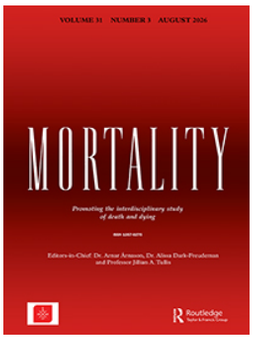

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Voluntary assisted dying views and experiences of Australians living with dementia: a qualitative study

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ABSTRACT

This study explored the views and experiences of Australians living with dementia relating to voluntary assisted dying (VAD) as an end-of-life care option. Semi-structured interviews were conducted online with 12 Australians living with dementia. The findings of this study identified that participants wanted VAD as an end-of-life care option to achieve improved quality of life, a good death, and to control their end-of-life care. Without this option, participants feared they are at risk of a poor dying experience, including potential abuse if they require residential care. The participants felt their living experiences of stigma and discrimination presented significant barriers to realising what they viewed as their right to VAD access. These findings highlight the importance of capturing the views of people living with dementia relating to VAD as an end-of-life care option, as without an in-depth understanding of their experiences, future end-of-life policy and practice may not reflect their end-of-life care preferences.

KEYWORDS

Dementia; euthanasia; terminally ill; Australia; death

Introduction

Dementia is a terminal condition that is currently the leading cause of death in Australia and the second leading cause of burden of disease (Australian Institute of Health and Welfare, 2025). Cognitive changes are the most common symptom associated with dementia, where people typically experience progressive changes in memory, communication, reasoning and problem solving, and mood (Dementia, 2024a). As the condition progresses, people living with dementia also experiences changes in physical function, including incontinence, loss of mobility, becoming unable to independently care for themselves, and loss of their ability to speak and swallow (Dementia Australia, 2024a).

Research suggests that people living with dementia wish to die free from physical and psychological pain and suffering; to die in their preferred location supported by their families; and to not be perceived as a burden (Mamun et al., 2023). However, people living with dementia disproportionately experience poor end-of-life outcomes, including a higher burden of distress, are given invasive interventions that do not improve quality

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or length of life, have a higher length and frequency of hospitalisation (Dementia Australia, 2019; Harrison et al., 2019), and are at an increased risk of suicide (Cooper et al., 2025; Dementia Australia, 2024b). End-of-life care outcomes for people living with dementia are complicated by ineffective service delivery in palliative care settings, where staff are often inadequately trained to meet their end-of-life care needs. This gap in service delivery often results in poorly managed and under recognised pain and an increased risk of falls, accidents and injuries (Dementia Australia, 2019).

These concerns about the inadequate end-of-life experiences of people living with dementia have prompted calls for voluntary assisted dying (VAD) to become legally available to Australians living with dementia (Dementia Australia, 2023). VAD is available to eligible Australians; however, stringent eligibility criteria relating to decisional capacity and prognosis (White et al., 2022) preclude people living with dementia from choosing VAD as part of their end-of-life care. The eligibility criteria across Australia differ from international jurisdictions such as the Netherlands, Canada, Belgium and Colombia (Trejo-Gabriel-Galán, 2021), where VAD is legally available to people living with dementia who meet eligibility criteria that are typically reliant on them having sufficient decisional capacity to make choices about VAD. International research with people living with dementia from Canada (Thériault et al., 2021), Belgium (Van Rickstal et al., 2023), and the Netherlands (Lemos Dekker, 2020) identified that, for the participants of these studies, choice to access VAD provides control over a potentially protracted dying experience, allowing them to ameliorate their risk of future suffering and dependence. Despite the value of living experience perspectives highlighted in international VAD research, recent research identified that the voices of Australians living with dementia are absent from VAD research (Matthys et al., 2024). Therefore, this study sought to redress this gap in VAD research through exploration of the question, *What are the views and experiences of Australians living with dementia in relation to VAD as an end-of-life care option*?

Methods

This study was the final stage of a wider mixed methods research project exploring how Australians living with dementia perceive VAD as an end-of-life care option (Matthys et al., 2024, 2025). Ethics approval for the project was received from the Charles Sturt University University Human Research Ethics Committee (H23635).

The study included a qualitative approach underpinned by a critical social gerontology (CSG) (Beresford, 2022; Cahill, 2022; Harbison, 2022) and phenomenological (Kidd & Carel, 2019) theoretical framework. CSG recognises dementia as both a disability and a terminal condition located in a society where the environment, institutions, and ideology create excess disability for the person and shape their living experiences (Beresford, 2022; Cahill, 2022). The CSG lens was integral to the theoretical framework as it acknowledged and revalued the experiential knowledge of the participants, as part of a cohort who are often marginalised in health discourses (Beresford, 2022).

The CSG lens was complemented by an epistemic injustice perspective to the phenomenology of illness (Kidd & Carel, 2019). The phenomenology lens was used to elicit an in-depth understanding of the complex pathographic testimonies of the participants, in the context of how their living experience of illness shapes their views about VAD (Kidd & Carel, 2019). Through the integrated critical and phenomenological theoretical

framework, it was possible to hold space for the participants' individual expressive capabilities, which supported them to speak in their own words about VAD as an end-of-life care option.

Participant selection

Participants were recruited via an opt-in process offered to all online survey respondents in the previous stage of the project (Matthys et al., 2025). Advice was sought from Dementia Advocates (Dementia Australia, 2025) and key industry stakeholders to ensure that the recruitment strategy would reach a wide range of potential participants who held supportive, opposing, and neutral views towards VAD. To maximise the diversity of the sample, the project was advertised through a wide range of networks including traditional and social media, via ageing and dementia-specific associations including end-user led groups, and through end-of-life stakeholders. Some groups declined to promote the research citing concerns surrounding cognitive capacity and the appropriateness of the research for the target group. Despite extensive efforts to recruit participants, the survey respondents who self-selected to participate were overwhelmingly supportive of VAD as an end-of-life care choice for people living with dementia, which impacted the sampling frame for this study. It is unclear why potential participants, particularly those with neutral or opposing views, did not engage in the study.

Participants were provided with information statements prior to their interview and were given the opportunity to ask questions. Consent to ongoing participation was assessed using a framework of process consent (Liamputtong, 2007) and assent and dissent (Black et al., 2010; Dewing, 2007) at the commencement of the interview and during wellbeing checks conducted throughout the interview. Formal cognitive screening was not undertaken, as these processes are known to exclude people living with dementia who would otherwise be capable of research participation, further reifying capacity-related stigma (Diaz-Gil et al., 2023).

Data collection

Data were collected using semi-structured interviews, where the participants were interviewed online using Zoom video calls. In three interviews, participants invited their care partners to be present during the interview. The contribution of care partners was minimal, and this data was not included in the analysis. The interviews lasted between 30 and 60 minutes and were completed by the first author, a social gerontologist with an extensive professional practice background working directly with people living with dementia in residential and community settings. The interview guide was informed by literature focused on the factors that shape health views in end-of-life care, VAD, and dementia, and the questions were formulated in line with the critical and phenomenological theoretical framework. The interview guide included questions exploring the participants' motivation to participate in the study, understanding of VAD, dignity and quality-of-life in end-of-life care, advance care directives, and relationships with health care practitioners and family and friends. The interview concluded by providing the participants with an opportunity to raise any issues relating to VAD that were important to them and that were not otherwise discussed in the interviews. To mitigate participant burden

during data collection, participants were free to choose the time of day that best suited their needs and were offered regular rest breaks throughout the interview (Liamputtong, 2007). The interviews were audio and video recorded and transcribed verbatim, and all participants were asked if they wished to engage in member checking; four participants provided feedback on their transcript. All transcripts were deidentified, and pseudonyms assigned.

Data analysis

Data analysis was conducted using reflexive thematic analysis described by Braun and Clarke (2022), supported by NVivo 14. Following familiarisation with the transcripts, the first round of coding was completed by all three authors to derive initial codes from the data. Codes were refined by the first author through discussion with the second and third author, and initial themes were constructed. A review of the potential themes was completed by all authors, and these themes were named and defined.

Participant description

Twelve participants ($n = 8$ female, $n = 4$ male) completed an interview. A summary of participant characteristics is presented in Table 1. All participants in this study were supportive of VAD as an end-of-life care option for people living with dementia and would like to have the option to choose VAD as part of their end-of-life care.

Findings

Three themes were produced from the thematic analysis. A summary of themes and exemplar quotes is provided in Table 2.

I need to live well, and die well

The participants in this study discussed their fear about how they would die without VAD as an end-of-life care option, and how they felt about the options that are currently available to them. The participants also expressed their belief that if VAD were available to them, it would help them to avoid future dementia-related suffering, and to achieve their desired quality-of-life, and a quality dying experience.

Most participants expressed that their desire to experience a good death was a key factor which influenced their views towards VAD as an end-of-life care option. The responses provided by participants were highly individualized; however, some commonalities across these responses were evident, including VAD offering an option to alleviate the suffering that participants worried will accompany end-of-life with dementia, and the desire for death to be peaceful, pain free, and fast: '*That you can drift off and be peaceful, and not in pain, . . . and hopefully you don't linger on' (Clara, 76)*. Participants also indicated that VAD would give them choice and control over the timing of their death: *'I would rather go at a time of my choosing. Painless, at a time of my choosing' (Joseph, 75)*. VAD allowing family to be present at the time of death was also important to participants: *'A good death means to me that I've got my family around me, and my, my wishes are known*'

Table 1. Participant characteristics.

Characteristic	Total (n = 12)
Age (years)	
55–64	1
65–74	5
75–84	5
85–94	1
Location	
New South Wales	4
Queensland	3
Victoria	3
South Australia	1
Northern Territory	1
Modified Monash Model	
MM1 (Major city)	5
MM2 (Regional centre)	3
MM3 (Large rural town)	2
MM4 (Medium rural town)	1
MM5 (Small rural town)	1
Dementia diagnosis (type)	
Alzheimer's disease	5
Frontotemporal dementia	4
Other	3
Time since diagnosis (years)	
1–5	6
6–10	3
11–15	2
16–20	1
Gender	
Female	8
Male	4
Cultural identity	11
White/European	
Aboriginal/Torres Strait Islander	1
Level of education	
High school	2
TAFE/Trade Certificate	2
University – Undergraduate degree	5
University – Postgraduate degree	3
Sexual orientation	
Straight (heterosexual)	11
Pansexual	1
Present relationship status	
Partnered	3
Single	1
Married	3
Separated/divorced	4
Widowed	1
Living arrangement	
Living with spouse/partner	5
Living with other family	1
Living alone	5
Other (Living in residential care)	1
Household income	
Not enough money	2
Usually enough money	4
Enough money	3
More than enough money	3
Self-reported health status	3
Very good	
Good	5
Fair	4

(*Continued*)

Table 1. (Continued).

Characteristic	Total (n = 12)
Political views	
Conservative	5
Progressive	3
Other (swing voter)	1
I prefer not to answer	1
I am not interested in politics	2
Religious beliefs	
No religion	8
Catholic	1
Anglican (Church of England)	1
Uniting Church	1
Other (Christian)	1

Note: Modified Monash Model (Department of Aged Care, 2024) defines the remoteness of a location. MM1: major city; MM2: regional centres population >50,000; MM3: large rural town, population between 15,000 – 50,000; MM4: medium rural town, population between 5,000 – 15,000; MM5: small rural town.

Table 2. Summary of themes.

Theme	Definition	Exemplar quotes
I need to live well, and die well	The participants' fears of how they will die without VAD access, and their belief that VAD can enable them to die well.	*"Since I've been in care and seeing people that are much more advanced, and their quality of life, there's no quality of life. What's the point of them being kept alive? I don't want that to happen to me" (Clara, 76).*
The views of others impact my choices	The participants' views towards other stakeholders, and the belief that their end-of-life care options are stymied by what they perceive as the stigmatising and discriminatory views and practices of these stakeholders.	*"You know, we're supposed to have a horn up or something sort of saying, oh look out! Here's a monster!" (Clara, 76).*
My needs and preferences should be respected	The importance of key stakeholders respecting the preferences and needs of people living with dementia; respect which is conveyed by supporting their right to choose VAD.	*"If the person's dying, I think that should be one of the last things, one of the last things they should be allowed to do is make their own choices about how they're gonna (sic) die . . . really it's the last thing you can choose for yourself, isn't it?" (Sandra, 65).*

(Sue, 74). Place of death was also highlighted as particularly pertinent to a First Nations participant, who said: *'Culturally, people want to die on country . . . Why can't people have VAD in culturally appropriate ways, so their spirit is free?' (Denise, 71).*

Along with the need for a good death, most participants felt that having VAD legally available to them as an end-of-life care option would improve their quality-of-life while living with dementia: *'I wouldn't have to worry about it then. It would take one less stress off me' (Sue, 74)*. Another participant remarked on the potential for VAD to promote quality-of-life by ameliorating concerns about needing to access aged care: '*Knowing that they have an ultimate alternative as opposed to, for want of a better word, suffer the system' (Harold, 70)*. Finally, one participant was despondent about people living with dementia having quality of life: *'I don't know how anything could improve the quality of life of dementia' (Ruth, 87).*

Concerns surrounding poor quality-of-life and fear of dying from dementia were raised by all participants as factors which influenced their views towards VAD: *'I'm really not*

scared of dying, but I don't, you know, I really want to live for as long as I can. But live as opposed to exist' (Elizabeth, 75). Most participants reported their fear of anticipated loss of dignity and independence at end-of-life, and experiences of prolonged death, as key factors contributing to their views about VAD. For some participants, this belief was strengthened through bearing witness to the end-of-life experiences of family and friends, which the views towards VAD: *'I'm living with dementia, and it's a familial dementia. I saw my Dad go through the disease without VAD and I don't want to go that way'* (Sue, 74). The participants also raised concerns about a range of scenarios that they anticipate facing as their condition progresses which influenced their desire to choose VAD, including lack of quality palliative and end-of-life care in rural communities, the quality of community aged care services, and dying in a hospital setting. However, of all these settings, the most frequently expressed fear shared by most participants was for their safety, and fear of dying from dementia in residential care as motivation to want to access VAD:

> You know, not everything is beautiful around aged care facilities. A lot goes on behind closed doors. We see medical restraints . . . people are tied to chairs . . . there's a whole, whole gamut of things . . . and it's a disgrace . . . I'm appalled at what goes on . . . The future looks bleak. (Ellen, 55)

Some participants used the findings of the recent Royal Commission into Aged Care Quality and Safety (Pagone & Briggs, 2021) to illustrate their fear of a bad death in residential care: *'And you know, dreadful things happen to us. We hear reports all the time and I don't want dreadful things to happen to me. I just want to be able to live a good life' (Elizabeth, 75)*.

When faced with the possibility of a poor quality of life and a poor dying experience, the view most consistently raised by the participants was that without VAD, suicide was their only choice at end-of-life. The participants acknowledged that some people living with dementia die by suicide and shared an understanding of what they perceive is a link between VAD eligibility, decisional capacity, and suicide: *'[People living with dementia] still have the capacity to attempt to kill themselves. So I think logically, they have the capacity to make that decision [VAD], with assistance' (Harold, 70)*. Other participants raised concerns that without VAD, they may be faced with unsafe situations if they attempt to end their lives:

> Now I can either, inverted commas, suicide, euthanise, which I would have to do on my own with risk, that it may not work, and that I may end up with severe disabilities . . . How do you ensure that safety . . . if you can't access VAD by law? (Denise, 71)

Along with suicide, some of the participants expressed frustration with palliative sedation, a practice which is legal in Australia. Some participants shared that they have witnessed this practice with family members *'[who] have unofficially been assisted to die by some of the umm, support staff, not openly, but umm, you know' (Harold, 70)*. The legal availability of palliative sedation, but not VAD, was also expressed as a source of frustration by some participants:

> Reality is, we know that when someone is dying and towards death, we know that they are generally given, if they're in pain, we give them morphine. And we increase the dose of morphine if they're in pain. And we increase the dose of morphine. And we increase the dose

> of morphine. Yes, until they gradually pass away. What is that? VAD, yeah in disguise. Tell me what the difference is? They've just waited until the very last moment to do VAD. That's the only difference. (Ellen, 55)

With the absence of VAD for them in Australia, some participants mused about the potential for international access to use this option: *'I mean it's either that, or . . . hop on a plane and take me overseas. And they'll put me to sleep' (Susan, 65)*. However, it was largely conceded that for most people with dementia, this option would likely be too burdensome: *'I have researched things like The Netherlands . . . but then I thought, well, me going . . . that might be a bit hard on my son, sort of rethought that' (Joseph, 75).*

The views of others impact my choices

This theme highlights the factors that participants believe prevent them from meeting their VAD preferences, thereby shaping their end-of-life care choices. These factors, which act as barriers to VAD, were attributed by the participants to conflicting views about VAD amongst key stakeholders and discrimination relating to dementia and capacity-related stigma. Some participants attributed their lack of access to politicians:

> Why do politicians have to stick their noses in? Why should they make the choices? Are they the ones dying? No. And why should they be making those choices? Nobody should be making the choices of anybody this time except the person who is dying. Because nobody knows their pain. (Ellen, 55)

This perceived barrier was also evident in the participants' critique of healthcare practitioners. While participants agree that the attitudes and actions of healthcare practitioners could influence their choices and experiences of end-of-life, they had different views about why this could be a barrier. Some participants intimated that paternalistic behaviours of some healthcare practitioners may create barriers to VAD for people living with dementia:

> Sit there and just listen to them. Don't tell them, oh, you gotta do this, or you gotta do that or this or that. Just sit there and allow them to tell you their problems . . . [hear what] we are trying to tell them, you know, instead of them telling us all the time. (Susan, 65)

This view was shared by another participant, who was unsure if their healthcare practitioners would be willing to discuss VAD with them:

> I won't know until I raise the question. I have a good relationship with my current GP, and she's a pretty broad minded person . . . [but] maybe there would be some, some objections. (Joseph, 75)

For other participants, the tendency for health care practitioners to prioritise quantity-of-life over quality-of-life created perceived barriers to VAD as an end-of-life care option for people with dementia: *'People being kept alive simply because someone else wants to keep him alive. And so, I think it's just the most crazy system you have ever seen' (William, 81)*. This led some participants to challenge the Hippocratic oath, where concerns were raised by some participants about other people having the power to prolong life as their primary objective, over individual choice. The lack of VAD as an end-of-life care option for people

living with dementia was also viewed by some participants as being a financial choice by some healthcare practitioners: *'A lot of times it will come down to financials. It's, you know, why would a doctor encourage VAD, if it means they are going to lose patients, basically? I mean I know that's harsh, but it's a business. It's how it works, isn't it?' (Sandra, 65)*.

The intersection of faith and medical practice was also seen as a barrier to VAD for people living with dementia by some participants:

> They will be punished in the next life, for what they do in this life, that they're taking a life, that they're murdering, it's a personal belief, valuing the sanctity of life … That's what interferes with informed decision-making by the medical profession (Denise, 71).

Other participants were more sympathetic to healthcare professionals with religious beliefs:

> I know some medical people would be against it too for religious reasons. But umm, you know for, for me for voluntary assisted dying, I would want people that are comfortable with the process and that it wasn't going to cause conflict for them within their own beliefs. (Elizabeth, 75)

This understanding did not extend to faith-based organisations and communities more broadly. Some participants were quite forthright in their views about people making decisions for them based on their religious beliefs:

> One of the problems is that you get, particularly God botherers, and umm, I've had a couple of arguments with them over this. Your God is a bit of a bloody problem. And that, you are just simply saying to people that you don't have a choice because we know better. And I have a real problem with that. (William, 81)

Other participants appealed to faith-based stakeholders as people who themselves hold religious beliefs: *'I'm actually Catholic, umm, and this did kind of, you know, stir a little, in me. But it's different when you actually have the shoes on your feet' (Ellen, 55)*.

The participants also reported a living experience of capacity and dementia-related stigma, and they believe that their consistent experiences of stigmatisation have resulted in discriminatory systemic barriers and human rights issues that directly impact their ability to access VAD. The participants believe that the current VAD laws discriminate against people living with dementia: *'There was a lot of press coverage about the laws in Victoria that are coming out, and they seem very discriminatory against people living with dementia' (Harold, 70)*. The impact of the discrimination reported by some participants was seen as an erosion of their human rights:

> Voluntary assisted dying is the right of choice to decide, if umm, life becomes too difficult to, to cope with … Except umm in my case, because I have dementia and cognitive decline, umm that right is denied. (Elizabeth, 75)

Some participants believed that the discrimination against them was particularly evident when held against the availability of VAD for other Australians living with terminal conditions: *'When you think of all the care, and the things that you can get when you've got cancer. I would get more care. Might not for my dementia' (Sue, 74)*. Because of this discrimination, the participants had a pressing need to be seen by VAD stakeholders as people and not be

reduced to a diagnostic label: *'We are still people. Just because we've got a label, we're still people, we're still people' (Clara, 76).*

My needs and preferences should be respected

The importance of key stakeholders including healthcare practitioners, family, faith-based groups, and the general public, respecting the views and preferences of people with dementia was explored by all participants. All participants stressed that, for them, respect is conveyed by other stakeholders by supporting their need to plan ahead, and to make informed decisions.

Across this theme, the need to plan ahead was particularly evident, with most participants expressing a desire to include VAD in their advance care directive, to be enacted when they no longer have capacity:

> . . . why can't we implement something into our health directives which includes VAD of some sort. Then we, as the people that are still capable of making these decisions and doing our advance directive, we put in there what we would like to happen. (Sandra, 65)

Most participants also explored timing of the enactment of advance care directives. For some participants, this was tied to functional capacity and quality-of-life: *'Once I lose the capacity to do things like swallowing. And once I lose my quality of life. That's when I would want it to end' (Ellen, 55)*. Other participants pointed to behavioural changes that may potentially be experienced as a time for enacting an advance directive: *'when my behaviour changes to the point that I am becoming violent and need to be to be heavily restrained, it's time. And I want assistance. I may not be able to self-administer at that stage' (Denise, 71)*. Despite their desire to receive VAD through an advance care directive, some participants raised concerns about how this would be operationalised:

> I know there's gonna be a lot of people out there, because there are nasty people out there, who are going to try and abuse that system, you know, with the VAD, you know. Kids that want inheritances and all that sort of garbage. There's a lot of people out there that can't be trusted, so there has to be pretty strict things in place, as far as that goes. (Sandra, 65)

This sentiment was shared by other participants, who discussed their safety, and the risk of people living with dementia being coerced into VAD. Some participants conceded that there is no easy way to mitigate the risk of coercion. However, as one participant explained, they felt there are worse things that will happen to them than being coerced into VAD, particularly experiencing abuses that they have no control over:

> You know you lose control of your bowels, you lose control of your bladder, and you are totally reliant on somebody else, who may not understand dementia. Who may not care for you. Who may assault you. I've been in aged care facilities, and I've seen the care that does not occur. No one should face those injustices as well. And we can't control that, no matter what we do. (Ellen, 55)

To reduce the risks associated with VAD and advance care directives, access to supported decision-making was raised by most participants. The participants' need to make informed decisions was captured through discussion of the importance of transparent, readily accessible access to information. This was particularly important as some participants raised concerns about the lack of visibility of VAD in dementia communities: '*Is it*

a bad thing that you, that people know that VAD exists, because some people might not even know about it, and it might be something that is going to suit them' (Sandra, 65). The need for accessible information was unique to the individual and suggestions included help sheets/pamphlets available online, and in places people living with dementia frequent, including medical or allied health clinics, memory cafes, and community organisations. Finally, some participants shared their frustration about the perceived restrictions on information that they believed would help them to make an informed choice about additional avenues for accessing VAD for their end-of-life care:

> Real information, for the person seeking real information around voluntary assisted dying. I mean, I have never seen an option of, I can go to Switzerland. I can go to Thailand to buy Nembutal, you know what I mean? (Denise, 71)

Although participants understood the type of information and supports they would likely need, there was some uncertainty about which stakeholder/s were best situated to provide this: *'Maybe doctors aren't the right people. I actually don't know. I, you know, I think health is responsible. Government and health are responsible for getting that information out there' (Elizabeth, 75)*. Despite this, most participants agreed that the accessibility and availability of information and support to people living with dementia was inherently problematic, and posed a potential future barrier in the context of VAD:

> Dementia is a chronic disease that has no wraparound services, no real education. [Peak body groups] put out a whole heap of general information, but I have never, and I'm in the space, and I have never seen anything on VAD, and I'm on [a key advisory committee]. (Denise, 71)

Discussion

This study explored the views and experiences of people living with dementia in relation to VAD as an end-of-life care option. The findings of this study revealed that all participants felt VAD would provide them with greater confidence to face their future, improve quality of life, and would allow them to die well. The desire for a good death expressed by the participants in the current study is also shared by people living with other terminal conditions in terms of wanting to be pain free, not having their life prolonged (Zaman et al., 2021), being able to contribute to the lives of others, and to be prepared for death (Krikorian et al., 2020). Despite their similarities with people living with other terminal conditions, a key finding of this study was the influence of fear on the views of the participants, who shared that they are not afraid to die, but are afraid of *how* they will die without VAD as an end-of-life care option. Fear of dementia-related suffering is commonly reported in the broader literature. The fear of dementia-related suffering expressed by the participants in the current study was shared with people living with dementia in a Canadian study, who cited a preference for VAD to avoid physical and cognitive decline, increased pain and dependence, and a potentially protracted death (Thériault et al., 2021). Dementia-related suffering is also the most common fear of Australians over 65 years, who fear the emotional, physical and social impact of dementia (Watson et al., 2023).

Along with dementia-related suffering, the participants in the current study also expressed a fear of suffering due to structural factors contributing to poor quality care delivered through the fractured aged care system. The participants' fear of poor-quality care is reflected in peak body advice, which raised concerns about the risk of a poorer

dying experience for people living with dementia (Dementia Australia, 2019). The risk of an unsafe death and poorer quality of life outcomes are also reported in the findings of the recent Australian Royal Commission into Aged Care Quality and Safety (Pagone & Briggs, 2021), which identified an unacceptably high level of abuse and neglect in residential care. In the context of wider VAD research, concerns surrounding residential care were shared by people living with dementia in international jurisdictions. A study with people living with dementia and their carer partners in the Netherlands identified that residential care was viewed as a direct threat to their autonomy, dignity and independence (Lemos Dekker, 2020). In a similar way, a study with people living with younger onset dementia and their care partners in Belgium suggested that for some participants, VAD meant they may be able to avoid entering residential aged care (Van Rickstal et al., 2023). The explicit safety concerns raised by the participants in the current study highlight the complex and nuanced views held by people living with dementia towards residential care.

The findings of this study also identified that for the participants, respect for their capability to make choices about their care was important to them, as was being able to retain control over their lives for as long as possible. Choice and control are foundational concepts of a ubiquitous narrative defining the delivery of care to older Australians, including those living with dementia who are at the end of their lives (Phillipson et al., 2022). Making choices about end-of-life care, which may include VAD, is supported by peak body and advocacy groups (Dementia Australia, 2023; Older Persons Advocacy Network, 2022). People living with advanced dementia will likely need support from a substitute decision-maker to make complex choices about their care. With individualised supports, people living with dementia can make choices and retain control over their lives for many years after diagnosis (Mattos et al., 2023). However, the reality of choice for people living with dementia is that their choices are often stymied by the influence and power of dominant stakeholders who prioritise paternalistic care practices (Foundas, 2025). The best-interest argument used by health care practitioners to justify paternalistic care practices can also lead to increased dependency and vulnerability for the person (Mortensen et al., 2023), concerns which were voiced by the participants in the current study.

The existing complexities of paternalism in dementia care underscore the findings of the current study, highlighting the intersection of vulnerability, cognitive capacity, and coercion. In terms of cognitive capacity, this study has highlighted that the participants clearly understand VAD, however, feel they have been excluded from building more inclusive pathways for VAD access. The participants felt that stigmatising views of cognitive capacity held by some key stakeholders were a major factor which shape their end-of-life care options, including VAD. From a theoretical standpoint, this finding suggests that people living with dementia are vulnerable to pathocentric epistemic injustices in the VAD discourses and care practices. Pathocentric epistemic injustices occur when the credibility of an ill person is unfairly deflated due to stigmatising views surrounding their ability to reliably share their living experiences (Kidd & Carel, 2019). In policy and practice settings, pathocentric epistemic injustice position ill people as voices not 'worth having on the table' (Kidd & Carel, 2019, p. 12), leading to the formation of unjust social structures which cause risk and harm to people with dementia (Biggs et al., 2019). This finding highlights the need to shift from deficit-based biomedical models that prioritise

prognosis and disease pathology and reduce people living with dementia to passive care recipients, to approaches which challenge key stakeholders to see how their practices increase vulnerability and disability for people living with dementia (Cahill, 2022).

The increased vulnerability of people living with dementia under biomedical models of VAD which inform policy was an area of concern for the participants. The participants in the current study were upfront in acknowledging that they are vulnerable to coercion in the context of VAD. However, coercion to access VAD if it was legally available to them was a minor concern for these participants. Instead, the participants considered the impact of dementia-related stigma, which would likely result in unmet care needs for them, leaving them increasingly vulnerability to coercion by key stakeholders who may choose care for them that does not align with their preferences. The concerns about coercion and safeguarding held by key stakeholders were contrasted by participants against what they perceive as a very real risk to their personal safety, particularly their increased vulnerability to poor quality care in residential settings. VAD laws in Australia are designed to safeguard people living with dementia from coercion into VAD by key stakeholders such as health care practitioners and family members (Komesaroff et al., 2024). These safeguards are important for the safe delivery of VAD, as informal coercion by medical practitioners and family members is known to occur in the delivery of care to people living with disabilities (Office of the Public Advocate, 2019; Raveesh et al., 2025). However, these stringent VAD safeguards deliver a poisoned chalice to the participants, who agree that VAD needs to be safeguarded, but not at the expense of their personal safety in systems which are not designed to meet their needs.

The findings of the current study also identified that the participants believe their lack of choice in end-of-life care is complicated by discriminatory legislation. The legislative frameworks governing access are specific to each Australian state or territory. In some cases, such as New South Wales, the legislation explicitly excludes people with a dementia diagnosis (New South Wales Government, 2023). In other jurisdictions, exclusion from VAD as an end-of-life care option is implied through safeguards relating to prognosis and capacity (Queensland University of Technology [QUT], 2025). In all states and territories, supported decision-making and autonomy are enshrined as principles underpinning these legislations, where decisional capacity is assumed (QUT, 2025). As such, dementia presents a site of contradictory legal issues; people living with dementia have a right make choices about their lives with support, a right which is included in state-based legislation, yet implicit or explicit eligibility criteria deny them access, even with appropriate support. State-based VAD laws are complicated further with the prioritisation of the rights of powerful medical and religious stakeholders in law through concessions including conscientious objection, and the absence of living experience perspectives in the research which shapes these laws (Matthys et al., 2024).

The complexity of the existing legal frameworks, which the participants believed may result in a poor quality and unsafe death, led them to consider their human right to make choices about their care. Human rights in the context of VAD are an ongoing source of debate, particularly relating to the balancing of rights for all key stakeholders (Cheyne, 2023). The *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD) (United Nations, 2006) is a critical benchmark for ensuring that state parties are compliant with their obligations under the convention (Cahill, 2022). The principles of the UNCRPD as a guiding framework to support access to VAD for people living with dementia are

recommended by Dementia Australia (2023), who note that this framework would promote choice and control over end-of-life care. Through a human rights approach to VAD, respect is conveyed through active and meaningful engagement with people living with dementia as citizens with equal political value (Bhakuni, 2023). Without a rights-based focus that centres their voices in VAD discourses, people living with dementia will likely continue to experience poor quality of life, and a poor-quality death until the hierarchical knowledge systems that shape the end-of-life care options available to them are deconstructed, and replaced with approaches that prioritise their dignity and citizenship (Bhakuni, 2023).

Strengths and limitations

This is the first known Australian paper to undertake an in-depth exploration of the views and experiences of Australians living with dementia in relation to VAD as an end-of-life care option. The strength of this paper is the contribution of the participants, who challenge the prevailing belief that people living with dementia cannot express preferences about VAD. This paper has several limitations. First, the sample was largely homogenous in terms of cultural identity, level of education, sexual orientation, and religious beliefs. Given the known barriers to health access for Australians from diverse backgrounds, future VAD research with people living with dementia should explore how these dimensions of diversity shape their desire for VAD as an end-of-life care option. Second, all participants in the current study were supportive of VAD access for people with dementia, a bias which is also somewhat evident in international research (Thériault et al., 2021; Van Rickstal et al., 2023). While this may be related to the reported shortcoming of the self-selection sampling method used in the previous stage of the project (Matthys et al., 2025), strong supportive and opposing views are common in VAD research (Thériault et al., 2021). Challenging stigma related to conversations about dementia and dying may support the inclusion of a more diverse range of voices in future VAD research.

Conclusion

The findings of this study, with 12 participants, showed that VAD is a wanted end-of-life care option for some Australians living with dementia that can support quality-of-life, and a good death. However, the participants' experiences were mired in stigma and discrimination, and because of concerns about suffering and safety, they believed they would suffer at end-of-life as care recipients of the current system. In contrast, having the option to choose VAD as part of their end-of-life care was valued by the participants, who felt it would help them to face the future with greater confidence; provide a safer end-of-life care option; and facilitate their right to make choices about their care that align with their personal preferences. These findings demonstrate the necessity and urgency of the consistent inclusion of living experience expertise across future VAD research, policy, and practice. Given the depth of the contributions by the participants demonstrating the capability of people living with dementia to actively engage in the VAD discourse, future debate about VAD access for people with dementia should be accompanied by a reconceptualisation of key stakeholder understandings of capacity, and what it means to be a *person* living with dementia.

Author contribution

CRediT: **Adrienne Matthys**: Conceptualisation (Lead), Formal analysis (Lead), Investigation (Lead), Methodology (Lead), Writing: original draft (Lead), Writing: Review & Editing (Equal); **Belinda Cash**: Conceptualisation (Supporting), Supervision (Equal), Formal analysis (Supporting), Investigation (Supporting), Methodology (Supporting), Writing: original draft (Supporting), Writing: Review & Editing (Equal); **Bernadette Moorhead**: Conceptualisation (Supporting), Supervision (Equal), Formal analysis (Supporting), Investigation (Supporting), Methodology (Supporting), Writing: original draft (Supporting), Writing: Review & Editing (Equal).

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Disclosure statement

No potential conflict of interest was reported by the author(s).

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Data availability statement

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

Ethical approval

Ethics approval for this project was received from the Charles Sturt University Human Research Ethics Committee (H23635). Informed consent was given in writing prior to the interview participation. Consent was confirmed verbally at the start of each interview, and in wellbeing checks during each interview.

References

Australian Institute of Health and Welfare. (2025, December 5). *Dementia in Australia*. Australian Government. https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/population-health-impacts-of-dementia/prevalence-of-dementia

Beresford, P. (2022). User involvement. In S. Torres & S. Donnelly (Eds.), *Critical gerontology for social workers* (pp. 161–176). Bristol University Press.

Bhakuni, H. (2023). Epistemic repair in global health: A human rights approach towards epistemic justice. *BMJ Global Health*, *8*(8), e013544. https://doi.org/10.1136/bmjgh-2023-013544

Biggs, S., Carr, A., & Haapala, I. (2019). Dementia as a source of social disadvantage and exclusion. *Australasian Journal on Ageing*, *38*(22), 26–33. https://onlinelibrary.wiley.com/doi/10.1111/ajag.12654

Black, B. S., Rabins, P. V., Sugarman, J., & Karlawish, J. H. (2010). Seeking assent and respecting dissent in dementia research. *The American Journal of Geriatric Psychiatry*, *18*(1), 77–85. https://doi.org/10.1097/JGP.0b013e3181bd1de2

Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE Publications Ltd.

Cahill, S. (2022). Dementia: A disability and human rights concern. In S. Torres & S. Donnelly (Eds.), *Critical gerontology for social workers* (pp. 146–160). Bristol University Press.

Cheyne, T. (2023). *Voluntary assisted dying bill 2023. Explanatory statement and human rights compatability statement (Human rights act 2004, s37)*. The Legislative Assembly for the Australian Capital Territory. https://www.legislation.act.gov.au/DownloadFile/es/db_68610/20231031-82225/PDF/db_68610.PDF

Cooper, M., Couzner, L., Smith-Merry, J., Draper, B., Low, L. F., & Cations, M. (2025). The role of dementia and mild cognitive impairment in deaths by suicide in Australia: A retrospective study of coronial records. *International Psychogeriatrics*, *37*(1), 100002. https://doi.org/10.1016/j.inpsyc.2024.100002

Dementia Australia. (2019, November). *Dying well: Improving palliative and end of life care for people with dementia*. https://www.dementia.org.au/sites/default/files/2024-02/DA-Dying-well-discussion-paper-QLD.pdf

Dementia Australia. (2023, April). *Dementia and access to voluntary assisted dying*. https://www.dementia.org.au/sites/default/files/2024-02/Policy-Position-Statements-April-2023.pdf

Dementia Australia. (2024a). *About dementia*. https://www.dementia.org.au/about-dementia

Dementia Australia. (2024b, October). *National suicide prevention strategy consultation draft*. https://www.dementia.org.au/sites/default/files/2024-11/National-Suicide-Prevention-Strategy-Submission.pdf

Dementia Australia. (2025, October 30). *Dementia Advocate Program*. https://www.dementia.org.au/get-involved/dementia-advocates-program

Department of Health and Aged Care. (2024, November). *Monash Modified Model*. Australian government. https://www.health.gov.au/topics/rural-health-workforce/classifications/mmm

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, *6*(1), 11–25. https://doi.org/10.1177/1471301207075625

Diaz-Gil, A., Brooke, J., Kozlowska, O., Jackson, D., Appleton, J., & Pendlebury, S. (2023). A human rights-based framework for qualitative dementia research. *Nursing Ethics*, *30*(7–8), 1138–1155. https://doi.org/10.1177/09697330231161687

Foundas, M. (2025). Dignity of risk in residential care: A call to reframe understandings of risk. *The Medical Journal of Australia*, *223*(4), 186–188. https://doi.org/10.5694/mja2.70002

Harbison, J. R. (2022). Human rights and older people. In S. Torres & S. Donnelly (Eds.), *Critical gerontology for social workers* (pp. 35–50). Bristol University Press.

Harrison, K. L., Hunt, L. J., Ritchie, C. S., & Yaffe, K. (2019). Dying with dementia: Underrecognized and stigmatized. *Journal of the American Geriatrics Society*, *67*(8), 1548–1551. https://doi.org/10.1111/jgs.15895

Kidd, I. J., & Carel, H. (2019). Pathocentric epistemic injustice and conceptions of health. In B. Sherman & S. Goguin (Eds.), *Overcoming epistemic injustice: Social and psychological perspectives* (pp. 153–168). Bloomsbury Publishing Inc. https://philarchive.org/rec/KIDPEI

Komesaroff, P. A., Chapman, M., Lamba, G., Kerridge, I. H., Stewart, C. L., Holmes, A., Lewis, S., & Philip, J. (2024). Should voluntary assisted dying in Victoria be extended to encompass people with dementia? *The Medical Journal of Australia*, *220*(9), 452–454. https://doi.org/10.5694/mja2.52273

Krikorian, A., Maldonado, C., & Pastrana, T. (2020). Patient's perspectives on the notion of a good death: A systematic review of the literature. *Journal of Pain and Symptom Management*, *59*(1), 152–164. https://doi.org/10.1016/j.jpainsymman.2019.07.033

Lemos Dekker, N. (2020). Anticipating an unwanted future: Euthanasia and dementia in the Netherlands. *The Journal of the Royal Anthropological Institute*, *27*(4), 815–831. https://doi.org/10.1111/1467-9655.13429

Liamputtong, P. (2007). *Researching the vulnerable*. SAGE Publications Ltd.

Mamun, M. R., Hirakawa, Y., Saif-Ur-Rahman, K., Hong, Y. J. Song, Z., Yoshida, Y., & Yatsuya, H. (2023). Good death for people living with dementia: A qualitative study. *BMC Geriatrics*, *23*(665), 1–11. https://doi.org/10.1186/s12877-023-04395-y

Matthys, A., Cash, B., & Moorhead, B. (2024). The representation of Australians living with dementia in voluntary assisted dying research: A scoping review. *Australasian Journal on Ageing*, *43*(4), 664–674. https://doi.org/10.1111/ajag.13371

Matthys, A., Cash, B., & Moorhead, B. (2025). 'It should be my choice': Voluntary assisted dying needs and preferences of Australians living with dementia. *Ageing and Society*, *46*(e5). https://doi.org/10.1017/S0144686X25100330

Mattos, M. K., Gibson, J. S., Wilson, D., Jepson, L., Ahn, S., & Williams, I. C. (2023). Shared decision-making in persons living with dementia: A scoping review. *Dementia*, *22*(4), 875–909. https://doi.org/10.1177/14713012231156976

Mortensen, A. H., Nåden, D., Karterud, D., & Lohne, V. (2024). Residents' experiences of paternalism in nursing homes. *Nursing Ethics*, *31*(2–3), 176–188. https://doi.org/10.1177/09697330231166085

New South Wales Government. (2023, November 29). *Voluntary assisted dying act 2022 No 17*. https://legislation.nsw.gov.au/view/html/inforce/current/act-2022-017#sec.4

Office of the Public Advocate. (2019, April). *Advance care planning and people living with dementia*. https://www.publicadvocate.vic.gov.au/your-rights/planning-another-s-future-care/medical-treatment-decision-making-and-advance-care-planning-for-people-living-with-dementia#:~:text=top

Older Persons Advocacy Network. (2022, August). *OPAN position on voluntary assisted dying*. https://s3.ap-southeast-2.amazonaws.com/cdn-staging.opan.org.au/uploads/2023/11/VAD-Position-statement-formatted.pdf

Pagone, T., & Briggs, L. (2021, March 1). *Final report: Care, dignity and respect*. Royal commission into aged care quality and safety. https://www.royalcommission.gov.au/aged-care/final-report

Phillipson, L., Smith, L., & Duncan, C. (2022). Perspectives and practices associated with consumer-directed care in Australia: Synergies and tensions in supporting planning and delivery of home care for older people with dementia. *Health and Social Care in the Community*, *30*(5), e2772–e2781. https://doi.org/10.1111/hsc.13721

Queensland University of Technology. (2025, November 25). *Voluntary assisted dying*. https://end-of-life.qut.edu.au/assisteddying

Raveesh, B. N., Lepping, P., & Palmstierna, T. (2025). Should medicine face up to coercion? *Journal of Psychiatry Spectrum*, *4*(2), 131–132. https://doi.org/10.4103/jopsys.jopsys_41_24

Thériault, V., Guay, D., & Bravo, G. (2021). Extending medical aid in dying to incompetent patients: A qualitative descriptive study of the attitudes of people living with Alzheimer's disease in Quebec. *Canadian Journal of Bioethics*, *4*(2), 69–77. https://doi.org/10.7202/1084452ar

Trejo-Gabriel-Galán, J. M. (2021). Euthanasia and assisted suicide in neurological diseases: A systematic review. *Neurologia*, *39*(2), 170–177. https://doi.org/10.1016/j.nrleng.2024.01.007

United Nations. (2006, December 13). *Convention on the rights of persons with disabilities (CRPD)*. https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd

Van Rickstal, R., De Vleminck, A., Chambaere, K., & Van den Block, L. (2023). People with young-onset dementia and their family caregivers discussing euthanasia: A qualitative analysis of their considerations. *Patient Education and Counseling*, *115*, 107882. https://doi.org/10.1016/j.pec.2023.107882

Watson, R., Sanson-Fisher, R., Bryant, J., & Mansfield, E. (2023). Dementia is the second most feared condition among Australian health service consumers: Results of a cross-sectional survey. *BMC Public Health*, *23*(1), 876. https://doi.org/10.1186/s12889-023-15772-y

White, B. P., Willmott, L., Del Villar, K., Hewitt, J., Close, E., Greaves, L. L., Cameron, J., Meehan, R., & Downie, J. (2022). Who is eligible for voluntary assisted dying? Nine medical conditions assessed against five legal frameworks. *The University of New South Wales Law Journal*, *45*(1), 401–444. https://doi.org/10.53637/FYID9182

Zaman, M., Espinal-Arango, S., Mohapatra, A., & Jadad, A. R. (2021). What would it take to die well? A systematic review of systematic reviews on the conditions for a good death. *Lancet*, *2*(9), e593–e600. https://doi.org/10.1016/S2666-7568(21)00097-0