worked best' in the VAD system. Data were included only if there was an express statement of gratitude, or BPW considered the participant was clearly raising the concept of gratitude. BPW analysed these data inductively line by line to identify domains in the concept of gratitude. Full transcripts were reviewed as appropriate to understand patient experience globally. RJ reviewed this subset of data again and SHB and EM reviewed a series of key data extracts selected by BPW and RJ.

TABLE 2 Characteristics of persons seeking voluntary assisted dying whose experiences were the subject of interviews (*n* = 28).

	Number
Characteristic	
Age (years), mean 70.8, SD 15.4	
20–29	1
30–39	1
40–49	0
50–59	3
60–69	7
70–79	8
80–89	6
90–99	2
Gender	
Women	13
Men	15
Location	
Metropolitan	16
Regional[a]	12
Highest level of education	
Some high school	7
High school	9
University—diploma	1
University—undergraduate	7
University—postgraduate (including graduate diploma)	4
Primary disease, illness or medical condition	
Cancer	18
Neurological	9
Other	1
Eligibility for voluntary assisted dying and death	
Assessed as eligible	24
Person died via self-administered medication	19
Person died via practitioner administered medication	3
Person died but did not take medication (natural death)	1
Person waiting to take medication	1
Person died prior to eligibility assessment completed	3
Person assessed as ineligible and died	1
Timing of voluntary assisted death or engagement with process	
July–December 2019	4
January–June 2020	6
July–December 2020	3
January–June 2021	10
July–November 2021	5

[a] One person classified as regional moved to a metropolitan area during the voluntary assisted dying process.

2.5 | Research poetry

The research poetry component illustrating identified domains of gratitude was led by RJ, with BPW providing ideas for poem content from data analysis and BPW, SHB and EM all contributing to the creative process. Research poetry drawing on participant voices provided an authentic way to reflect the magnitude of emotion they repeatedly expressed about gratitude for VAD.

Miller's five-step approach was used: immersion, creation, critical reflection, ethics and engagement.[3] Immersion occurred during thematic analysis and while creating the poetry. Key data were extracted into a Word document. Researchers read and re-read the data extracts 'until the text reveal[ed] its key messages'.[3]

Creation occurred initially through BPW identifying striking phrases, which could evoke emotion or new insights. Examples were powerful metaphors (e.g. 'I've bought insurance') or unusual phrasing inviting seeing the topic in different ways (e.g., 'Thank you Dan'). RJ built on these phrases to create initial draft poems. Filler words were removed, sentence structures and order of words were changed for poetic impact, while ensuring poems remained true to participants' words and meaning. No words were added or modified (including pronouns); however, some were repeated. Some poems used one transcript, whereas others drew on multiple transcripts.[3] See Table 3 for a poem creation example and the decision to create polyvocal poems.

Critical reflection occurred through the research team reviewing the initial poems and discussing ideas for refinement, including length, imagery, repetition, tone and highlighting contrasting feelings. After this discussion, BPW reviewed the initial drafts and suggested specific refinement, and then RJ updated the poems, including drafting a further poem ('The loveliest way to die') to elucidate contrasting experiences. The decision to nest poems within the relevant theme/subtheme was also made to illustrate themes in an engaging way (Tables 4–9). The poems were further refined through additional critical reflection. In particular, the research team considered the rationales for the polyvocal poems adding a statement for each poem explaining choices made.

Ethical engagement included sending the draft article to participants who were included in the poems for comment. Seven participants replied. One simply acknowledged receipt, but the other six were all positive about presenting findings through research poetry (including references to emotions it evoked). Five reported that their deceased family members would have approved, with reference to the person's legacy and their words

TABLE 3 Poem creation decisions.

Example of creating a research poem	
Interview transcript (Patient 1, male, 88)	**Poem**
The main difficulty for me was not - well, how can I say it - not [0:14:46] about how awkward this is going to do and how difficult. It was my uncertainty about the efficiency of the method. **The particular method** that **I had in mind**, which seemed the best in my circumstances that was available, **had some uncertainty about it**. **You can make mistakes**, or if you did this wrong or that wrong **you could screw up** on it. So that was my main concern, about how efficient it would be ... It was a great sense of relief. My whole attitude towards this medication is **it's as though previously if I had a motor car and was driving it around** everywhere without insurance that I'd be **not looking to have an accident but aware** that **the accident could occur** and I'd be grateful if I insured my car. **Now**, this is the same. **I've bought insurance**. That is sitting there, and **if and when I need it, I know that I can use it**. [0:59:28 - If the opposite had occurred] the action would be my health has got to a point that I've had enough or I definitely have decided to go, then a very I assume safe method is sitting there waiting for me to use. The previous method which is still sitting there in the room, the equipment for **a do-it-yourself thing before the VAD application**, has got some difficulties with it, some uncertainties with it. And I was very grateful to have what is a - I think they call it the - oh god, I can't think of the word. Anyway, a well above acceptable method from all the other - **I** mean we **could** go and **jump off a high building or lay down in front of a train**. **They're** methods. But **this is so far above all the homemade methods** that **I was very grateful to get it**.	**I've bought insurance** I could jump off a high building Or lay down in front of a train They're homemade methods A do-it-yourself thing The particular method I had in mind Had some uncertainty about it You can make mistakes You could screw up Before the VAD application It's as though I had a motor car and was driving it around Not looking to have an accident But aware the accident could occur Now I've bought insurance I know that I can use it if and when I need it This is so far above all the homemade methods I was very grateful to get it
Choice to use polyvocal poems Polyvocal poems were made for three key reasons: (1) the theme was represented so strongly in multiple transcripts and drawing on multiple transcripts highlighted the common experience and the strength of the theme; (2) to juxtapose different experiences; and/or (3) to improve the poem's artistic quality. Because gratitude is only one part of our data for the wider study, participants' comments on gratitude formed only one (small) part of transcripts. This meant that to construct poems that were engaging to read, aesthetically interesting, and best reflected (our interpretation) of the participants' comments, multiple voices were used.	

being immortalised. Five participants also reported the poetry (and wider gratitude findings) resonated with their experience and that of their family member who sought VAD. Some minor changes were made to the article after this feedback (additional context for a quote and some methods suggestions); no changes were suggested to poems.

In respect of engagement with poetry, EM (research poet) and SHB (poet) are expert poets. While drafting the poems, RJ read a combination of research and literary poetry for inspiration.

2.6 | Research ethics

This research was conducted in accordance with ethics approval from the Queensland University of Technology Human Research Ethics Committee (2000000270).

3 | RESULTS

Gratitude was expressed by the sole patient speaking about their own gratitude, family caregivers reporting on a patient's expressions of gratitude and family caregivers expressing their own feelings of gratitude. We identified three themes on gratitude relating to what people were grateful for, who people were grateful to and other feelings mixed in with their gratitude, such as ambivalence.

3.1 | What people were grateful for

Gratitude for the choice of VAD was spontaneously raised by many participants. This was often accompanied by statements of how important this was to them, with some participants physically showing emotion during this part of the interview (e.g. speaking with emphasis, crying). Its significance was also demonstrated by several participants who, when asked to identify the best part of their experience, named gratitude for VAD. We identified four sub-themes, with participants often expressing more than one.

The first was gratitude that VAD would allow the patient to avoid a bad death. Participants described the sorts of deaths they and patients were concerned about and had seen: those that were 'long and protracted and unkind' and involved suffering both with pain and loss of dignity. Some participants described patients' feelings of fear about how they might die, for example, 'I know he felt lucky [to have VAD], because he was terrified about drowning to death' (Family caregiver 1, female, 31). One participant expressed gratitude for VAD because it meant not having to take their life in other ways which, unlike VAD, may not work and might cause suffering (Table 4).

The second sub-theme was the converse: patients and family caregivers were grateful for a good death (Table 5). Reflecting literature on what constitutes a 'good death',[38] this included having choice about the process of dying, being at a preferred place of death and surrounded by loved ones, participating in meaningful

TABLE 4 I've bought insurance.

I could jump off a high building
Or lay down in front of a train
They're homemade methods
A do-it-yourself thing

The particular method I had in mind
Had some uncertainty about it
You can make mistakes
You could screw up

Before the VAD application
It's as though I had a motor car and was driving it around
Not looking to have an accident
But aware the accident could occur

Now I've bought insurance
I know that I can use it if and when I need it
This is so far above all the homemade methods
I was very grateful to get it

– Patient 1, male, 88

This is a univocal poem representing the experience of the sole patient interviewee in our study. We chose to construct this research poem using a single voice because it provided a complex and stirring account of this participant's desire to end their own life by any means necessary, and their gratitude for having VAD as a simpler, more reliable and non-painful means of death compared to other methods such as suicide. We decided it was important to convey, undisturbed, the voice of the only patient we were able to interview for the study. We also felt that the discussion of VAD as an insurance policy was a striking metaphor that encapsulated relief and gratitude about the availability of VAD in an artistic and aesthetic way.

TABLE 5 The loveliest way to die.

I know he felt lucky
Yes, she was lucky you might say
What Dad got was beyond beautiful
She died very peacefully in the end
A kind, peaceful, gracious death
But she was in a coma which was not what she planned for her ending
To choose the time and place
It would have been the loveliest way to die
At home, surrounded by family
She wanted to have her family in that room
He got his final wish
To have music playing, candles going
"I love you", they were his last words
To say goodbye, quietly and gently
He had the final say
She couldn't have that and that will haunt me

– Family caregiver 1, female, 31; Family caregiver 3, female, 48; Family caregiver 4, female, 66; Family caregiver 5, female, 62; Family caregiver 6, male, 78; Family caregiver 7, female, 53; Family caregiver 8, male, 66; Family caregiver 9, female, 60; Family caregiver 10, female, 79

– Family caregiver 11, female, 64

This is a polyvocal poem representing voices from eight interviews (10 participants). The voices captured in the left-aligned text represent the interviews with the first set of family caregivers listed above. The italicised and indented words draw on only one interview with Family caregiver 11, female, 64.

We made a choice to draw on multiple voices in the left-aligned text because the discussion of gratefulness for having a good death came through strongly and was echoed by many participants. Most of the patients whose experiences were reported in our study achieved access to VAD and were, according to reports of family caregivers, grateful that VAD provided a 'good' death for them. By using multiple voices, we sought to illuminate the strength and consistency of views about VAD being a good, peaceful, and kind death.

The italicised and indented text represents only one voice. This was an artistic choice to highlight the sense of isolation and disappointment that the participant expressed as a result of the patient they supported missing out on their choice for VAD. We sought to highlight that this patient wished for the same things in their death as those who did achieve access to VAD and there was symmetry between what was wished for in the experiences of those who accessed VAD and those who missed out. The choice to juxtapose this experience and the disappointment of missing out against positive experiences was intended to reflect the relative strength of the positive experiences as opposed to the negative experiences that were reported in our study. The patient whose experience was discussed in Family caregiver 11's interview was one of only four patients whose experiences were reported in our study who missed out on their choice for VAD, with most patients being able to experience the kind of VAD death they had wished for.

predeath rituals, and having pain and other symptoms well-managed.

One participant reported their loved one's final words before drinking the medication:

> He looked around and he says, "This is perfect, thank you," and then he drinks it.
> (Family caregiver 2, female, 36)

Family caregivers also expressed gratitude for the quality of their loved ones' deaths through VAD: for example, 'a kind, peaceful, gracious death'. One family caregiver said:

> What Dad got was beyond beautiful... everything to a T. ... It was too perfect... he got his final wish and he died with dignity, no pain, no anything, and he was heard.
> (Family caregiver 3, female, 48)

By contrast, one participant, whose loved one lost decision-making capacity during the VAD assessment process and was unable to access it, expressed her deep sadness about VAD not being possible.

A third sub-theme was gratitude for the 'choice', 'control' and 'empowerment' of having VAD available (Table 6). A part of this sub-theme that was emotionally significant for participants was patients retaining 'a choice when everything was being taken away' by the illness:

> The best thing [about VAD] – I think [patient] probably said it best – it allowed him to keep something of himself when almost everything else had been taken away [by cancer].
> (Family caregiver 2, female, 36)

> I am grateful that he got to go his way, and not by that ... [H]e always said: he didn't want MND [Motor Neurone Disease] to win. He didn't want it to completely [take over] his life, so I think he had the final say.
> (Family caregiver 9, female, 60)

Family caregivers also reported their own feelings about the importance of choice for the patient:

> The biggest positive was seeing how empowering the option to have VAD was for Dad. It gave him so much comfort knowing that he had this option that was in his control.
> (Family caregiver 12, female, 25)

> It was his choice ... [and] the cancer never gave him a choice. He took that back and that's the only power he got back ... the best part was actually watching Dad, his shoulders drop and the relief to go "Thank fuck for that." [laughs]
> (Family caregiver 3, female, 48)

The fourth and related sub-theme was gratitude for the 'peace', 'relief' and 'comfort' the choice of VAD brought (Table 7). This was important for the patients in our study:

> It was a great sense of relief ... if and when I need it, I know that I can use it.
> (Patient 1, male, 88)

Family caregiver participants also reported their loved ones expressing similar thoughts:

> He just kept using the language of "I feel so relieved that this is an option for me. This kind of makes this whole process feel just a lot more manageable."
> (Family caregiver 1, female, 31)

TABLE 6 Peeling away an onion.

Cancer had taken so many things away from him
His health
His hobbies
His peer group
You become very, very isolated
Culturally, we are afraid
Afraid of saying the wrong thing
So people say...
Nothing
Like peeling away an onion, he lost everything
Other than this core part of him
His ability to go with agency

– Family caregiver 2, female, 36

This is a univocal poem representing an interview with Family caregiver 2. Although the sentiment encapsulated in this research poem about the staged erosion of meaningful aspects of life was expressed in multiple interviews, we felt that this transcript, on its own, best encapsulated this theme. Our choice to only use only one participant's voice was primarily an artistic one because we felt that the metaphor of 'peeling away an onion' was powerful and expressed artfully by this participant such that we did not need to draw on further transcripts to convey the theme.

TABLE 7 This is perfect, thank you.

She was sitting in the doctor's surgery
In the waiting room
Her voice was going by then
Everything was being taken away from her
She was so scared of what was happening
Terrified about drowning to death
How long and protracted and unkind those deaths are

She was told she had motor neurone disease
She looked at me and she said “I'm happy now”
What was happening to her was terminal
She knew she would be able to have the choice
She felt comfort, relief
She had a way out

He received this medication, he felt lucky
That empowerment was given back to him
“It's mine, I've got this”
I know that I can use it when I need it
He had control
You could see the difference.
The most happy and peaceful in a long time.

She had no choices with how the disease panned out.
She couldn't make any other decisions.
When almost everything else had been taken away.
It allowed him to keep something of himself.
At home, surrounded by her family.
He had the final say.
She would be able to avoid the worst ending.

He died with dignity.
Out of pain.
Respectful.
I'm grateful that he got to go his way.

– Patient 1, male, 88; Family caregiver 1, female, 31; Family caregiver 2, female, 36; Family caregiver 3, female, 48; Family caregiver 4, female, 66; Family caregiver 5, female, 62; Family caregiver 6, male, 78; Family caregiver 8, male, 66; Family caregiver 9, female, 60; Family caregiver 12, female, 25; Family caregiver 13, female, 61; Family caregiver 14, female, 46; Family caregiver 15, female, 41; Family caregiver 16, female, 45; Family caregiver 17, female, 57; Family caregiver 18, male, 46; Family caregiver 19, female, 46; Family caregiver 20, female, 62; Family caregiver 21, female, 37.

This is a polyvocal poem, representing voices from interviews with the sole patient interviewee, Patient 1, and the above family caregivers. Pronouns have not been changed. This poem represents all the voices of participants whose data were coded to this specific theme. We decided that a polyvocal poem using all voices was powerful in conveying the strength of this theme. Our choice was also an artistic one to make the poem more engaging and to provide a panoptic sense of the overarching theme of ‘what people were grateful for’, rather than it representing a particular sub-theme.

> I noticed a great sense of relief in my mother to know that she had it there … relief of knowing she had a way out when she wanted to.
>
> (Family caregiver 13, female, 61)

3.2 | Who were people grateful to

Often, participants' expressions of gratitude were directed towards health professionals who were supporting the VAD process. This includes state-funded VAD care navigators, local VAD hospital or health service coordinators, doctors who assessed patient eligibility and guided patients and families through the process, and pharmacists who provided the VAD medication.

> When [the doctor] said “yes” he agreed with the diagnosis [to confirm eligibility for VAD]; she held his hands and said “Thank you.” Yeah, it was a very, very powerful, emotional time.
>
> (Family caregiver 13, female, 61)

> We had given letters to the VAD team afterwards to say “thank you”.
>
> (Family caregiver 3, female, 48)

> [All] the way through I've been in contact with the navigators … I could not have done it without them.
>
> (Family caregiver 5, female, 62)

The other main group towards whom gratitude was expressed was those who enabled VAD law to pass. A number of participants specifically thanked ‘lawmakers’ and the Victorian Government, with particular mention of the then Premier (Daniel Andrews) (Table 8).

> Mum had to stand right at the end and give that little speech … before taking the medication … she's looking at us and saying “Thanks to everybody who got the legislation through.”
>
> (Family caregiver 22, female, 57)

> [Dad] thanked the government at the end. He said “I want to thank the government for giving me this and thank all the doctors that helped me” … he said “I just want to thank the government for giving me this opportunity.”

TABLE 8 Thank you Dan.

Mum had to stand right at the end and give that little speech.
To thank everybody for making this possible.
"Thanks to everybody who got the legislation through".
(We're hovering thinking she's going to fall over).

> *"Thank you Dan".*
> *What he did, what his government managed to get through.*
> *Under some quite extraordinary opposition.*
> *Monumental.*
>
> *They were his last words.*
> *Apart from "I love you".*

And then she swallowed the medication.

– Family caregiver 7, female, 53; Family caregiver 22, female, 57; Family caregiver 23, male, 66.

This is a polyvocal poem representing three voices of family caregivers. Family caregiver 22's voice is represented in the left-aligned text and was included because of the powerful imagery it conveys (and was a story powerfully told in the interview). Family caregiver 23's and Family caregiver 7's voices are represented in the italicised and indented text and Family caregiver 23 provided the title. We felt the title reflected the personal nature of VAD – a very familiar and informal expression of personal gratitude from a citizen to the most senior politician in the State.

Further choices to make this a polyvocal poem were twofold. First, it is unusual to see lawmakers thanked for passing law (as noted in the Discussion below) and it struck the research team as unusual that multiple participants raised this in their interviews. In particular, it was striking that patients chose to spend some of their last moments thanking governments and lawmakers. It highlights the real and human impact of democratic, lawmaking processes on people's lives (and deaths) and we wanted to encapsulate that by drawing on these three unique but similar experiences. The second rationale related to the quality of the poems. We felt that the quality of the research poem was strengthened by combining the voices, rather than only using one, to convey the gratitude people felt towards those involved in passing the law.

> ... They were his last words ... apart from "I love you" and all that sort of stuff.
> (Family caregiver 7, female, 53)

> I wrote a letter to Dan [Andrews]... [F]or what he did, what him and his government managed to get through under some quite extraordinary opposition, disgraceful opposition ... so I felt the need to send him a brief little letter and just say "Thank you Dan and your group and thank you to the VAD people for having achieved something that is monumental."
> (Family caregiver 23, male, 66)

TABLE 9 Mixed feelings.

He had the final say
He got to go his way

It's awful in one sense
But we're so blessed in another

I want that for my loved one
But it's still not right

Because Dad's not here
I wish he was here

– Family caregiver 9, female, 60; Family caregiver 3, female, 48

This polyvocal poem represents the voices of Family caregiver 9 (normal text) and Family caregiver 3 (italicised text). The choice to merge these two voices to create a polyvocal poem was primarily an artistic one. This is an example of the point noted above of including more than one voice in cases of limited data. While both transcripts conveyed the mixed feelings and ambivalence felt by participants about their loved one's death, we felt that when discussed together the poem was aesthetically and artistically stronger than if we had included only one voice.

3.3 | Other feelings are mixed with gratitude

Gratitude for the choice of VAD was often reported as mixed or entwined with other feelings (Table 9). Generally, this involved acknowledging sadness from their loved one's death:

> But [VAD] was beyond fabulous ... but it's still not right because Dad's not here. So, it's awful in one sense, but we're so blessed in another and so was he.
> (Family caregiver 3, female, 48)

4 | DISCUSSION

Gratitude for VAD was an important concept expressed by participants, both in relation to their own experience of VAD and, for family caregivers, the patient's experience they reported. They expressed being grateful for avoiding bad deaths and enabling good deaths. They were also grateful for the choice, control and empowerment VAD brought, as well as feelings of peace, relief and comfort knowing VAD was available. These aspects of gratitude for VAD resonated broadly with the international literature. Further, although there is no Australian scholarly research specifically on gratitude for VAD, these findings resonated with grey literature, including oversight board reports.[26–28]

Another finding of this research was to whom this gratitude was directed. Unsurprisingly, gratitude was expressed towards health professionals who assist patients and family caregivers seeking VAD. This reflected Australian literature on facilitators and barriers to accessing VAD, where health professionals were identified as essential for system function.[13]

But perhaps more striking and unusual was the repeated gratitude from participants for the government, lawmakers and others who enabled the law to pass. This may be partially due to Victoria's VAD law being new so the work to pass and implement the law was fresh in people's minds. Also potentially relevant is that lawmakers were granted a conscience vote; hence, support for VAD was their choice, not a party edict. Again, this gratitude—both for governments and health professionals, as noted above—is reported often in VAD oversight board reports.[26–28]

The concept of gratitude can impact how a VAD system functions. For family caregivers, as noted above (mixed feelings theme) and in the limited research on grief after VAD in Australia[25] and internationally,[20,21,23] gratitude can help buoy families after losing a loved one. Gratitude from patients and family caregivers for health professionals supporting them with VAD can also help sustain the VAD workforce.[39,40] This may be particularly important in Australia, with limited health professionals providing VAD and ongoing workforce sustainability issues.[41–44]

Gratitude for VAD may also be of interest for jurisdictions contemplating passing VAD laws. These are difficult public policy decisions, and law reform has historically been difficult.[6] While there are various considerations in deciding whether to legalise VAD, understanding how these laws are being perceived by system users can inform reform debates.

Beyond reporting findings about gratitude, we have also represented the voices of patients and family caregivers more directly through poetry. For a topic such as VAD, poetry can help represent the depth of emotion and gratitude people feel. It can also amplify participants' words and voice to increase their representation.[1] By using poetic enquiry, we sought to speak *with* rather than *for* participants.[2] This is particularly appropriate because autonomy is an important reason why people seek VAD.[45–47] By using participants' voices directly,[3] we sought to refocus control back to patients and family caregivers and their experiences.

Finally, poetry can evoke emotional and empathic responses.[1] It may also invite open conversations.[4] VAD is a new end-of-life choice in Australia, and the reform process was difficult.[8] Scholarship globally highlights that secrecy and stigma about VAD remain even in more established systems, potentially impacting bereavement.[17,21,23,48] Secrecy and stigma may be amplified because VAD is sought mostly by older persons, and ageing narratives often focus on healthy ageing.[1] Through research poetry, this article aimed to invite open and empathic conversations to help reduce stigma and secrecy about VAD.

4.1 | Limitations

This study draws on the first interviews with family caregivers and a patient seeking VAD in Victoria. Early system users can only provide a point-in-time perspective. For instance, we anticipate higher expressions of gratitude for a new VAD law. Another limitation is that interviews were primarily with family caregivers whose perceptions may differ from patients' due to grief, bereavement and their relationship with the patient.[49–51] Finally, our sample may be more favourably disposed towards VAD, given some recruitment was via patient interest groups.

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CONFLICT OF INTEREST STATEMENT

Ben P. White has received funding from the Australian Research Council, the National Health and Medical Research Council, Commonwealth and state governments and philanthropic organisations for research and training about the law, policy and practice relating to end-of-life care. In relation to voluntary assisted dying, he (with colleagues) has been engaged by the Victorian, Western Australian and Queensland governments to design and provide the legislatively mandated training for health practitioners involved in voluntary assisted dying in those states. He (with Lindy Willmott) was also engaged by the

Western Australian Government to be involved in the statutory review of the *Voluntary Assisted Dying Act 2019* (WA). In addition, he (with Lindy Willmott) has also developed a model bill for voluntary assisted dying for parliaments to consider. Ruthie Jeanneret was employed on the Victorian, Western Australian and Queensland training projects.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available upon request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

Ethics approval was obtained from the Queensland University of Technology Human Research Ethics Committee (2000000270). This research was conducted in accordance with the Australian National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research 2007 (updated 2018). This research was conducted in accordance with the requirements of this ethics approval. All persons interviewed gave free and informed consent to participate in this research.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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